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for people with hand osteoarthritis

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Erklärung zur Verfassung der Arbeit

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Kurzfassung

Arthrose ist die weitverbreitetste Gelenkserkrankung weltweit. Millionen von Menschen leider unter ihrer Last und sind einer kontinuierlichen Verschlechterung ihres Gesundheitszustandes ohne Hoffnung auf Heilung ausgesetzt. Handarthrose ist eine Ausprägung, welche sich auf die Finger- und Handgelenke auswirkt, und damit Betroffene vor zahlreiche Herausforderungen in ihrem täglichen Leben stellt. Aufgrund der steigenden Anzahl an Betroffenen und der damit einhergehenden Last auf das Gesundheitssystem, wird es für das Gesundheitswesen immer schwieriger entsprechende Dienstleistungen innerhalb der finanziellen Rahmenbedingungen zu erbringen. Um diese Situation zu entschärfen, wird der Übergang zu einer Gesundheitsversorgung in denen die Betroffen selbst in der Lage sind ihre krankheitsbedingten Herausforderungen weitgehend zu meistern wichtiger. Zur Unterstützung dieses Übergangs haben Technologien bereits ihren Nutzen gezeigt. Das Ziel dieser Arbeit ist es die Herausforderungen im täglichen Leben mit Handarthrose zu verstehen, und daraus die Möglichkeiten und Anforderungen an Technologien abzuleiten.

Im Rahmen dieser Arbeit kam ein adaptierter anwender-orientierter Designprozess zum Einsatz, mit Schwerpunkten auf den Menschen mit Handarthrose und der Entwicklung eines Prototyps. Dabei wurden zuerst Interviews mit 6 TeilnehmerInnen in deren Umfeld durchgeführt. Es folgte eine Fokusgruppe mit 5 TeilnehmerInnen und ein Workshop mit 8 TeilnehmerInnen. Die gewonnenen Daten wurden mittels Thematische Analyse untersucht. Basierend auf den Ergebnissen der Analyse wurden folgend eine Beschreibung der Benutzergruppe, Szenarien für den Einsatz von Technologien, Anforderungen an diese Technologien und ein konkreter Prototyp abgeleitet. Die Ergebnisse zeigen neue Erkenntnisse aus dem täglichen Leben mit Handarthrose aus der Perspektive der Betroffenen, und zeigen die Verbindung zwischen Symptomen, Aktivitäten des täglichen Lebens und den Umgang damit. Zudem zeigen die Erkenntnisse Probleme in Bezug auf Kenntnisse und Anwendung von Selbsthilfe-Praktiken und verfügbarer Technologien auf. Durch den verwendeten Designprozess wurden eine repräsentative Beschreibung der Anwendergruppe erstellt, Anwendungsfälle für Selbsthilfe-Technologien identifiziert und Anforderung an solche Technologien beschrieben. Die Ergebnisse zeigen die Wichtigkeit die Bedürfnisse aus dem täglichen Leben der zukünftigen NutzerInnen einer Selbst-Hilfe Technologie besser zu verstehen um diese entsprechend in neue Technologien zu integrieren. Zudem zeigen die Resultate eine Anzahl von Möglichkeiten für solch spezialisierte Technologien auf.

Abstract

Osteoarthritis is the most common joint disease worldwide. Millions of people are suffering under its burden facing a continuous worsening and no existing cure. Hand osteoarthritis is one type of the illness, affecting hands and fingers, and thereby challenging an individual's daily life and activities. Given the high prevalence within population and the pressure put on conventional health systems, those are less capable of delivering adequate care within their financial boundaries. This situation demands a shift to a modern self-care approach, focusing on people empowerment. Technologies have already shown their benefits in supporting this shift and giving people capabilities to take care in their own hands, having the health system as a supporting and guiding instance. Therefore, the aim of this thesis is to investigate and gain understanding of the challenges people living with hand osteoarthritis experience and therefrom derive the opportunities and implication for possible application of self-care technologies.

An adapted user-centered design process was applied, with focus on user research and prototyping. During user research in-situ interviews were conducted with 6 participants, a focus group took place with 5 participants and a workshop was conducted with 8 participants. The resulting records were examined via thematic analysis. Based on the analyzed user research results, within the design process a persona, scenarios, design implications and a prototype were created. The results provide new insights into the daily life with hand osteoarthritis from the individual's perspective, show the relation between symptoms, daily activities and coping practices, and further indicate gaps in the practice of self-care and technologies. Through the prototyping design process a representative user description, scenarios for self-care technology applications and implications for the design of technology for people HOA were established. Based on these results, we conclude that understanding the needs of individuals living with HOA is fundamental to build helpful technologies and a range of opportunities for such specific technologies exists.

CONTENTS

1 INTRODUCTION

The introduction section outlines the motivation for this thesis, the underlying problem, the aim that should be achieved and the methodological approach, explaining how this aim will be achieved. Furthermore, the introduction explains the contribution of this work to the field of computer science and describes the following sections within.

1.1 MOTIVATION

Today western countries are already facing the first impacts of a population becoming more and more elderly [1]. This ongoing demographic shift increases the pressure on health systems to provide adequate care for individuals within the available financial conditions [1]. A major challenge for those health systems is the treatment of chronic diseases, which are showing higher occurrences within the elderly [1]. One of those chronic illnesses is osteoarthritis (OA) [1], from which millions of people are suffering – and its tendency is increasing [2]. OA affects the knees, hips, hands or feet, and counts as the most common joint disease worldwide [3], [4]. Here, the main focus is on hand osteoarthritis (HOA), from which individuals experience a range of physical and psychological problems that are worsening over time [3]. This starts by minor pain and stiffness in affected parts of hands, and ends with disability to perform regular daily activities [3]. Given the high amount of affected people and the accompanying problems, the burden on the health system and society is high [3].

As the health system is pushed further to its limits, it directly affects people suffering chronic conditions who are highly depending on appropriate care [1]. Faced by this situation the change to a modern self-care paradigm becomes important [1]. Following the self-care approach, individuals are empowered to take responsibility back in their own hands, having the health system and its providers as guiding and supporting companion [1]. Especially patients suffering from chronic conditions as osteoarthritis are in need for daily self-care. From the beginning, day by day they have to decide how to manage their situation [1]. Although they become real experts on their disease over time, a lot of frustrating, hard lessons must be learnt without proper support [1]. Therefore, it must be established, that individuals reach a proper level of self-efficacy and health literacy to be aware of fruitful practices, to know how to deal with their challenges and to be capable of conducting adequate care on their own [1].

Meanwhile, information technology evolves rapidly, providing new opportunities in a wide range of disciplines, like the medical system [5]. Today's everyday technology already proved success in improving the daily lives of individuals suffering under the burden of chronic illnesses [5].

Bringing the aspects of the necessary shift to the self-care paradigm, individuals suffering from osteoarthritis demanding support, and nowadays possibilities of technologies together, founds the motivation of this thesis, i.e. searching for helpful applications of self-care technologies to improve the life of people with HOA.

1.2 PROBLEM STATEMENT

Today advanced research exists on the fields of hand osteoarthritis, see sections 2.1, 2.2, care and self-care, see section 2.3, and information technology, see section 2.4, each of them offering a broad range of their own aspects. The existing research within medical research field of HOA covers the symptoms of HOA, its impacts on daily life, recommendations and proper application on coping practices. Self-care practices are also investigated and their practices and issues documented. However, the individual's perspective is rarely taken into account within those studies. Furthermore, the areas of application of self-care technologies are defined and implementations and their effects studied. Qualitative research is nowadays less popular and in this specific area is rare and often quantitative studies fail to create a complete picture of the very individual needs and miss to reveal their underlying intentions.

Given the gain of importance of interdisciplinary research and the rare conduction within the intersection of the mentioned fields with the aim to drawing it all together, this baseline offers opportunities for further investigations. Especially individuals with hand osteoarthritis and their specific needs as potential users for self-care technology are less researched, see section 2.4. However, this deep understanding of such specific user groups and their situations is mandatory to ensure effective, helpful and successful new technologies, especially for those already experiencing various challenges and constraints in their life. Otherwise, any provided technology is likely to fail, leading to frustration for creators, and more for consumers.

1.3 AIM OF THE WORK

This thesis tackles the gap of understanding the target user group, i.e. people suffering from hand osteoarthritis, and it withdraws therefrom opportunities and implications for proper self-care technologies. As underlying assumption for this study we suppose that people suffering from hand osteoarthritis are experts in knowing and coping with their condition. Each affected person knows which challenges appear day by day, and how to cope with them – or where they are unable to cope with them properly.

The aim of this thesis is to gain a deeper understanding of the users and their issues. Based upon those outcomes we expect to find proper uses and design implications for self-care technologies, and finally come up with a prototype encompassing these findings. Therefore, the central research question of this thesis is:

“What kind of challenges individuals living with hand osteoarthritis experience and what are the opportunities for and needs on self-care technologies on those issues?”

This broad question is split into two separate research questions.

RQ1: What kind of challenges do individuals living with HOA experience?

First, there is a need to get to know the affected individuals, their daily lives and experienced challenges. Not only their directly perceived symptoms are of interest, but also how these symptoms influence and constrain their life, how they are coping with those issues, what kinds of coping strategies do they know and apply, and which problems are accompanying their coping practices.

RQ2: What are the opportunities and needs of self-care technologies for people with HOA?

The outcomes of the research conducted on the individuals lay the fundament for the definition of a proper self-care technology prototype. First, the target user of this technology must be described. Second, proper use cases of technology must be identified for this target user. Third, design implications respecting the specific demands of the target user must be defined. Based upon these outcomes, a proper concept for a self-care technology can be created.

1.4 METHODOLOGICAL APPROACH

The methodologies used within this thesis consisted of mixed qualitative user research methods, whose outcomes informed an open exploratory design process, leaned on user centred design process. Thereby, the focus was on the user’s experiences and perspectives, taking their expertise as fundament for the creation of helpful technology.

The methodological approach of this thesis consisted of the following steps:

- Comprehensive literature review
- Field research through application of user research methods
- Thematic analysis of the gathered data derived from user research
- Creating a persona to represent the target user group
- Describing potential use cases for self-care technologies
- Defining design implication for self-care technologies
- Creating a prototype based on the persona, use cases and design implications

First, a comprehensive literature review was conducted. The goal was to revisit literature for a better understanding of the disease itself, with its origin and prevalence, the impact of hand osteoarthritis on people’s health and life and existing coping strategies. By explaining the modern approach of patient empowerment and self-care, the transition towards self-care technology was made, showing their areas of application and current implementations.

Second, patients with HOA were recruited as study participants and field research was conducted on them. In order to do that, three qualitative methods were used, i.e. the interview, focus group and workshop. By conducting the so called “in-situ” interviews at the homes of participants we wanted to get familiar with them, their situation and their living contexts. The focus group served to encourage discussion and to get different opinions about problems, and how to cope with them. Finally, a workshop took place to figure out what is important to the individuals regarding their problems and coping practices and to gather ideas for potential helpful technologies. To gain a deeper understanding of the user, the following questions were of interest:

- Who are the affected people and in which situations are they living in?
- What kind of challenges do they experience within their (daily) life?
- Are they able to cope with those challenges, and if so, how do they cope with them?
- Which problems accompany those coping practices?
- What kind of technologies are they using within their daily life personally, but also regarding their condition and what is their perspective on those?

Third, the outcomes of the applied user research methods underwent a thematic analysis to discover the main themes for individuals with HOA, and to answer RQ1 through a compelling story about life with hand osteoarthritis.

Fourth, the results of the analysis informed the further design process, tackling RQ2, including the creation of a persona to describe the target user group, finding opportunities and uses for the application of self-care technologies and defining the design implication for technologies in this field. Those outcomes were then used for the creation of an example prototype of a self-care technology reflecting the demands of individuals with HOA.

1.5 CONTRIBUTIONS

This thesis contributes to the disciplines of computer science and user research, focusing on the specific user group of people with hand osteoarthritis and the application of self-care technologies. The key findings of this study should provide a deeper understanding of the individual situation of people with HOA, and inform about further developments of self-care technologies within this area by highlighting user needs, technologic opportunities and design implications.

1.6 STRUCTURE OF THE WORK

The structure of this work consists of the following parts:

- Chapter 2 – Literature review – encompasses the literature related to this thesis research fields, comprising background knowledge about the hand osteoarthritis disease itself, its impact on people's health and life, existing coping practices and the areas of application and existing implementation of self-care technologies in this area.
- Chapter 3 – Methodology – comprises the methodological approach used within this study. It states the chosen study design, the process of participant recruitment and it details the applied methods and their practical implementation.
- Chapter 4 – Emerged themes – presents the outcomes of the applied user research methods, categorized within their themes and subthemes, and includes a description and found example statements.
- Chapter 5 – Living with hand osteoarthritis – summarizes the emerged themes as a compelling story about living with hand osteoarthritis.
- Chapter 6 – Prototyping – includes the description of a persona as representation of the target group based on the study participants and emerged themes, potential scenarios for self-care technologies derived from the user research, defined design implications for such technologies, and a concrete prototype.

2 CHAPTER 7 – DISCUSSION

This chapter goes back to the initial research question of this thesis and discusses how the results of the conducted research answer it. Therefore, the key findings are named and the results are compared with the given literature to draw out what is new and what restates or differs from existing research. Furthermore, the limitations of this study and potential future work are described.

2.1 KEY FINDINGS

2.1.1 Challenges for people living with HOA

The first research question RQ1 addressed daily challenges of individuals with hand osteoarthritis. The conduction of qualitative user research and its analysis brought up several problem areas, namely the development of osteoarthritis, every day challenges, self-care practices, and professional treatment. Thus, our starting assumption was met, which was that individuals are experts on their condition-related domain, and their problems are taken as opportunities for self-care technologies. Overall, the results build upon the given literature on HOA symptoms (see section 2.1.3), the impact on people's life (see section 2.2), and coping practices (see section 2.3), but they further contribute with new challenges to the existing evidence. The outcomes provide a better understanding of the daily life with HOA from the individuals' perspective, give new insights into the relationship between symptoms, activities and coping, and show people’s limitations, capabilities and accompanying problems on coping practices.

2.1.1.1 Difficulties to start coping

Literature states the importance of an early awareness and an early start of coping to attenuate and control the effects of the condition´s worsening progress [7]. Despite this necessity, individuals perceive their condition at an advanced stage, and start with proper counter measures even later. Individuals reported the challenge to notice their rare, short lived symptoms and signs, and do not relate those to the beginning of the chronic condition. Instead, such occurrences vanish quickly from their minds and they decide to ignore or suppress them, mentioned as bad coping techniques “keeping up” and “covering up” in literature [45]. With time they get used to those problems, thereby letting the disease evolve without any proper counter measures. As frequency and intensity of symptoms are continuously increasing, daily activities become harder to accomplish and at some time a trigger point is reached. This point is often perceived after a severe incidence, letting people realize their condition and taking up first counter actions. However, until this point time has gone by, which could have been used to establish adequate awareness and coping practices.

2.1.1.2 Impacts of HOA on daily life

The findings of the user research confirm and further detail the stated literature (see section 2.2). Results build upon the existing evidence on hands impaired motoric function [37], [10], [27], i.e. handling heavy or small objects and writing, impacted areas of daily living [34], [31], [36], i.e. household chores and mobility, and named impacts from individuals with rheumatic arthritis [30], i.e. opening a new milk carton or jars, cutting, washing, tying shoe laces and doing buttons. Although the stated evidence on the changing appearance of hands mentioned as major concern [22], [35] was partly confirmed by individuals attributing their hands as ugly and trying to hide them in social interactions, others provided a different opinion on it, not seeing it as a major concern and accepting it as it is.

In general, tasks that are done using hands and fingers become difficult to do, and thereby need more time to do them, leading to a reduced work load people with HOA can manage within a day. Handling heavy objects was related to pain and loss of strength, especially affecting household chores. Tasks as carrying a stack of plates when preparing dishes, bringing food from the kitchen to the dinner table, putting a pot of water on the oven when cooking, carrying a bucket of water around when wiping up the floor, or taking a heavy product from the shelf when shopping, are all considered as troublesome. Dealing with small or flat objects was related to reduced dexterity and control, affecting tasks as cleaning up small pieces of glass, picking up medication pills, or turning pages of a newspaper. Furthermore, heavy or small objects are predestined to get out of control and being dropped unintentionally, leading to embarrassment when other people are around, or costs if things got damaged.

Besides the challenges regarding the attributes of objects, the movements of pressing or pulling with hands and fingers, especially if dexterity is required and only few fingers are involved, are burdensome and related to pain. Troublesome tasks involving pressing are cutting hard food as carrots or melons, doing buttons, either when dressing up or using a remote control, or using a mechanical interface of an iron. Pulling tasks are pulling the flap to open a milk carton or tying show laces.

Additionally, impacts on other areas of daily living were found. Activities related to doing handicraft, either when assembling furniture, screwing, using a needle for sewing or holding a nail between two fingers are problematic. Also, gardening tasks, like pulling out weed, harvesting food, or digging holes when planting become burdensome. Furthermore, personal activities as putting on make-up, holding a razor or brushing teeth are considered as painful.

Several new insights were reported on the limitations in the area of mobility. First, keys are harder to hold and use, especially if they are small, making it more difficult to open or lock doors. Second, doors and windows that are already hard to open and require additional strength in hands and fingers are even harder to deal with and painful to open when affected by HOA. Using transport vehicles such as cars, bikes or public transport bring their own difficulties. Hands get cramped when holding the wheel while driving a car, or using a manual gear change is painful. Pulling the brakes on a bicycle was also reported as troublesome. Within public transport getting proper hold is more difficult. Moreover, mobility is also restricted by weather and climate [31]. As individuals are more sensitive to cold and wet conditions, they try to avoid them, for example by not going out on cold and rainy days.

More details were provided on the task of writing. Thereby, the challenges on writing depend on the ergonomic of the used writing utensil and the duration of the activity. Hand writing gets problematic when using an uncomfortable pen, it is painful to type on conventional mechanical keyboards when doing it over an extended period, and when using touchscreen keyboards such as on smartphones, letters are harder to press because of the reduced dexterity

Besides the physical impacts, individuals shared new aspects on the perceived psychological impact of their condition. Overall, the condition requires a high level of motivation and ambition to go on and keep coping with it, and creates a high amount of frustration and fear on individuals. People confirmed the stated evidence on frustration [24]regarding the available controls for their condition. Furthermore, frustration was derived from the unstoppable continuous progress increasing limitations on daily activities and life, dealing with the health system, which lacks proper support and adequate guidance, and non-working or non-effective coping practices. Regardless of this challenge, individuals reported the need to maintain a high level of ambition and motivation to keep coping with the ongoing progress and the importance of adopting a positive attitude regarding their coping practices. Nevertheless, they lack support, and they don't experience the recommended cognitive strategies, as positive thinking, communication and pushing oneself [29], [99], [100]. This contributes to further negative experiences and leads to resignation. Thereby people fear the future and share a pessimistic look towards it, especially the fact that their condition takes over other still healthy body parts and that they will lose important skills and functioning, like when they have to give a hand signature.

2.1.1.3 Challenges of the health system

The ongoing demographic shift brings the healthcare system to its limits, especially regarding the treatment of chronic conditions as HOA [1]. Therefore, provision of adequate help and the transition to the self-care paradigm is of importance in state of the art care [1]. Although literature states and recommends what is required[1], [46], [55], [56], [92], for example individualization of treatment regarding patient needs [43] and providing mixed treatment programs with guidance [48], the results of this thesis indicate that individuals experience quite the opposite when dealing with the actual health system, which is not yet capable of delivering a holistic care approach focusing on individual empowerment and self-care. Moreover, individuals face various challenges with professional treatment, which requires them to not only tackle the burden of their condition on their own, but also to get experts when dealing with the health system, adding one more burden to their life.

Consulting a trusted doctor is part of the first counter measures that people start with. Thereby individuals experience that doctors are not knowledgeable in HOA and not capable of providing any help or not able to tell them what to do. Moreover, identifying the condition and getting the correct diagnosis may require several attempts and years, leading to improper care actions. Furthermore, doctors fail to provide a holistic approach, a guiding path to follow, and tend to prescribe professional treatments only, which is conflicted with recommendations in literature [49], as patient education [46], and focusing on non-pharmacologic treatments over pharmacologic ones [44], [45].The prescription and advice for taking pain medication was controversially discussed. When some used it as their preferred coping strategy against pain, others reported problems with adherence, and took it only in cases of severe pain or even refused to take it regarding its impacting side effects.

The outcomes of user research confirm the needs of individuals, such as having an individualized relationship with a practitioner knowledgeable in OA who provides a holistic approach [49], and restate the problems of lack of help and information, lack of understanding the impact of HOA, and dealing with contradictory pieces of advice, even after consulting professional care providers [50], for example as seen on joint injection therapy. As a result, individuals lack self-care practices, guiding information and accompanying support to perform them. As a consequence of these challenges, at best, individuals try out several care providers until knowledgeable professionals and proper help are found, take part in medical studies to receive helpful information, and do self-research to figure out a way on their own. In the worst case scenario, frustration with the system leads to a reduced utilization of it and its members, leaving people with improper support and guidance.

Another aspect of the problems in the health system is the increased economic impact. Not only costs for medication and special equipment must be taken [41], but also the public health system is reducing cost coverage on available therapies and treatments. This situation gets even worse when professional care providers tend to prescribe costly treatments, which only brings people to their finical limits following their care suggestions.

2.1.1.4 Difficulties on coping

Overall, the outcomes of this study confirm that the recommendations on non-pharmacologic coping practices, i.e. exercising, splinting, physical modalities, and assistive devices were known and conducted by the individuals [43], [46]. However, the knowledge about them and the experience on those practices varied, as they depend on the capability, knowledge, teaching skills, and the guidance and support of their consulted health professional (see section 7.1.1.3).

The fundaments about the condition, knowing coping practices and how to deal with the condition is an adequate patient education in the beginning (see section 2.3.1.1). Nevertheless, when consulting health professionals, for example general practitioners, people heard that there is nothing they can do about their condition and that they have to take it as it is. In the worst case, people got frustrated and let the disease worsen, and in the best case, they tried other ways to gain knowledge, for example through self-research or taking part in medical studies. For self-research individuals used books or searched the Internet. Indeed, unguided self-research lead to other problems, as people end up with the wrong disease and derive incorrect information, leading to even more frustration.

Hand specific exercises as mentioned in the literature (see 2.3.1.2) were done by individuals. However, people lack continuous support and adaptable programs as recommended in the literature [70]. Instead of adequate support, they only got simple instructional sheets. Also, the incorporation of exercises in daily life [73] was confirmed as a problem, as exercises were considered as time consuming, exhausting tasks. Additionally, varying exercise belief [86], [87] could be restated, as for some it was the best coping practice they can do, others experienced it as too painful to do, perceiving no positive effect or were just too lazy to do it. Besides these specific exercises, people experienced that doing physical activities, for example going to the gym or Nordic walking, and just keeping their hands and fingers active were positive counter measures, but they didn´t possess the knowledge about what kind of activities are beneficial for their condition, and they lacked non-expensive professional support.

Although the provision of assistive devices (see 2.3.1.3) is recommended by the literature [59], [89], individuals had varying experiences. Whereas some received specific tools or recommendations from their health professionals, for example an opening aid or a cooling bag, others had to do self-research to find proper tools, for example in the Internet or visiting orthopedic shops. Recommendations of guidance or proper preselection was not seen [88], [89]. The usage of opening aids [99], [101] and thermal applications (see 11.1.6.3) was confirmed by participants. Moreover, a shared coping practice, which was mentioned in the literature [100] was changing the tools individuals used. People replaced tools or devices that were considered too uncomfortable or even painful to use. Important factors therefore were being of low weight to reduce load in hand and fingers, being of bigger size to be easier to grasp, being ergonomic, described as being round, soft, not slippery, and having a proper handle, having convenient interfaces, for example without buttons that must be pressed like touchscreens, and ease the task that is tried to be accomplished with the tool, for example through electrification, like in the case of a tooth brush. Issues regarding assistive devices were the need for ubiquitous availability, proper ergonomics and easy to apply, else they won't be used.

Another practice stated in the literature [31], [93], [96], [102], [98], [101]and confirmed by participants was the application of heat, e.g. through hot compresses or warm water. Furthermore, they use heating beds and heating handles. Besides local heat application, people generally need a warm surrounding. They prefer warmer environments, such as warmer climates and heated rooms and they dress with warmer clothes than usual, all with the goal to keep their bodies and hands warm, which reduces the problems and their intensity caused by the condition.

A common form of self-care practice mentioned in the literature [98], [99], [100] and confirmed by the individuals was changing and adapting the way activities are performed. People reduce their amount of workload, take more breaks within their activities, do their work slower and more carefully, or even try to avoid painful tasks. Besides the tasks themselves, troublesome hand gestures are changed or avoided. For example, individuals figure out the best grip of a tool before using it, try not to involve painful fingers, use their whole hand, or use their second hand as support. People figured out those working alternations mostly on their own, and the literature recommendation for professional guidance on how to alter working methods and movement patterns [97], [101] was not experienced. Although changing the way of doing activities makes people independent, applying it in their daily life was considered time-consuming, exhausting, and sometimes even frustrating, as they have to try it several times until a proper new way is found. If tasks get too painful or people can't do them anymore, they ask other people for help, confirming the existing evidence[29], [31], [100]. Therefore partners, relatives, working colleagues or even foreign people are asked for support to help them or to take over problematic activities. Indeed, not always are others around, not every task can be delegated to someone else who may not be capable of doing it, and asking foreign people may be perceived as awkward and embarrassing. Besides asking for help, paying for support, for example for supporting in household chores or driving the car was mentioned as useful, but also expensive.

Another form of self-care practice as stated in the literature was changing the diet [29], [93], [102]. In this regard, individuals faced the lack of knowledge and information about what is the proper nutrition for their condition and they struggled with the incorporation of new nutrition plans in their daily life.

2.1.2 Opportunities for and requirements of HOA self-care technologies

The second research question RQ2 required finding the opportunities and requirements of self-care technologies for people with HOA. Therefore, the applied prototyping design process provides a characterization of a typical user with HOA through the persona. As the literature lacks a representative description of HOA individuals, the results from user research allowed the realization of a descriptive and representative user characterization in form of a persona, which serves as an underlying base to build on when designing technologies for individuals with HOA. Furthermore, opportunities of needed application are identified through the description of scenarios, and design implications of self-care technologies for users with HOA are stated. Finally, a concrete prototype shows the possible implementation based upon the outcomes. In line with the hypothesis, the results state that derived information from user research is able to provide a technology design process focusing on user needs and their requirements.

2.1.2.1 Application scenarios for HOA self-care technologies

The identified application scenarios for HOA people build on the existing evidence for stated application areas of self-care technologies (see section 2.4.1), but further provide the underlying problems and needs that explain the reason, and additionally show a new area of application. The identified scenario of "Understanding of and awareness for HOA" (see section 6.2.3) fits into the application area of "Providing health-related information". The scenario "Finding HOA health professionals" (see section 6.2.2) partly matches the area of "Collaboration of patients and health professional", even before collaboration can be established, proper health professionals must be found. The scenario "Providing coping strategies" (see section 6.2.4) targets two areas, namely "Providing health-related information" and “Supporting, guiding and suggesting care activities”. For example, individuals experienced a knowledge gap and difficult access to coping practices, which causes the need for applications in the area of providing and suggesting activities (see section 2.4.1.3). The scenario “Exchange individuals’ experience” (see section 6.2.5) directly addresses the application area “Connecting patients”. The scenario “Disease monitoring and assessment” (see section 6.2.6) covers two stated areas, first “Collection of health-related data” and second “Collaboration of patients and health professionals”. The identified area of application “Providing personal assistance” (see section 6.2.1) is not mentioned by the stated literature and thereby offers a new area to consider by future development of self-care technologies of HOA individuals.

Overall, the results show that identified scenarios for HOA individuals overlap with the areas of application mentioned in the literature. Indeed, the identified scenarios show that it is not enough to focus on one single area of application, but on the underlying problem and reason that may connect these areas or focus on specific parts of these areas to provide a helpful technology. Furthermore, the stated areas should be extended by the area of personal assistance, offering possibilities for new applications.

2.1.2.2 Design implications for HOA self-care technologies

The identified design implications for self-care technologies of HOA individuals support the stated literature, but further detail and enhance demanded implications of HOA technology, providing new insights on what is necessary to create a proper technology for these people. Identified implications are the minimum load on hand and fingers, proper ergonomics of hand and grip, non-stigmatizing appearance, robustness, warmness, availability, and time efficiency.

The literature states that if technology is perceived as an enabler that solves present problems it is likely to be used, but if it is seen as a reminder of disability it will be abandoned [88]. Therefore, technology for individuals with HOA must recognize the impact of the condition on fingers and hands. The design of technology must enable people using it with as minimal involvement and load on hands and fingers as possible (see section 6.3.1).

Furthermore, the results confirm that usage depends also on device-related factors, such as technical and ergonomic features [89], but there is a lack of concrete information about what technical attributes are of importance and what makes a technology for HOA individuals ergonomic. The outcomes show that people with HOA have specific ergonomic needs on any device or tool. The results confirm the given literature that the device must be of low weight [89], [90], but further name features as a wider surface to get a good grip on it, and having its handle to be round, soft, thick, but not angular, not thin and not slippery (see section 6.3.2).As individuals have reduced control on their hands, any device is in risk of being dropped unintentionally. Therefore, robustness is one more important requirement (see section 6.3.4).

Another feature that must be considered is that device or its material gives or provides warmness, as individuals feel uncomfortable with coldness in their hands (see section 6.3.5).

In accordance with the stated literature, design implications, such as non-stigmatizing appearance to avoid unwanted attention that challenges users identity [88], [113] (see section 6.3.3), ubiquitous availability when needed [89], [90] (see section 6.3.6), and having time efficient technology [121], [133]as having HOA is already perceived time-consuming in daily life and another time requiring task would make another burden, are important aspects for individuals (see section 6.3.7).

2.1.2.3 Issues of existing technologies and applications

The literature review gives an overview of implementations of self-care technology for chronic condition as osteoarthritis, their tackled use cases, and different kinds of used technology, i.e. web, mobile or wearable (see section 2.4.2).Despite the stated availability and helpfulness of mentioned applications, usage of such technologies was rarely reported by individuals within this study. Several factors contribute to this situation. First, people were not aware of the existence of such technologies, which is caused by the digital divide, i.e. as elderly people are not comfortable with new technologies, negative reservations, i.e. that such applications cannot be trusted, and negative experience, for example when using the Internet for self-research, are hindering people to explore and make use of new applications. Second, available applications are mostly targeting the English speaking area, which makes another barrier for elderly German-speaking people. Third, the mentioned implementations were designed for a more common purpose, i.e. dealing with a range of chronic conditions or arthritis in general, but they lack specific solutions for fulfilling the demands of HOA individuals. For example, user interfaces are designed to be used by hands, the application depends on text-based information, and it is designed for a specific device, e.g. only via computer or smartphone. Even though the given literature on available implementations focuses on possible scenarios and used technologies, it lacks the incorporation of design implication and misses the emphasis on the importance of a holistic concept for the development of self-care technologies for individuals for HOA. When designing technologies for HOA not only the requirements of a software application must be taken into account, but also the needs and demands on how it will be used and on which hardware device it will be accessible.

Therefore, the developed prototype demonstrates a concrete concept for a self-care technology respecting the individual’s needs on scenario and design, bringing the findings together. It provides a feasible solution to tackle the existing gap on coping practices combining the provision of such practices and experience exchange. The video-based approach allows the reduction of load on fingers and the smartphone as target device addresses the implications of ergonomics, non-stigmatizing appearance and availability.

2.2 LIMITATIONS

The overall study design of this thesis has two major limitations, which are the use of qualitative methods and an incomplete design process.

First, the applied qualitative methodologies within user research limit the generalization of the results. The chosen small sample size for the used qualitative methods doesn´t allow the generalization of outcomes. Furthermore, generality is limited by the shared characteristics of participants, i.e. living in Vienna or the suburbs of Vienna and being treated by the General Hospital of Vienna. Participants from other areas and with different treatment history may also show other results.

Second, the prototyping approach covers only parts of a complete user design process. Although the persona incorporates mixed individual perspectives, it can't encompass the various experiences of the whole user research results. Therefore, descriptions of further representative user types are necessary. Furthermore, the completeness and relative importance of the defined scenarios and design implications can't be stated, and must undergo further investigations, i.e. taking these results back to the individuals for evaluation. The same counts for the created prototype. It serves as an example concept in respect to the findings, but to establish the evidence it represents, a proper helpful self-care technology must be further evaluated and feedback from people with HOA integrated.

Despite the given limitations, the outcomes contribute to important insights into the life with hand osteoarthritis and the people's perspectives. The prototype represents a grounded example of opportunities and needs on self-care technologies used by HOA individuals.

2.3 FUTURE WORK

The outcomes of this study provide several starting points for future work. First, based upon the mentioned limitations, further research is needed to establish the reliability of identified user needs regarding scenarios and design implications. Second, as this study only covers the first parts of a user-centered design process, further work should go on, and take the developed prototype “My helping hand” back to the individuals for evaluation, iteratively incorporating feedback, until a first version can be implemented. Third, the identified user scenarios and design implication offer new ideas and opportunities for other kinds of technology that can be developed based upon these findings.

3 CONCLUSION

This thesis is based on the motivation to support people with hand osteoarthritis within the shift to a new self-care paradigm by utilizing nowadays technology. As a new self-care paradigm requires patient empowerment, technology should be an enabler to achieve and strengthen this empowerment, giving individuals more capabilities and opportunities to handle their condition and its accompanying challenges on their own. Regarding the existing burden derived from a chronic condition as HOA, any provided technology must be based on the needs of individuals and their requirements on such application to be considered as helpful and not another challenge to cope with. Any successful technology must be based on a concrete idea or demand. Therefore, this thesis focused on the fundamental stakeholder of any technology, its potential users, which are individuals suffering from HOA, to reveal their experiences, impacts and challenges in their daily life. This target was achieved by conducting a user-centered design approach. Through qualitative user research consisting of interviews, a focus group and a workshop, understanding of the individuals and insights on their daily life was gained, thereby identifying concrete challenges, derived either directly from the condition´s symptoms or when coping with those. The collections and analysis of individuals' experiences built the proper fundament for the next steps within the design process. The outcomes informed the creation of a persona to describe the target user. Based upon this user description, possible application scenarios and design implication on a technology were identified. Finally, a concrete prototype tied all those findings together by giving an example concept for a helpful self-care technology. Although the results of this thesis confirm the literature regarding the impacts of HOA on daily life, problems of coping practices, application scenarios and design implications, new challenges, opportunities and requirements on technology could be identified. Besides issues on the areas of handicraft activities or mobility, also the difficulties to start coping in the early stages of HOA and the challenges faced when dealing with the given health system contributed to the existing evidence. Furthermore, individuals struggled when coping with their condition regarding the low quality of patient education and lack of support on coping practices. In terms of self-care technologies, people rarely reported experiences or did not know about their existence, and the stated implementations within the literature missed to incorporate the full requirements for HOA people, consisting of valid scenarios and demanded design implications. Overall, this thesis emphasizes the importance to respect user needs, especially when developing technologies for critical areas as chronic conditions. Therefore, building a technology based on an identified use case with the solely focus on the software is not enough, but the whole concept of how this application can be accessed, how the user interacts with it and what kind of hardware device is running in their hands, must be aligned towards the user.

- **–** provides the reflection of the key findings of the conducted research compared to the research question and existing literature. Furthermore, the limitations are stated and potential future work is outlined.
- Chapter **Fehler! Verweisquelle konnte nicht gefunden werden.** – **Fehler! Verweisquelle konnte nicht gefunden werden.** – summarizes the process and findings from this thesis.

4 LITERATURE REVIEW

The literature review of this thesis covers a broad range of topics related to the research question. The goal of the review is to describe the fundamental concepts, as the disease itself, possible coping strategies and self-care technologies, to gain a better understanding. Furthermore, issues and gaps are identified.

The review is structured in four parts. First, the disease, hand osteoarthritis, is explained and its prevalence, risk factors and diagnosis are described. Second, the impact of the condition on people's health and life is outlined, comprising the physical, functional, psychological and economic impacts. Third, strategies of coping with the disease are named, consisting of the conventional non-pharmacologic and pharmacologic therapies, and the approaches of patient empowerment and self-care practices. In the last section, self-care technologies are described by showing their areas of application and current implementations. Finally, the summary draws on interesting findings of the review that provides the base for further research within this thesis.

4.1 HAND OSTEOARTHRITIS

Osteoarthritis (OA) is the most common type of arthritis [2]. It is a chronic, degenerative disorder of the articular cartilage associated with hypertrophic bone changes [6]. As no cure for OA is available, it is a major cause for pain and disability worldwide, requiring focus on prevention and early treatment [7].

This section comprises important background knowledge about the disease itself, involving its prevalence, causing risk factors, symptoms and diagnosis. The extended explanation of the pathogenesis is within the appendix section 13.1.1 Pathogenesis.

4.1.1 Prevalence

In Austria a general study on the prevalence of self-reported, doctor-diagnosed OA was conducted [8]. 8.9% of men and 18.4% of women with OA reported severe pain within the last 12 months in hands or fingers, indicating the prevalence for hand osteoarthritis (HOA) [8]. Further information about the epidemiology is in the appendix section 13.1.2.

4.1.2 Risk factors

HOA has a multi-factorial etiology, that can be grouped in systemic and local factors, including modifiable and non-modifiable ones [9], [10]. Whereas systemic factors increase the basic risk for developing osteoarthritis, the local factors influence the site and severity of OA [4]. Important systemic risk factors are age [9], especially over 50 [11], female gender [2], [9] and genetic predisposition [12]. Important local risk factors are obesity, also for developing HOA

[13], [14], injuries or traumas of the joint or parts of its composite structure [15], [9], and mechanical factors, as through repetitive joint usage and excessive joint loading associated with mechanical stress during manual labor [15], [10]. Further information about risk factors is in the appendix section 13.1.3.

4.1.3 Symptoms

The most common symptoms that patients with osteoarthritis experience are pain, bony enlargements, tenderness and stiffness [6], [15]. Pain at joints in general and on usage, that tends to worsen with activity, especially after periods of rest, also called gel phenomenon, is commonly seen [6], [15]. The existence of Heberden or Bouchard nodes and/or bony enlargements with or without deformity are also regularly found at distal and proximal interphalangeal joints [6], [15], as illustrated in Figure 1.

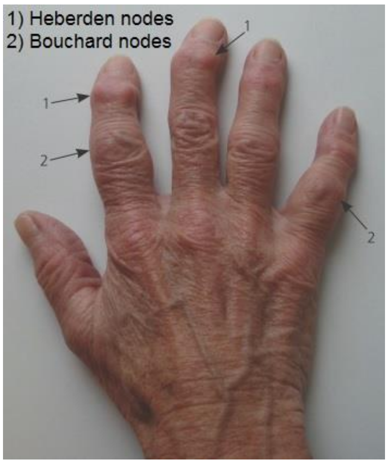


Figure 1: OA Hand showing nodes at PIP and DIP joints [6]

Morning or inactivity stiffness of one or a few joints lasting up to 30 minutes is a typical symptom of osteoarthritis [6], [15]. Also joint locking, joint instability and higher tenderness, especially over the carpometacarpal joint of thumb, are reported [6]. Typical for these symptoms are their asymmetric appearance, as one hand can be affected, whereas the other is not [6]. All these symptoms result in functional impairment, limiting the daily activities of a patient´s life [6], [15].

4.1.4 Diagnosis

A common approach for diagnosis is the clinical definition based on symptoms [7]. Recognizable symptoms are developed at an advanced stage of the disease, prompting the patients to consult health professionals [7]. The American College of Rheumatology (ACR) classifies hand osteoarthritis within a physical examination, if a specific combination of features is present [16]. The main focus is on 10 selected joints, consisting of the 2nd and 3rd distal interphalangeal (DIP) and proximal interphalangeal (PIP) and the 1st carpometacarpal (CMC) joint of both hands [16], as illustrated in Figure 2.

Figure 2: Selected hand joints for ACR classification [17]

The patient must have pain, aching or stiffness in the hand and 3 of the following 4 features must exist [16]:

1. Hard tissue enlargement of 2 or more of the 10 selected joints
2. Hard tissue enlargement of 2 or more DIP joints
3. Fewer than 3 swollen metacarpophalangeal (MCP) joints
4. Deformity of at least 1 of the 10 selected joints

The problem of using symptoms to define the presence of osteoarthritis is that it is detected at an advanced stage, giving it limited capabilities for early diagnosis and successful intervention [7]. To exclude familiar disease as psoriatic arthritis, rheumatoid arthritis, gout or hemochromatosis, differential diagnosis and further examinations through e.g. blood tests are necessary [15]. Other approaches of diagnosis are in the appendix section 13.1.2.

4.2 IMPACT ON PEOPLE'S HEALTH AND LIFE

Osteoarthritis impacts the health and life of affected people in various ways. A study named the main concerns of patients with HOA as pain, stiffness, functional disability, psychological consequences, aesthetic concerns, participation in leisure activities and participation in family roles [18]. Overall, OA is associated with a lower quality of life [8] and a poor health status [19]. The following Figure 3 illustrates the reported quality of life of women and men with and without osteoarthritis [8].

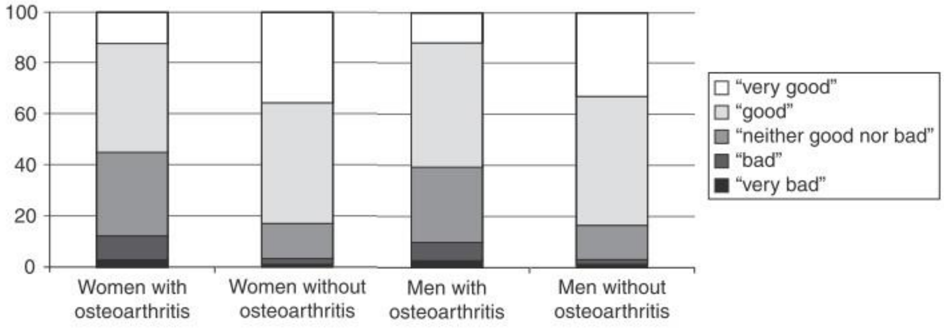


Figure 3: Quality of life for women and men [8]

As outlined in the following sections the main reasons for a reported low quality of life are the experience of pain, limitations in daily activities and aesthetic discomfort [20], [21], [22].

4.2.1 Physical and functional impact

The main signs of osteoarthritis are pain, stiffness and tenderness, varying by localization and severity [6], [15], [3], [19], [8], [23], [24], [25], [26], [21]. Pain worsens with activity of the joints, especially after resting periods [6], [15]. Research states that a higher severity of pain is associated with a lower quality of life [20]. Stiffness typically occurs after inactivity of the joint, e.g. after waking up in the morning, and lasts up to 30 minutes [6], [15]. A higher sensitivity at and around the area of the joint, in medical terms a tenderness on palpation, is perceived [6], [15]. Other reported signs comprise an instability, temporarily locking, reduced mobility of the joint and painful resisted motion [6], [26].

Experiencing the effects of OA results in disability and functional impairment of the affected body parts and increases the physical and psychological burden on the affected, leading to restrictions on daily life [12], [3], [19], [27], [23], [25], [26], [21], [28]. As an example, a major reported problem are activities requiring higher grip strength combined with twisting hand [26] and performing vigorous activities [29]. The loss of strength, i.e. the lower grip strength in HOA, and the perception of fatigue lead to limitations in life and daily activities [12], [19], [27], [24], [26], [30]. Within a study, participants described fatigue as exhaustion, which is increased by pain, pain medication, aging, weather and poor sleep and which affects their mental health and physical function [31]. The level of dysfunction depends on the severity of pain, tenderness, the level of grip and pinch strength, the number of affected joints and the presence of nodules [32]. Having a closer look on the affected joints of the hand, people with CMC joint OA have higher pain and disability than those with interphalangeal joints OA [33].

4.2.1.1 Impact on activities of daily living

OA patients report limitations to do their normal daily tasks, and its negative influence on their occupation, leisure, social life and relationships [3], [24], [34], [35], [36]. It becomes harder to participate in social activities, to do self-care, sports or household chores and the level of mobility outside the home decreases [34], [31], [36]. A frequent use of healthcare providers, analgesics and poor sleeping quality is reported [37], [19].

In HOA fine motoric function is impaired leading to difficulties carrying bundles or heavy objects, lifting 10 lbs., writing, eating, getting dressed, and handling or fingering small objects [37], [10], [27]. In rheumatic arthritis, having comparable effects on hand function, difficulties with tasks of the upper extremity as opening a new milk carton, washing and drying the whole body, cutting meat, dressing, including tying shoe laces, and doing buttons or opening previously opened jars are reported [30].

The definition and research methodology of ADLs is described in the appendix section 13.1.5.

4.2.2 Psychological impact

Patients perceive the effects of OA in various ways, but a negative emotional condition was captured among them [35]. Their concerns regarding the disease were identified as psychological, coping, medication, social and financial [38]. Among elderly people OA is seen as part of the normal aging process requiring acceptance, not treatment, whereas others described managing it as frustrating and upsetting compared with the available controls [24].

The psychological burden of OA includes emotional anxiety, distress, devalued self-worth and loneliness [3], [19], [22]. Through the decline of life activities, especially engaging in recreational activities and social interactions, and an aesthetic discomfort regarding the look of the hand, the risk for depression raises [35], [39], [40]. The change of the appearance of the hands is perceived as embarrassing, and a major concern, especially for women and those with a high burden of HOA [22], [35]. The aesthetically dissatisfaction results in a negative impact on their daily life, related to depression and negative illness perception [40].

4.2.3 Economic impact

The out-of-the-pocket and insurer expenditures are high and increase by age and progress stage of the disease [41], [42]. Main factors are the costs for medication and special equipment [41]. Giving the high prevalence of OA, the aggregate effects on health care expenditures for society are large [3], [42].

4.3 COPING PRACTICES

To cope with the named consequences of OA, several ways exist for affected people. Those strategies range from professional therapies, such as non-pharmacologic and pharmacologic ones, to patient empowerment and self-care practices. The therapies and practices will be described in the next sections to highlight current possibilities and their accompanying issues. Treatments that are not the focus of this thesis research questions or provide little opportunity for self-care technologies, i.e. splinting, physical modalities, surgery, alternative therapies, pharmacologic treatment and joint injections, are described in the appendix under the section 13.1.6.

4.3.1 Recommended treatments

According to the EULAR the optimal management of hand osteoarthritis consists of non-pharmacological and pharmacological treatment modalities [43]. To target the entire disease, a multimodal approach is suggested, having conservative non-pharmacologic approaches as the primary therapy followed by pharmacologic therapies [44], [45]. Non-pharmacologic approaches comprise patient education, exercising, splinting, application of physical modalities and assistive devices [46] and have shown significant functional and symptomatic improvements [47]. Non-pharmacologic management of the disease is of a high importance just like medicinal measures [46], and according to state-of-the-art treatment guidelines should be preferred over providing medications [44]. To ensure effective treatment, this should be individualized bearing in mind the patient's requirements, wishes and expectations [43]. Furthermore, the attributes of the prevalent osteoarthritis, such as localization, severity, pain, disability and restriction of quality of life must be taken into account in order to choose a proper therapy program [43]. Since HOA causes a wide range of impairments and limitations, mixed treatment programs with supplementary guidance and individual adapted treatments are suggested [48].

According to OA patients, their needs, e.g. to control disease symptoms, rely on health services in the areas of medical care, pharmacologic therapy, physiotherapy, exercises and alternative medicines [49]. Regarding care givers, patients prefer an individualized relationship with a practitioner knowledgeable in OA care who provides a holistic approach, including conventional and alternative therapies [49]. Furthermore, a better alignment of health services is an important need to the patients, especially in primary and secondary care, as the amount of different institutions, offerings, information and therapies can be other barriers for attaining an optimal cure [49], [50]. As unmet needs, patients describe a general lack of help and information, lack of understanding the impact of HOA on them, and contradictory advice in how to manage their disease [50]. To satisfy these needs, it is important to reduce clinical uncertainty by increasing high-quality evaluations on treatment options and the provision of written information incorporating the patients experience [50].

In the next sections, interesting conventional treatments and their issues are described, providing opportunities for the application of technology.

4.3.1.1 Patient education

Patient education is nowadays a regular treatment option for patients with OA. The form of education programs varies from simple provision of health-related information [45], [51], to teaching self-care [52], [53] showing self-management techniques [54], [55], [1] to intensive health coaching [56], [57], [58]. Programs are delivered by lay leaders [55] or health professionals [59], as well as disease specialized nurses [48], [52], [60], [61], occupational therapists [48], trained clinical assistants [52], and trained health educators [52], [62]. The delivery of education should be adjunct to primary care and provided on a regular basis [45]. Prolonged and proactive educational follow-ups to an initial education program are suggested to reinforce new skills and ensure a more sustainable effect [52]. According to patients, physicians were the preferred source of information and writing the preferred format [38].

Forms of delivery include written information [63], telephone calls [52] and personal sessions for individuals or groups [52], [60], [61]. Mailed information packs and online education programs are valuable especially to younger people with OA, whereas social media, group self-management programs or telephone helplines were rarely used and not highly valued as source of disease-related education and support [63].

4.3.1.1.1 Delivered content

Educational programs encompass various topics. Adoption of a new lifestyle and maintaining a general good health, e.g. weight loss, nutrition, smoking cessation and low consumption of alcohol are suggested [44]. Managing joint pain is addressed by teaching pain coping skills and showing how to achieve control over pain through proper rest and positioning of the affected body part or utilizing ice and heat [52], [60], [62]. Problem-solving skills [52] and self-management techniques are shown to enhance self-efficacy for coping with pain, fatigue, and limitations in activities or participation [48]. Physical home exercises are lectured to improve strength and joint mobility [48], [62]. Instructing and practicing ergonomic principles, as joint protection techniques like avoiding tight grip [64], is recommended for HOA patients [45], [52], [48], [62], [59]. Bad coping styles as comforting cognitions, decreasing activity and pacing lead to more disability in patients with hand OA and must be changed [65]. Furthermore, assistive devices and their usage are demonstrated [62], and, if applicable, proper splints are recommended [48]. A study revealed that the majority of patients were interested in learning more about illness specific topics, like the disease itself, and about traditional and non-traditional health management topics [38].

Special forms of patient education, i.e. self-management education and health coaching, are described in the appendix section 13.1.7.

4.3.1.1.2 Benefits

Education improves health-related quality of life for patients with hand osteoarthritis [61]. Beneficial physical outcomes of educational programs include improvements in physical health [45], reduced pain [45], [60], control of pain [52] and improvement and preservation of functional status, i.e. of the hand [45], [51], [52], [60]. Psychological improvements include reduced psychological distress, increased self-efficacy, and higher overall satisfaction with health [60]. Teaching pain coping skills increased usage of such coping strategies and lead to reduced use of pain medication [60]. Demonstrating assistive devices increased usage of such devices [61]. Delivering a self-care education program reduced frequency and costs for primary care visits, which exceed the program costs [53]. Enhancing a simple joint protection program by adding an exercise regimen and splinting showed higher improvements in pain, stiffness, grip force and daily activities than the single protection education program [66].

A supportive social environment is of high importance for affected people to keep their valued activities going and protects them against negative effects on their quality of life [23], [36]. An improper understanding of OA and bad coping techniques can make the OA patient feel lack or loss of social support [45]. On one side, the lack of knowledge about OA within the population, considering OA as a minor disease or the fact that OA is not always visible to others, can lead to a lack of social support for affected people [45]. On the other side, bad coping techniques as “keeping up”, i.e. keeping the same level of activity, or “covering up”, i.e. hiding the illness, are applied by people, stating that everything is fine regardless of the disease [45]. Patient education can tackle those issues. By explaining patients that such coping behaviors are leading to a loss of support, help and understanding of their situation in their social life, they can use those in a more thoughtful manner [45]. Increasing health literacy within population may also lead to a higher awareness and understanding of specific illnesses [45]. Another way to face the lack of social support is the provision of health-related information in a regular and personal manner, e.g. via telephone interviews [45].

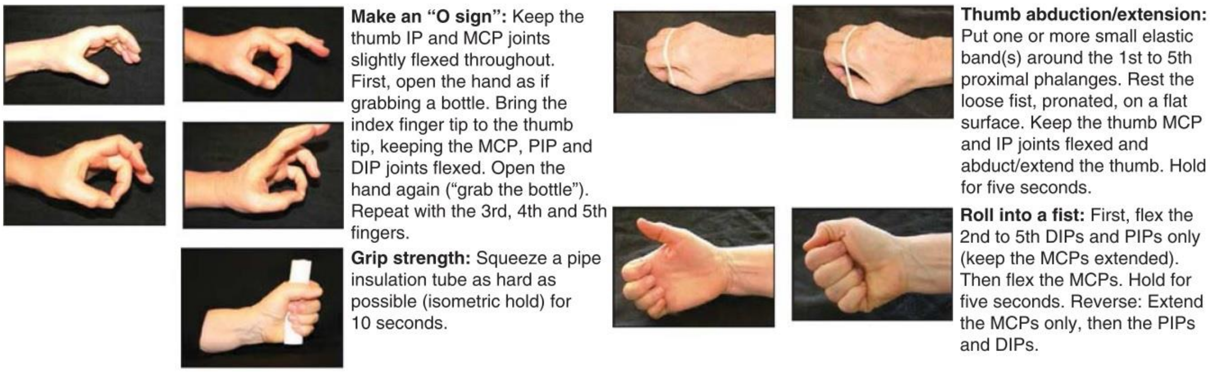
4.3.1.1.3 Issues

To ensure higher outcomes for educational programs, patients’ beliefs [67] and their treatment adherence must be tackled [60]. Patients’ beliefs, i.e. fears and avoidance, can limit efficiency and implementation of education programs and must be assessed and tackled in the beginning [67]. A high treatment adherence must be ensured to increase effectiveness of delivered programs [60].

4.3.1.2 Exercising

Exercise is seen as an important maintenance therapy and recommended for patients with HOA [44], [68]. In general, a moderate mechanical loading is necessary for maintaining healthy cartilage [69]. The goal of exercising in therapy is to increase strength and endurance [46], and especially to strengthen joint-stabilizing muscles [44]. For patients with HOA, motion and strengthening exercises are recommended. These improve pinch and grip strength, range of motion and stability of the first CMC joint [54]. Doing exercise allows the patient to take a proactive role in disease management, i.e. empowering self-management [44], [70].

Various forms and designs of exercising programs exist, depending on the types and compositions of single exercises, and parameters as session frequency, length, intensity and intervals [71]. Special exercises and relaxing techniques can be done for warm-ups and stretching, e.g. yoga [71], [72]. For specific exercises elastic bands can be utilized, and diaries can help the participants track their progress [71], [70]. Developed programs should focus on the localized impairment, functional limitations and disability secondary to inactivity [45]. The following illustration, Figure 4, shows 4 examples of typical exercises that maintain and increase the range of motion, grip strength, and joint stability of finger joints [71].



Make an "O sign": Keep the thumb IP and MCP joints slightly flexed throughout. First, open the hand as if grabbing a bottle. Bring the index finger tip to the thumb tip, keeping the MCP, PIP and DIP joints flexed. Open the hand again ("grab the bottle"). Repeat with the 3rd, 4th and 5th fingers.

Grip strength: Squeeze a pipe insulation tube as hard as possible (isometric hold) for 10 seconds.

Thumb abduction/extension: Put one or more small elastic band(s) around the 1st to 5th proximal phalanges. Rest the loose fist, pronated, on a flat surface. Keep the thumb MCP and IP joints flexed and abduct/extend the thumb. Hold for five seconds.

Roll into a fist: First, flex the 2nd to 5th DIPs and PIPs only (keep the MCPs extended). Then flex the MCPs. Hold for five seconds. Reverse: Extend the MCPs only, then the PIPs and DIPs.

Figure 4: Exercises for finger joints [71]

Helping participants to start up with exercising, programs should be taught and practiced in regular sessions supervised by professionals, as trained instructors or physiotherapist [44], [72], [73], [70]. Important influencers for the uptake of exercising are health professionals, peers and family or friends [70]. After the initial session a continued contact between participants and instructor should be provided to reinforce learned practices and accommodate or refine the program for personal needs [70]. Adaptable programs, which take the needs and situation of individuals into account, are preferred by individuals to be implemented and integrated in daily life [70]. For example, the patients need to keep a balance of rest and exercise, depending on the severity of their problems [46].

4.3.1.2.1 Benefits

Exercising promotes beneficial effects for osteoarthritic (hand) joints and improves general physical health, overall impact of OA and patients' well-being [74], [75], [76]. Main impacts as pain [6], [44], [68], [72], [77], [78], joint stiffness [78], fatigue [68] and disability [6] [70] are reduced, and hand function is preserved and improved [44], [78], [79], [80]. Strengthening exercises increase functional physical fitness [79] and hand strength [81], especially grip and pinch strength [68], [82] and improves people's ability to perform their daily activities [68], [79]. Yoga has been shown to be effective for providing relief in hand OA and improve tenderness and finger range of motion [72].Higher self-efficacy [70], confidence to manage their disease independently [70], and engagement in other physical activities [77], are seen in people doing exercise.

For hand osteoarthritis, exercise programs can be mixed with various other therapy forms, as joint protection [43], [80], manual therapy [83] and splints [84], [85], to improve outcomes.

4.3.1.2.2 Issues

The received benefits from exercising depends on the adherence to it [44]. Regular exercising and adherence to the program is mandatory for a sustainable and long-term positive effect [44], but not exercising is common and doing it regularly is even more challenging for patients [86], [76], [73], [87], [70]. Several reasons indicate non-compliance and must be understood and tackled by health professionals [73]. The willingness and ability to accommodate exercises in everyday life [73], exercise beliefs [86], [87], the physical capacity and confidence about the ability to perform exercise [86], [87] and severity of disease [73] are indicators that people do exercise or not. For example, people that never exercised or believe that exercising is damaging their joints hardly start doing out without proper treatment and support [87]. In addition, other factors as enjoyment, social support, priority setting and context play their role [87] and the experience of adverse events, such as increased finger joint inflammation or hand pain, can lead to withdrawals [78].

In the short-term, participants that experience beneficial effectiveness for their symptoms are more likely to stick to the program [73]. Referral schemes, supervised courses, going to gyms, individualized programs and self-management techniques can help to ease the start with the program and enhance adherence [76], [87]. For example, gyms are preferred by starters, because of the available supervision and social support received there [87]. Furthermore, professionals should try to bolster exercise beliefs to overcome perceived psychological constraints and to strengthen confidence in the ability to do exercise to overcome setbacks and believed barriers [77].

4.3.1.3 Assistive devices

According to the Canadian Association of Occupational Therapy assistive technologies (AT) are defined as "*any device or product that is useful for a person's enhanced functioning and participation*" [88]. The provision of assistive devices is recommended by the ACR for HOA patients to compensate for different impairments [59], [89]. The main aim of ATs is to help and assist people in performing their activities of daily living (ADLs) regarding present disabilities, as impaired hand dexterity or low grip strength [59], [89], [64]. Furthermore, progression of impairment should be prevented, independent task performance increased and the burden on the care-giver decreased [89]. Commonly seen devices within RA patients having hand problems were the tap turner and dagger knife with built up handle [64], and ATs were regularly used for eating or drinking activities [90]. Figure 5 illustrates the results from a study of HOA patients and their usage of provided ATs [90].

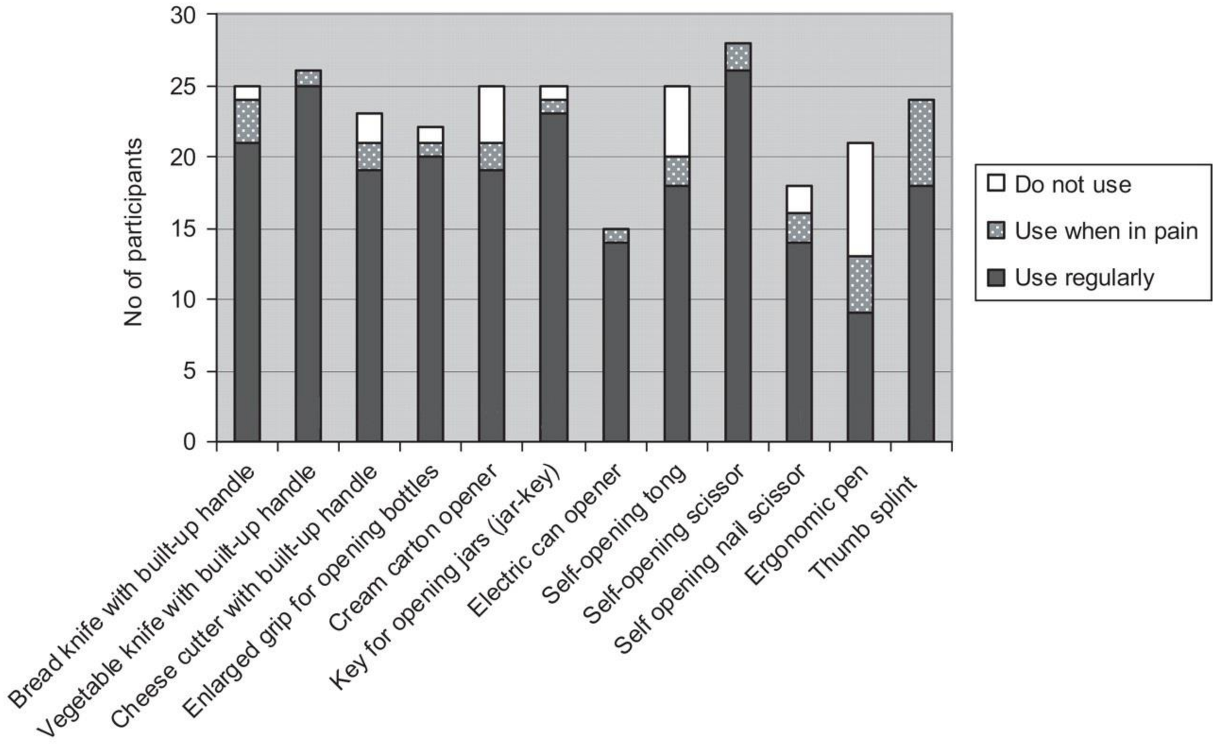


Figure 5: Usage of ATs within HOA patients [90]

4.3.1.3.1 Benefits

Assistive devices are effective for maintaining the integrity of the joints, pain, disability and difficulties in daily life [54], [64], [90]. Activity performance and the satisfaction with the performance, i.e. comfort during activity performance, in daily life is improved [64], [91]. Independence and easiness for doing tasks that haven’t been possible anymore are improved [64] and people can keep their regular roles in life and work [90]. In addition, ATs are a cheap alternative or addition to other available cost intensive treatments and their usage is well tolerated within HOA patients [91]. From a technical and ergonomic perspective ATs were rated as reliable, safe, sturdy, comfortable, and acceptable by patients [89].

4.3.1.3.2 Issues

Although a lot of devices are used, substantial numbers are never used or discarded shortly after their acquisition [89]. According to research, up to 50% of ATs are abandoned, resulting in financial costs for individuals and the public system [88]. Furthermore, the consumer receives negative experiences from misuse or abandonment and is still not able to engage in desired occupations or to perform activities of daily life properly [88].

Within selection, prescription and provision of an AT, e.g. by health professionals, it is important to evaluate and match patients’ needs [88], [89]. A poor selection will lead to non-usage and do people more harm than good, e.g. by limiting ability to interact in daily environments [88]. In the beginning, trainings and briefings to an AT can increase usage rates and improve satisfaction [89]. In general, willingness to use ATs increases by severity of disease, e.g. manifesting in loss of grip strength [64], [90], but also personal, environmental, and device-related factors, such as technical and ergonomic features, determine usage [89]. If an AT is perceived as an enabler and solves present problems, usage and incorporation in daily life are very likely, whereas when it is seen as a visible reminder of a disability or limits daily occupations, it becomes a barrier and may be abandoned [88].

Using ATs can be perceived as a stigma for one's disability and may negatively change one's appearance, leading to unwanted attention [88]. Other people may see users of AT as vulnerable people that need help or charity and have lower expectations of them [88]. Also, opinions and attitudes of other people on ATs have a strong influence on a person's acceptance and willingness to adapt [88]. Those peers can provide information and guidance within selection and utilization of ATs [88]. Use of ATs depends on the individual comparison of perceived effect with respect to their problems with hand function, pain, and performance in ADLs [90]. Devices that are difficult to operate, e.g. if too heavy, unreliable, defective, fail to achieve their purpose, too awkward to use or are simply not available when needed are often discarded [89], [90].

4.3.2 The self-care approach

Nowadays, treatment provided by health professionals is restricted in time, leading to few hours per year for personal interaction between them and their clients [92]. Therefore, it is essential to establish a collaborative partnership between patients and professionals and to focus on empowerment and self-management education [1]. Patient empowerment and self-management give the individual an active role, responsibilities and skills to self-manage their chronic condition [1], [92]. A practical approach of patient empowerment is patient-centered care (PCC) [92]. In PCC the unique needs, concerns, and preferences of the individuals are considered, and the aim is to empower the patient by taking responsibility on their treatment [92]. In order to achieve this, PCC utilizes 5 activities: patient education, patient involvement including shared decision-making, patient empowerment including self-management, involvement of family and friends and physical and emotional support [92].

According to the WHO, self-care is defined as "*activities individuals, families, and communities undertake with the intention of enhancing health, preventing disease, limiting disease and restoring health*" [93]. Those activities can be "*derived from professional and lay experience*" and "*are undertaken by lay people on their own behalf, either separately or in participative collaboration with professionals*" [93]. Effective (self-)management of OA depends on applying a holistic approach, from sufficient self-care practices to the management of psychosocial consequences and life style changes [94], [95]. Delivered treatments with focus on self-care activities and self-management skills have higher outcomes in safety, effectiveness and costs [92]. There is a general improvement on patients´ well-being [95] and those practicing self-management reported less pain [96] and improved self-efficacy [97]. Furthermore, self-management approaches can increase patients' knowledge, symptom management, use of self-management behaviors, self-efficacy and aspects of health status, e.g. improving depression [95].

4.3.2.1 Practices

A common form of self-managing and coping with HOA is activity accommodation by changing and adapting the way activities are performed [29], [35], [96], [98], [99], [100]. For example, people search for different ways to be able to lift and carry stuff, to do housework or to open packaging [98], [99], [100]. A professional guided recommendation to alter working methods and movement patterns of affected joints is known as joint protection principles, including the use of assistive devices and techniques, such as activity pacing [97], [101]. Assistive devices to ease tasks, e.g. for opening packaging or cutting food, are commonly used within OA patients and considered as very effective [99], [101]. Alongside changing the activity itself, the tools and objects people have to deal with, e.g. clothes, are changed [100].

A common form of accommodation is activity pacing and interruption [99], [100]. The aim of pacing is to not overdo things, which could worsen or trigger symptoms as pain or fatigue [99], [100]. Therefore, people plan their daily tasks, split them up in multiple, but shorter time blocks including breaks [99], [100]. With this strategy people slow down and take more time to perform activities [99], [100]. Beside slowing down, resting the hands, using relaxation methods, massages, correct positioning and splints are common forms of preventing pain or to deal with fatigue [31], [102], [98], [100]. If those adapting approaches fail, a last option is to reduce, limit, stop and finally avoid specific activities as a way of coping with the disease symptoms [31], [35], [98], [99], [100].

Lifestyle adaption, manifesting in changing nutrition, i.e. avoiding certain foods and using special dietary supplements are also common self-care activities for HOA [29], [93], [102]. Besides those adapting activities, cognitive strategies, such as positive thinking, positive attitude, communication and pushing oneself to keep on going are important forms of self-management in daily life with OA [29], [99], [100]. Also, asking others for help and accepting assistance in activities are regular ways of coping for HOA patients [29], [31], [100].

There are various conventional non-pharmacologic and pharmacologic therapies people can apply at home. Performing exercises and self-application of heat, e.g. as hot compresses or warm water, are common and effective self-care approaches [31], [93], [96], [102], [98], [101]. To fight against pain, most people take their prescribed medication [93], [98], [100].

4.3.2.2 Issues

Regardless of the benefits, only around 20% of OA patients perform optimal self-management according to clinical recommendations [96], and those with a lower educational level tend to do less self-care activities [102]. Common barriers for individuals to conduct self-care activities are physical limitations, i.e. regarding their disease, lack of knowledge, financial constraints, logistics of obtaining care, and the need for social and emotional support [94].

In order to improve and establish self-management abilities, health professionals should be trained to promote, facilitate, maintain and foster those practices with their patients [95], [98]. Beside professionals, e.g. occupational therapists, as deliverers of self-management skills [97], [98], also peer education with experienced patients as lay tutors can be used as a proper alternative and cost-effective way [95], [99]. In order to improve the design, content and relevance of written information and patient education programs, such material should be developed together with patients, include their recommended self-management strategies and be easily available soon after diagnosis [99].

4.4 SELF-CARE TECHNOLOGY

An aim of this thesis is to come up with concepts for self-care technology that helps HOA patients with their everyday challenges or issues in coping and treatment. Nowadays, lots of OA patients are using technology to gain more information about their issues, e.g. by searching the Internet, and to communicate with their caregivers, e.g. through emails [103]. Modern technologies provide different opportunities to help patients manage their disease. This section will show the areas of application for self-care technologies, and what kind of technologies is already implemented. As specific literature on hand osteoarthritis is few, related rheumatic and chronic conditions are additionally considered. Important requirements and design implications, as patient involvement, effectiveness and motivational user experience, are described in the appendix section 13.1.8.

4.4.1 Areas of application

There are 5 main areas for the application of self-care technologies. Starting from providing, collecting and managing disease- and health-related information, to treatment evaluation, care suggestions and communication and collaboration with health professional or other fellow patients.

4.4.1.1 Providing health-related information

A first way to support self-care and -management is to provide high-quality information about the disease, related treatments, care activities and self-management strategies in an easy to understand format [104], [105], [106], [107], [108]. For example, a study within OA patients reports that around 70% uses search engines or online forums to get more information if they don’t understand the instructions from their clinicians [103]. Medical search engines can offer an opportunity to search this information on disease-specific topics [109]. To ensure proper high-quality information, findings from evidence-based medicine and recent scientific news must be attributed and incorporated in those applications [104], [107], [109]. Patients using such applications can increase their competence handling relevant, disease-related information and it shifts the patient-caregiver relation to a more collaborating partnership in disease management based on a shared burden of responsibility for knowledge [110].

4.4.1.2 Collection of health-related data

As people have the desire to learn about themselves and they are motivated through self-discovery and curiosity, health information, such as signs and symptom, and contextual information, e.g. social activity or exercise lengths, can be collected, aggregated and made available to patients and health professionals [5], [111]. The collection of data can be done by self-tracking of biological, physical, behavioral or environmental information [112]. Data capturing can be done through qualitative methods, e.g. with self-reported questionnaires describing levels of pain or mood, or quantified forms as monitoring devices, e.g. automated wearable devices measuring one’s pulse [5], [112], [113], [110]. Collected data, and the act of collection as taking a measurement, can help patients to understand and be more aware of their disease, body and habits, which is essential for developing confidence in self-managing a chronic condition [5], [111], [110], [114]. On a longitudinal view, the retrieved data make it possible to track one’s health and condition and provides a grounded base for monitoring progression and activity of the disease [104], [106], [113].

Collection of data should be easy and best if done automatically to reduce patients’ efforts [111], [115]. Personal data should be displayed in an easily readable, graphical format, it should provide ways for introspection or self-experimentation and it should support the discovery of patterns and trends informed through medical evidence [111], [112].

Personal, health-related information, such as captured data, treatment plans or prescriptions should be available at one place and accessible for patients and their caregiver [106], [113]. Within an OA study, around 70% of people tracking or monitoring disease reported to already share the captured results to their physicians [103].

4.4.1.3 Supporting, guiding and suggesting care activities

Interactive technology offers the opportunity to deliver and support individualised self-management activities, especially in early disease stages [107]. When learning about a condition, an application can provide care practices and give feedback to develop and improve self-management, e.g. through making suggestions for specific activities or treatment adjustments based on available information [106], [5]. Such feedback can be based on the tracking of individual’s conditions and treatment actions [106]. For example, a prescribed pain-coping skills training can be delivered online [116]. Supporting self-management can be realized with features, as alerts for taking medication, explaining therapeutic and side effects of treatments and giving practical tips to improve one's condition [104]. Findings show that an online self-management program positively impacts self-efficacy and catastrophizing [117].

A widely used scenario is the guidance and assessment of physical activity and exercising [113], [118], [119], [116], [120]. Physical activity improves quality of life, but anticipated pain exacerbation, lack of confidence and long-term adherence is challenging for individuals with chronic conditions [118], [119]. Through guidance, support and motivation, technology can address these challenges and provide the individuals a tool to self-manage and track their physical actions [118], [119]. For example, provided calendar features for goal setting, planning, and recording of physical activity performance and progress help people to reach therapy goals [119].

4.4.1.4 Collaboration of patients and health professionals

Patients usually have regular, co-located meetings with their health professionals to review their condition, adjust treatment and discuss their other issues [5]. Therefore, effective and valuable communication between patient and their caregivers is essential to ensure adherence, compliance and engagement of the patient [103]. A study within OA participants reports that answering upcoming questions after a meeting with their clinician, most prefer phone calls over email and text messaging to communicate with their doctor [103].

Nowadays application of technology provides new ways of patient-caregiver interactions that can benefit communication, collaboration and coordination of care and therefore plan treatments more effectively and save patients' time and costs [5], [121]. Applications can enable remote feedback and advice from caregivers, and provide a more informed interaction with them [108], [5], [113], [122], [123]. New technology, such as videoconference tools for remote consultations, online forums for discussions and recorded consultations, educational sessions, e.g. trainings, can be available independent from location and time [5], [110], [116], [123]. For example, self-reported symptoms and collected data of the patient can automatically be reported and monitored by health professionals, creating a fundament for discussion, enabling an enriched treatment and compliance evaluation and informing clinical decision-making [104], [5], [121].

4.4.1.5 Connecting patients

Patients have the need to connect with other people suffering the same condition [5]. By sharing and exchanging their experiences regarding their condition, people can learn from others, understand how others cope with it, validate their practices and theories and gain emotional support [110], [5], [112]. Technology can therefore facilitate new ways of communication and interaction to support patients collaboration, from simple chat tools for contacting peers, to a system enabling patients to perform care activities or exercises together [104], [108], [5], [112]. As an example, online forums or online support groups, empower people to talk about their experiences and concerns, forming a recorded knowledge base of lay experience and giving new patients the opportunity to learn and discover issues they will face [110], [5], [112]. Especially the provision of emotional support through fellow sufferers in online discussions has an important effect, giving lonely people the feeling of belonging to a group and making them feel safe [110], [5]. For example, social support elements on websites lowered health care utilization, medication overuse and increased empowerment [124].

4.4.2 Implementations

Literature provides a wide range of applied technologies for chronic condition, especially rheumatic diseases, as OA. Regularly used technologies are web applications for personal computers, mobile applications for smartphones and monitoring applications connected with wearable devices [5]. Less implementations are seen for desktop application, tablets and smart televisions [5].

4.4.2.1 Web

Web-based applications are regularly used to deliver clinical interventions to their users and therefore show beneficial outcomes [108], [117], [124], [125]. The former obstacle utilizing such technology excluded senior, minority and lower-income people, but this digital divide is narrowing day by day [110]. Delivering physical activity and exercises to patients is a commonly implemented use case, showing positive outcomes for pain and function [116], [120], [126], [127], [128], [129], [130]. A mix of different features is often provided, containing related information, communication tools, task and scheduling support, assessment instruments and progress tracking [120], [131], [132]. Learning materials about the disease, physical activity and exercises, self-management and coping strategies are regularly provided [108], [116], [125], [128], [132]. Enabling patients to communicate with health professionals or fellow patients is done via synchronous, e.g. Skype, or asynchronous tools, e.g. as e-mail and discussions forums [108], [116], [120], [125], [128], [131], [133]. The typical web-based intervention is used once a week, modular in set-up, updated once a week and used for about 10 weeks [131].

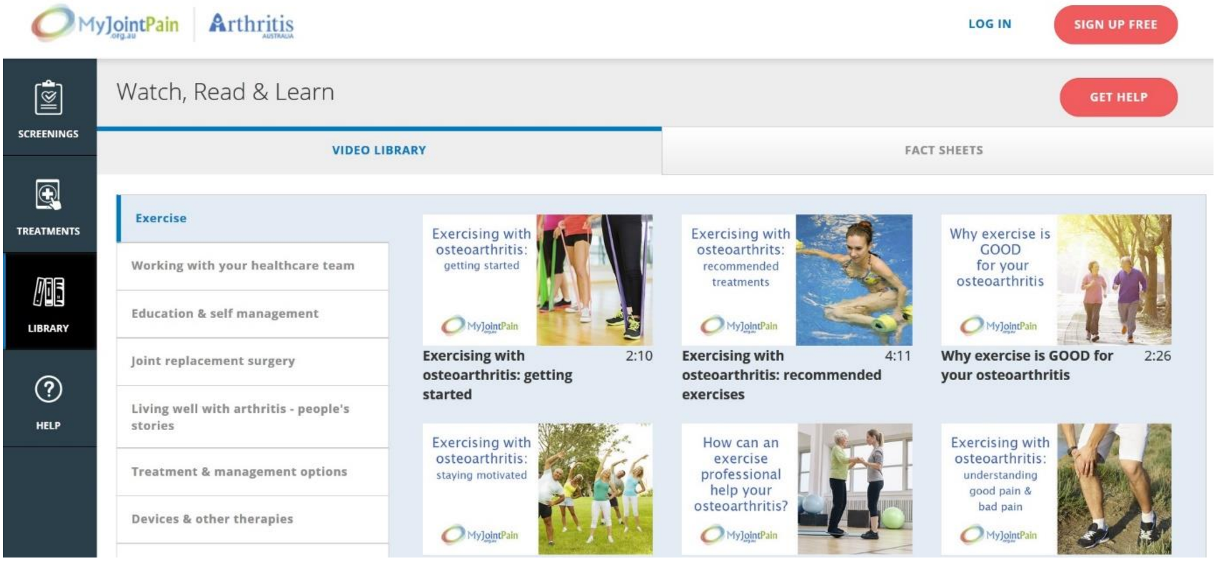
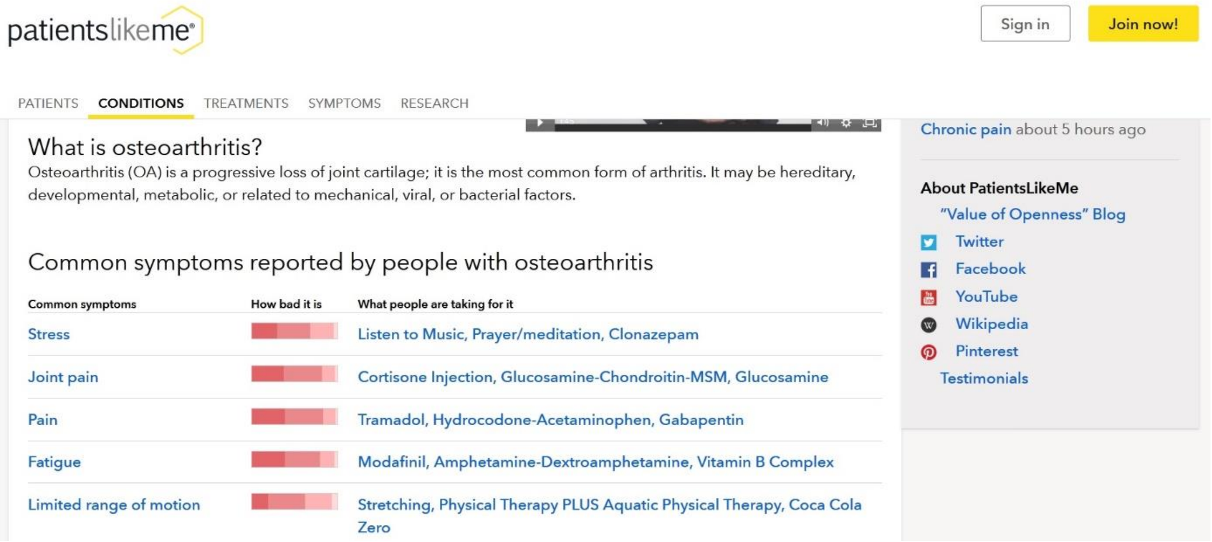


Figure 6: Disease-specific library provided by MyJointPain.org.au [132]

Special types of websites are health social networks, which are successful in bringing people with shared interests together [112]. Those sites provide functionality, as emotional support, information sharing, Q&A with health professionals and quantified self-tracking [112].



What is osteoarthritis?

Osteoarthritis (OA) is a progressive loss of joint cartilage; it is the most common form of arthritis. It may be hereditary, developmental, metabolic, or related to mechanical, viral, or bacterial factors.

Common symptoms reported by people with osteoarthritis

Common symptoms	How bad it is	What people are taking for it
Stress	▨	Listen to Music, Prayer/meditation, Clonazepam
Joint pain	▨	Cortisone Injection, Glucosamine-Chondroitin-MSM, Glucosamine
Pain	▨	Tramadol, Hydrocodone-Acetaminophen, Gabapentin
Fatigue	▨	Modafinil, Amphetamine-Dextroamphetamine, Vitamin B Complex
Limited range of motion	▨	Stretching, Physical Therapy PLUS Aquatic Physical Therapy, Coca Cola Zero

Figure 7: Looking up OA at PatientsLikeMe.com [112]

4.4.2.2 Mobile

Nearly 50% of participants within an OA study reported owning a smartphone, which is used daily by 75% of them [103]. The most applied use case was making phone calls, around 75% used it for text messaging or browsing the Internet, and nearly half for sending emails [103]. Beside the conventional functions, mobile devices have evolved to enrich functionality and are regularly used for providing chronic disease self-care technology, also called m-Health applications [106], [5], [134]. Mobile-health apps are able to deliver health-care in an easy, cost-effective, continuous, pervasive manner, independent of location and time [105], [106],

[134]. Especially smartphones, which are nowadays globally present and accepted in society, provide a reliable, computationally powerful base for developing personal, intuitive and information intensive applications to support their users in daily activities [105], [134].

The conventional style of communication can be improved by sharing data and using new communication forms between patients and health professionals, e.g. sending advice and guidelines to a distributed community [105], [134]. Smartphone applications have been developed to provide access to health-related information, informing about the condition, and delivering a disease-specific educational and psychosocial, lifestyle and treatment interventions [105], [134], [135]. Mobile apps, which provide self-management programs, enriched with guidance and support in managing disease-related symptoms, disease consequences, treatments and lifestyle changes are required and already used by patients, giving them a more active role in treatment and improve their quality of life, health care utilization and self-efficacy [104], [105], [134]. One example of this is the support within a physical activity program for patients with rheumatic disease, providing features as personal goal setting, crafting exercise plans, high customizability for adjustments and communication with peers [136]. Another area of application of mobile technology is measuring, monitoring and assessing a condition and its symptoms [105], [134], [135]. Especially the need of chronic conditions for continuous monitoring and regular assessment through health professionals providing feedback can be done remotely and asynchronous by mobile applications and shows beneficial outcomes [134], [137], [138]. To enhance such use cases, modern built-in sensors in the smartphone, e.g. accelerometers measuring motion or body-worn, ambient sensors, e.g. measuring heart rate are utilized to establish a rich data set [134], [139].

Still, the moderate to high price of smartphones is not affordable for people on lower socioeconomic levels and the understanding and adaption of new technologies is harder for elderly people, which limits utilization [104], [105]. Another concern is the rare availability of high-quality apps which have proper medical evaluation and provide outcomes from evidence-base medicine [137].

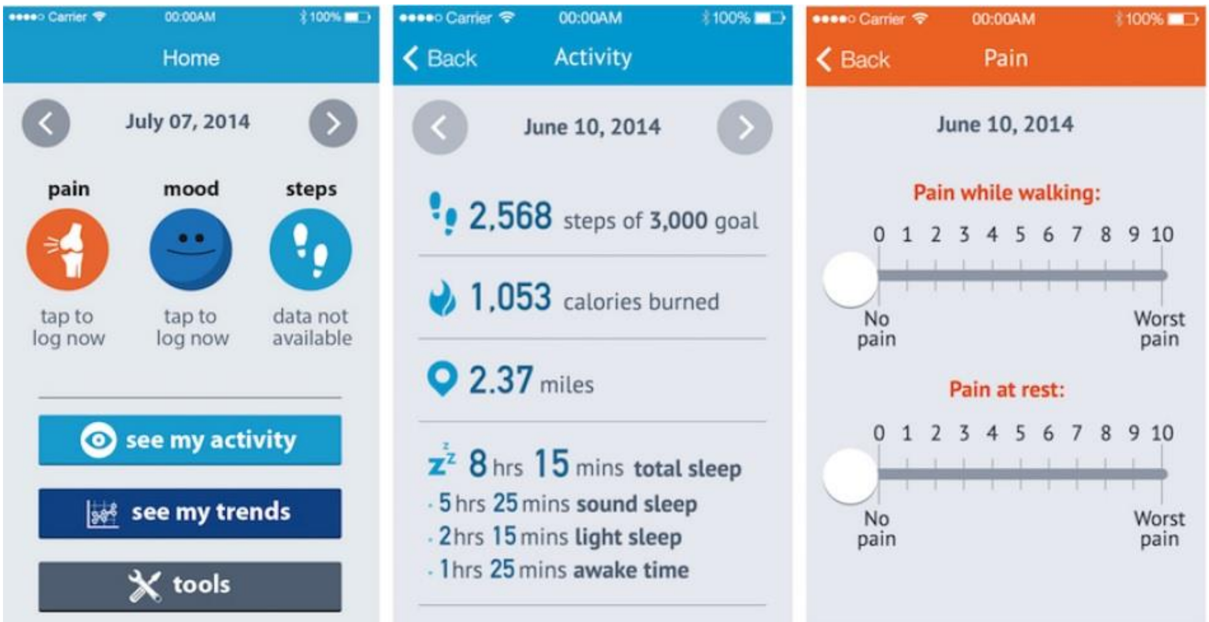


Figure 8: App OA Go with monitoring and activity support [139]

4.4.2.3 Wearables

The third form of applied technology are small, unobtrusive wearable devices, especially wearable sensors measuring and monitoring specific values [110], [5], [113], [114]. They were used for exercise guidance, assessment, unobtrusive data collection and continuous monitoring, helping patients managing their medical conditions at home, e.g. within OA rehabilitation [110], [113], [140]. By connecting the devices to the internet, data can be communicated, e.g. to a health professional or assessed manually or automatically by program [110]. Wearable technology showed beneficial outcomes for OA management, i.e. for the effectiveness of and compliance to a delivered treatment and patients were supportive using them [113], [121], [140]. Patients reported benefits as feeling in control of their condition, providing awareness regarding disease progress, empowering self-management and improving communication with their clinician [140]. Beside those advantages, collected data is rarely integrated into proper chronic disease self-management programs and evidence for sustained effects is lacking, regarding a focus on feasibility and short-term outcomes of available studies [114].

4.5 SUMMARY

The literature review describes the disease itself, the influence on the sufferer's daily life, coping strategies including their issues and the opportunities of self-care technology. The final goal of this thesis is to come up with a helpful self-care technology. Therefore, it must be clear which problems are relevant to HOA patients and how those issues are offering opportunities for technologic implementations. Two identified gaps need further consideration within this study.

First, there is very little literature about HOA patients' experiences regarding their daily impacts, challenges, coping practices, treatments and used technology. It is important to identify the relevant issues and needs for their daily life and their daily activities. Therefore, it must be investigated which disease impacts are relevant to them, what kind of coping strategies are they aware of, what kind of coping do they perform and what are their related experiences on them. Furthermore, it is of interest how impacts and coping are connected, e.g. what kind of coping is performed against what kind of impact.

Second, self-care technologies for HOA patients are rare. Therefore, the aim of this thesis is to come up with promising concepts that reflects patients' needs. In order to develop a helpful technology we must establish who the user will be, what the use case will be, and what the design implications are. Within the literature review the named impacts of the disease, e.g. psychological and economic impacts for HOA patients or treatment issues, e.g. finding a proper health professional, individualize and adapt treatments, deliver education or self-care practices, or social support, already allow ideas for helpful technologies, but they must be reviewed for their relevance and feasibility.

5 METHODOLOGY

This chapter describes the overall methodological approach used for this study, consisting of the subsections study design, participants and applied methods. Within the participants' subsection the recruitment including the application to the ethic commission is described. Within the methods' subsection literature background and implementation of each method are explained.

5.1 STUDY DESIGN

People with chronic conditions, such as OA, have specific demands on technology, e.g. regarding their disabilities, and therefore their involvement and participation in the creation and design process is of importance to ensure an effective and useable solution for their problems [105], [106], [118], [123], [134]. Consequently, patients' needs, knowledge and expertise, e.g. their coping strategies, should be investigated and utilized to build useful technologies that support daily self-care [118], [141].

Taking this into account, the overall design of this study covers parts of a user centered design process (UCD) by focusing on user involvement and founding the concept for a proper technology based on their expertise and perspective [142]. Therefore, in the first stage, qualitative user research methods of interview, focus group and workshop are used to gain a deeper understanding of the individuals, their issues and needs [142]. The outcomes will be analyzed and used to inform the further prototyping design process. This process consists of the creation of a persona to identify and characterize the user group, the description of possible application scenarios and the design implications for a proper self-care technology. Based upon those results a prototype of a self-care technology for HOA people is developed. The following illustration gives an overview about the overall methodology and study design.

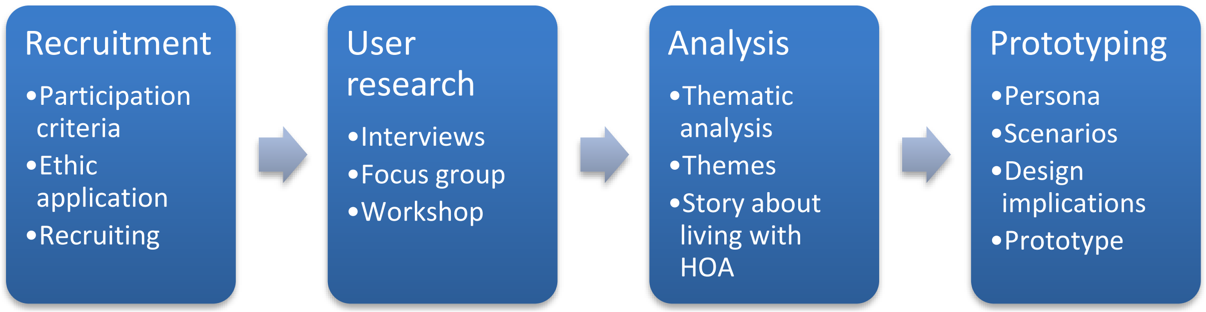


Figure 9: Methodological approach

5.1.1 Cooperation

This thesis is part of a research project in cooperation between the Vienna University of Technology, the Medical University Vienna and the St. Pölten University of Applied Science. The project was partly sponsored by the Ludwig Boltzmann Gesellschaft.

5.2 PARTICIPANTS

In this subsection the recruitment process is described, starting with the definition of the required sample size and participants criteria, over to the application at the ethic commission, and ending with the final recruitment of proper participants for each method.

5.2.1 Sample size

Qualitative research typically uses small sample sizes with a diverse range of participants. Indeed, choosing a predefined sample size within qualitative methods is limited, and therefore we follow the pragmatic approach of saturation [143]. Considering the aim of the user research to inform the following prototyping design process, saturation is given when data is sufficient to derive user description, scenarios and design implication, and nothing new relevant is added during conduction of the methods [143]. To start with the suggested sample size, we have about 6 people for the in-situ interviews [144], 6 for the focus group [145] and about 8 [146] for the design workshop. Supposing that not everyone will take part in every method and a small dropout rate about 10%, the maximum number of participant recruitments was targeted 1 – 2 more for each method. Furthermore, the recruitment goal was to have a core group of people attending every method, filled up by others as demanded to reach the maximum sample size.

5.2.2 Participation criteria

Participants had to be diagnosed with hand osteoarthritis and had been in ambulatory treatment rheumatology outpatient clinics of the General Hospital of Vienna, at least once in the past 5 years. Their age may vary between 18 and 85, and they must be psychologically and physically self-capable to cope with their daily life. Capableness was determined through the possibility to get to the hospital for attending the study on their own. Furthermore, people with additional diseases that require special treatment were excluded. Matching defined criteria was first assessed by the available data at the outpatient clinic, and reassessed during the first contact, i.e. phone call, with the potential candidates.

5.2.3 Ethic commission

For accessing patient data and contact permission, the study was submitted online at https://ekmeduniwien.at to the institutional review board and ethics committee of the General Hospital of Vienna, positively reviewed and confirmed by this commission. The application included a description of the study, an informed consent for the participants, a personal CV, an initial interview guide with example questions and a conflict of interest statement. The mentioned documents are available in the appendix section 13.2.

5.2.4 Recruitment

With the help of a doctor from the rheumatologic outpatient clinic of the General Hospital of Vienna and her working colleagues, a list of potential participants was created. Patients were called, the study was explained and we asked for their participation. On agreement or interest, personal data was noted. Email addresses were added too, in case they had one. Afterwards, e-mails, consisting of a brief study description, explaining purpose and procedures, and the informed consent were sent to the participants. For every user research phase separate appointments were organized with the potential participants and one day before a reminder was sent by e-mail, phone call or text message. The informed consent was returned by e-mail or during first appearance within the study.

5.2.5 Handling patient data

Personal patient data was separated from the collected data of the study. Every participant received a unique code during the study, written on the informed consent, to link it to the data sets. Personal data, e.g. contact data, was used within the study only for organizational purposes and afterwards discarded. Only the code, year of birth and gender were saved afterwards. Data will not appear in the records of the patient at the clinic so the treatment of patients will not be affected by anything that patients might say during the qualitative study. The patients received information about handling their data in the informed consent.

5.2.6 Recruited participants

13 participants were recruited for the study, thereof 8 female and 5 male hand osteoarthritis patients between the ages of 57 and 77. The problems when contacting potential patients were the outdated set of contact data, invalid phone numbers or only mailbox answering. The reasons for not being interested or able to participate were no interest in the study subject, a bad personal health condition, no more problems with their hands, moved too far away from Vienna or hard to schedule a possible appointment regarding occupation, nursing duties for relatives or holidays. Within the focus group, 2 participants did not show up, 1 because of illness and 1 without notification, and within the workshop, 2 participants missed the appointment because of sickness.

Code	**Characteristics**		**Participations**		
	Sex	Year of birth	Interview	Focus group	Workshop
MQOA-IV01	M	1948	✓	✓	
MQOA-IV02	W	1942	✓		✓
MQOA-IV03	M	1952	✓	✓	✓
MQOA-IV04	W	1958	✓		

MQOA-IV05	M	1958	✓		✓
MQOA-IV06	W	1961	✓	✓	
MQOA-FK01	W	1941		✓	
MQOA-FK03	M	1953		✓	
MQOA-WS03	W	1941			✓
MQOA-WS04	W	1947			✓
MQOA-WS05	M	1959			✓
MQOA-WS06	W	1955			✓
MQOA-WS07	W	1951			✓
13			**6**	**5**	**8**

Table 1: Recruited patients and their participations

5.3 METHODS

In this subsection all applied methods within this study are described, including their literature background, their justification why the method was used, and implementation details during application.

5.3.1 In-situ interview

As one of the fundamental axioms in social sciences, it is stated that what people say they do and what they actually do is not always the same [144]. This counts for health habits too, and therefore in-situ interviews, a combination of contextual inquiry and observation, can tackle that issue and deliver interesting insights [144]. First, contextual inquiry consists of observing and talking with your participants in their contexts as they do their real daily activities, revealing participant's practices and needs [147]. Second, participant observation is a method in which the observer joins daily life of the people under study, here in the role of researcher, observing things that happen and listening to what is said [148]. Before applying those methods it is essential to know what the central concern is, who, what, where and when to observe, and what to ask [147].

Besides the familiarisation with the participants and their context, the interviews started from basic facts of patients' osteoarthritis, to how OA is affecting and changing their daily life, and ended with coping strategies and treatments. The following topics related to the central research question were tackled within the interviews:

- Experienced problems regarding their condition
- Impact on daily life, including affected activities of daily living
- Coping strategies, including self-care practices and accompanying issues
- Usage of technology as part of coping strategies

For the interviews a guide was created, containing a checklist for necessary preparation tasks and a step-by-step code of conduction, comprising introduction steps to the interview, interview topics, example questions and post-interview doings. The developed guide is available in the appendix section 13.3.1. Given the complexity of human behaviour, it is impossible to notice and record in real time everything that is of interest to the researcher [144]. Thus, audio records of the full interview supplemented by photographs of specific objects and video records of actions were taken, which give the possibility for a better understanding of the interviewees' environment and habits, e.g. to watch records multiple times with different observational focus and viewing point [144]. Six interviews took place at the homes of the participants, varying between 1 and 2 hours, resulting in 6 audio tapes between 30 and 50 minutes, 12 photographs of found objects and 7 video clips of interesting activities. Each interview was reflected upon by writing up positive and negative experiences and collecting points for improvement in the next session. Reflection notes on the conducted interviews are in the appendix section 13.3.5.

5.3.2 Focus group

Focus groups are a form of group interview that take advantage of communication between research participants and other group interaction in order to generate data for a specific topic or research question [145]. The discussions can provide information about a range of ideas and feelings that individuals have about the given issues, as well as illuminating the differences in perspective between groups of individuals [149]. The method is commonly used in the scope of health care and disease issues for exploring people's knowledge, their experiences, what they believe, what they think, how they think and why they think that way [145]. The concept of the focus group was adapted here to accomplish an explorative discussion group for sharing experiences, ideas and thoughts.

For recruitment, an invitation e-mail was created and sent to the participants of the interviews and other eligible patients, describing the goal and form of the oncoming study part (see appendix section 13.4.1). A guide was developed, containing goals, questions, preparatory and organizational tasks to do, (see appendix section 13.4.2). Patients were asked to bring a personal object that is meaningful and important in their daily lives regarding OA, with our intention to encourage discussions and break the ice [150]. Related to the central research question, the goals of this session were the following:

- Finding out which kind of challenges people with HOA experience in their life and ADLs
- How they are coping with those challenges
- Gathering notions about existing methods and solutions

Therefore, the session was split into 2 parts, first discussing general, specific and ADL-related impacts of OA, and second discussing people's coping strategies, their brought-in objects and a prepared set of other available solutions and technologies. To have an easy start into the discussion, the session was started with a write-down action, i.e. “Write down 3 impacts of OA on your life and activities”. The discussions were audio recorded and transcribed [145]. As recommended 5 patients participated, the session lasted about 2 hours with a short 10-minute break, and took place in an adequate conference room at the General Hospital of Vienna [145], [149]. The output was 2 audio records, together lasting about 2 hours. A reflection on the conducted focus group is in the appendix section 13.4.6.

5.3.3 Workshop

A design workshop is not a specific method itself, but rather a set of creative and collaborative activities, e.g. discussions, games or role playing, utilizing materials, e.g. Post-Its, cards or posters, and involving concerned stakeholders to create a participatory design process [146], [151]. The format of this session was an adaption of the concept of a Future Workshop, comprising a critique and fantasy phase [151]. In all phases small and large pieces of papers, i.e. Post-Its and Posters, were used to document and describe individual thoughts, opinions, and outcomes of the participants [151]. Discussions were audio recorded and transcribed. As in the previous session an invention e-mail was developed, describing goal and format of the session, and sent to eligible participants (see appendix section 13.5.1). Additionally, a conduction guide was developed, covering the session goals, conductional steps and preparative steps, as well as the required materials of the workshop (see appendix section 13.5.2).

The first phase of the workshop consisted of 2 subsequent critique phases on the topics “Problems of OA” and “Managing OA”, each starting with a poster session for gathering and prioritizing issues, followed by a discussion round. In this phase, participants criticised current situations and practices and clustered the outcomes into a number of problem areas [151]. The individuals wrote down their thoughts on a given issue on Post-It’s, i.e. impacts of OA on daily life in the first session, and management of OA in the second one. The initial broad topics were detailed and supported with specific areas found in the earlier sessions, e.g. detailing impacts of OA by problems in the household. At the end, the participants had to prioritize the given outcome by putting a red marker on their 2 most important concerns in the first session, and by marking good and bad management strategies in the second. Both poster sessions concluded with a discussion round of the previously mentioned issues.

The second phase consisted of 2 fantasy phases, based on 2 scenarios on the topics “Ideas that will ease my life” and “OA website”, giving participants the opportunity to describe their wishes and thoughts under 2 defined scenarios. First, an empty page only showing the question “What can make the world for people with osteoarthritis easier?” for gathering people’s ideas, and second, a website context displayed by an empty browser window on the page with the aim to let participants describe a website that fulfils their needs. In the fantasy phase, the participants create visions and come up with ideas about how to deal with the problems identified in the previous phase [151].

10 patients confirmed participation, but due to sickness 2 dropped out. Finally, 8 patients took part in the session, which lasted about 2 hours, from which 15 minutes were for the introduction, 60 minutes for the first part, 30 minutes for the second part and proper breaks in between. It took place in an adequate conference room at the General Hospital of Vienna (see appendix section 13.5.3). The output of the session were 2 main posters (see appendix section 13.5.4) covering issues of impacts and management, 1 audio record about 40 minutes of discussion, 16 filled prepared scenarios for ideas that can ease life and proper websites. Additionally, 2 study colleagues observed the session and produced 8 pages of written notes. The audio record was transcribed and all retrieved data, i.e. the transcript, the summary of posters and scenarios, and notes was structured and gathered in one document for starting coding within the thematic analysis. Reflection notes are in the appendix section 13.5.5.

5.3.4 Data collection and preparation

Through the 3 methods data was collected by audio recording devices producing audio tracks of talks and discussions, by video recording devices producing photographs of interesting objects and short video clips of actions, and by participants, facilitator and assistants producing written notes. Analogue material, such as written notes, posters, and prepared scenarios was digitalized, and the audio records were transcribed.

5.3.4.1 Transcribing audio records

Transforming audio records into written form is apart from a straightforward technical task, the first interpretive process within data analysis [152]. Regarding the study, its aim and applied methodological approaches, considerations and decisions must be taken into account in order to represent captured data [152]. Therefore, decisions regarding the level of detail, e.g. skipping non-verbal dimensions of interaction, data interpretation, e.g. distinguishing “I don’t, no” from “I don’t know”, and data representation, e.g. verbalization of “Hwarryuhh” as “How are you?” must be made [152].

As the languages used in the interviews were a varying set of German Austrian slangs, the audio data was transformed into standard German with respect to keeping found evidence in order to gain a better understanding and comparability. Typical slang words were translated into their German relatives. To enhance readability of the transcript, wrong grammar or word order were corrected. Talking artefacts, which add no more value to the transformed data, i.e. thinking pauses during the conversation, stammering as “Ähm, ähm,…”, repetitive use of words as “Yes, yes, yes”, half sentences used when searching for the right words like “How should I say it…”, “Let me say it as,…”, informal confirmations as “Yes, yes,…”, “Mhm”, “Aha”, “…, or?” and noises as coughing were shortened to the relevant information or, if possible, omitted. Interesting non-verbal features, e.g. gestures pointing at a hurting finger, were added to the transcript. All adaptions during transcriptions were performed trying not to lose or change the meaning of what was said.

Each transcription file names the source, i.e. the name audio file, length of the audio record, date of the session, e.g. interview or focus group, date of the transcription, name of the interviewer and transcriber and the used source and target language, i.e. German. The transcription files of the interview are named according to the code of the interviewee and the interviewee himself is represented through the information about gender and year of birth. In the transcription files from the focus group all participants are named with their study code, and all text parts are linked to those codes, linking passages with participants. Each transcript contains timestamps, marking the times within the audio record. Square brackets explain non-recorded occurrences, such as pauses within sentences, unexpected interruption by pets or phone calls, and interesting gestures of the participants, e.g. pointing to a hurting finger. For the focus group, associated talks have their separate passages, and agreement or disagreement within discussion is mentioned in square bracket explanations.

The appendix provides example snippets of the created transcripts for the interview in section 13.3.2 and for the focus group in section 13.4.3.

5.3.5 Thematic Analysis

Thematic analysis is a qualitative research method for systematically identifying and organizing patterns of meaning related to the defined research question, so called themes, across data, on which the researcher retrieve insight and can make sense of collective and shared meanings or experiences [153], [154], [155]. The benefits of thematic analysis are its accessibility, which suits for multi-method research and non-qualitative experts, and its flexibility, which allows researchers to focus on data in various ways, e.g. from analysing meaning across an entire data set to examining a particular aspect in depth [154].

Before conduction, decisions regarding possible forms of method application and perspective of the researcher must be made, justified and consistently applied throughout the application [153], [154]. Choices must be made on what counts as a code or theme regarding to the research question, semantic or latent themes, inductive vs. deductive or theoretical approach, experiential versus critical orientation to data, and essentialist vs. constructionist theoretical perspective [153], [154]. Assuming a knowable world and reporting experiences and meanings of that world, for this study a more inductive, bottom-up approach will be taken, where codes and themes derive from the content of data itself, participant or data-based meaning will be prioritized, giving an experiential orientation and an essentialist theoretical framework [154].

A full thematic analysis was performed on the complete collected output of all user research methods. The data set consisted of the created transcripts, written notes, photographs and videos. Aligned to literature's best practices, the following phases were conducted: familiarising with the data, generating initial codes, searching for themes, reviewing potential themes, defining and naming themes, and producing a final report [153], [154], [155].

Familiarization started while listening or watching the records and conducting the transcription. The data was studied multiple times with the aim to detect interesting items towards the research question and critically analysed about its meanings, involving considerations as "How participants make sense of their experiences?", "What assumptions do they make out of their experiences?", and "What kind of world do they reveal?" [154].

Through the initial code generation phase, codes that identify and represent features of the data related to the research question regarding different perspectives on what, why and how participants are saying and doing something, were generated [154]. For each code its corresponding source, e.g. text passage within the transcript, was marked and linked with a unique identifier, i.e. applied method, number of session and page. Derived codes were rather semantic, also called descriptive, staying close to the content of the data, instead of latent, also called interpretive, providing an interpretation of the given data [154]. For handling the collection of codes mainly Microsoft Office, i.e. Word and Excel, were used and MAXQDA was tried out. Examples of the initial coding are provided in the appendix section 13.3.3 for the interviews and in section 13.4.4 for the focus group.

In phase 3, codes evolved to themes that "capture something important about the data related to the research question and represent some level of patterned response or meaning" [154]. Therefore, similar or overlapping codes were clustered into broader topics that result in sub-themes and themes [154]. For giving a better overview on the set of themes mind maps were created, showing composition of themes down to its related codes. The appendix provides two mind maps, one for the coding outcomes of the interview in section 13.3.4 and one for the focus group outcome in section 13.4.5. The goal was to create distinctive themes that may stand alone, but also setting them in a natural order to show their relations and how they build on each other [154].

In phase 4, potential themes were reviewed, whereby first they were checked against related codes and their corresponding data extracts, and second they were checked against the entire data set to receive a distinctive and coherent set of themes capturing the most important and relevant elements of the data [154]. Within the review non-fitting codes were relocated, theme boundaries needed to be adapted, codes and themes were discarded, and themes were broken up or merged [154]. The key questions asked were "Is it a theme, or just a code?", "Is it telling me something useful about the data set and the research question?", "What does it include and exclude?”, “Is there enough meaningful data to support the theme?”, and “Is the data consistent and not too diverse?” [154].

In phase 5, themes and sub-themes were defined and named [154]. The goal was to create themes that don’t try to do too much, have therefore a singular focus, directly address the research question, can be described within a few sentences, and aren’t repetitive or overlapping, but may be built on each other [154]. Furthermore, their names were chosen to be informative, concise, and catchy [154]. In this phase, data extracts for each theme were selected, which provides meaningful, compelling examples illustrating analytical points across the data set [154]. The quoted extracts build the structure of the analysis, and their interpretation and meaning regarding “what” and “why” they are interesting regarding the research question were explained in a narrative, describing manner to the reader [154].

Finally, the results were written up as a report, providing a compelling and clear story about the data based on the analysis and making an argument that answers the research question [154].

5.3.6 Persona

In traditional development, user models, which personalize technology towards a given user group, are rarely used, and adoption rate of patient technologies is low in elderly age groups regarding suitability, perceived usability and anticipated benefits linked to the usage of the new innovation [156]. Nowadays, development must emphasize the special requirements of aging patients and their progressive worsening of physiological and psychological abilities [156]. Therefore, personas can be a proper methodology for capturing the conceptual model of the aging patient group with chronic illness and inform the design of technology in this area [156]. Without the use of personas, design decisions are often done without communication of underlying assumptions and without respect to the people who will use the product and how it is considered to be used [157]. Additionally, a persona helps to define for whom and for whom not the technology is designed for [157].

For this study one persona was created to identify and describe the potential target user and guide the definition of user scenarios and design of the prototype [156], [158], [157]. It represents a mash-up of potential users aggregating characteristics from different people, instead of a specific individual human [158]. The description of user’s characteristics is composed of text and image, which are generated for helping to understand, describe, focus and clarify the user’s goals and behavior patterns [158], [157]. Beside demographics, the persona not only includes a user’s name, photo, likes, dislikes, habits, background, expectations, key goals, prior experiences and anticipated behavior, but also how they think, feel and behave [156]. Input was derived from participant data and outcomes of the conducted qualitative research [158], [157]. The illustration Figure 10 shows data that if available, it was considered for informing the persona [156].

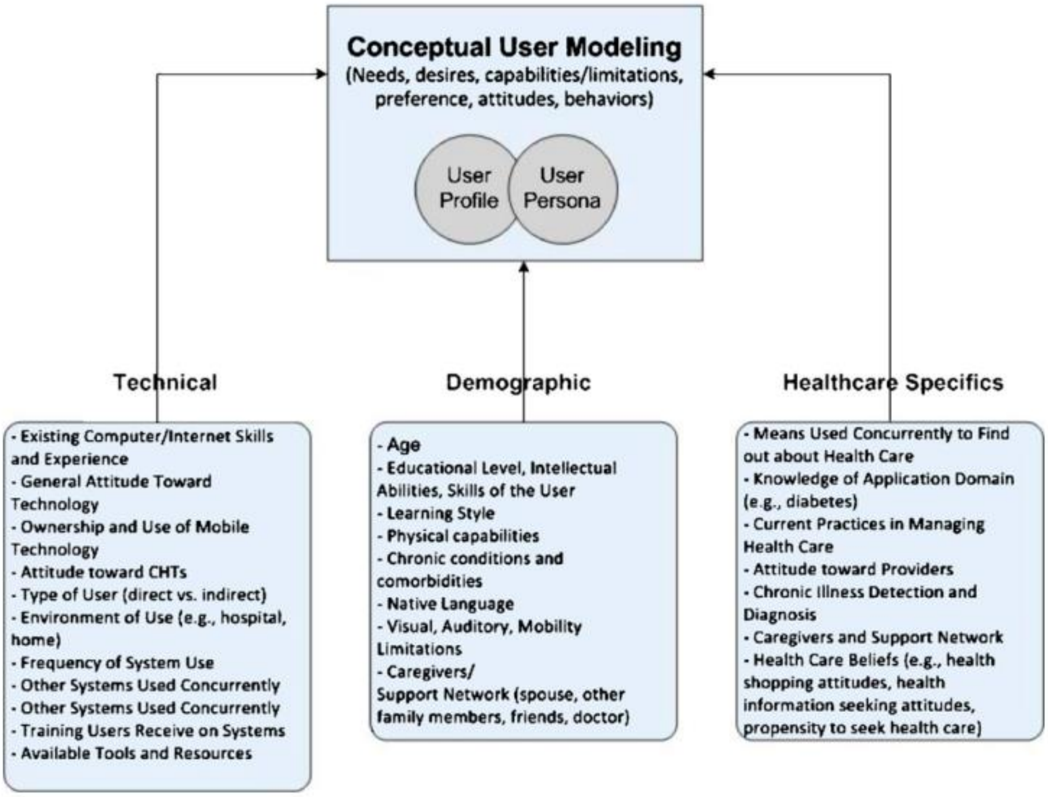


Figure 10: Potential data informing the persona [186]

5.3.7 User scenarios & design implications

User scenarios are stories about the user doing an activity via a provided technology, giving details about the problem, motivation and solution [159]. The goal of those scenarios is to describe potential problems and a feasible technologic solution for it [159]. Based on the problems described in the persona, scenarios are derived, describing specific problems and their possible solution via a self-care technology.

Beside the potential scenarios, the concrete design implications are described to reflect the unique user needs for a new technology.

5.3.8 Prototyping

For making the gathered data of this study matter and be visible, it is important to incorporate interesting findings into a conceptual model, i.e. a prototype [144]. In general, a prototype represents an initial implementation, the conceptual model of a system with the aim to learn more about a specific problem, it's complexity, it's surrounding context, and the possible solutions for that problem [160], [161]. Especially in software development, prototypes are used to stepwise replace specifications by implementation, effectively inspire and guide the design of technologies, gain a better understanding of the given requirements, i.e. through reducing ambiguity, incompleteness and inconsistency of requirements, convey design ideas in relation to existing practices by supporting walkthroughs with stakeholders, avoid costs for a full product development cycle, or worse, avoid costs of developed product satisfying the wrong requirements [144], [160], [161], [162].

For this study, the method of rapid prototyping was applied upon the created persona, identified scenarios and designed implications. The aim of rapid prototyping is the identification and clarification of requirements by quickly building a cheap and simple prototype of a system in early stages of a project where user requirements are vague and poorly understood [161], [163]. In further research the produced prototype may be utilized as learning device for providing feedback to the project, and serves as a tool for experimenting with new ideas and safety factors in risky developments [163].

During implementation, first, a concept for the prototype is defined, describing its specific use case and workflow. For proper visualization of the concept, the method of sketching is applied, representing the major idea of the prototype. Furthermore, the consideration regarding the defined scenarios and design implications are stated. Finally, the workflows of the potential technology are detailed and supported by mock-ups.

6 EMERGED THEMES

The purpose of the thematic analysis applied on the user research outcomes was to give an answer to the first part of the research question about which problems and challenges HOA patients experience and how they deal with it. The results are presented here in a structured form, as the final themes and subthemes evolved from the raw data.

6.1 PROBLEMS AND IMPACTS

Hand osteoarthritis make participants experience a set of disorders and problems. These issues put a higher burden on the life of each individual and affect their daily activities.

6.1.1 Experienced disorders

People with hand osteoarthritis suffer several disorders in their hands and fingers, namely pain, losing strength, deformity, stiffness, reduced dexterity, losing control and insensitiveness.

6.1.1.1 Pain

A common experience amongst participants was pain. One individual stated, "*It is painful.*" (IV04/1) and another described the condition as "*It starts hurting me in the root joints of my fingers, in both hands.*" (IV03/1). Pain may be permanent, "*A permanent pain that is always there.*" (IV03/4), or temporary "*After doing specific activities for about 5 minutes, I can already feel the pain.*" (IV06/05). Doing specific hand gestures become painful, and was described as "T*here are these gestures, when you have to grasp something, then I already can feel it.*" (IV06/5), or "*Grasping something with pressure is simply painful.*" (IV04/2). Moreover, the resting position of the hand can be problematic, "*If I am sitting here on the chair while watching TV with my hand on the arm of the chair, regularly there is no pain. But there are phases when it starts painfully stabbing me.*" (IV03/2).

6.1.1.2 Losing strength

Another shared disorder is loss of strength in hands and fingers. Interviewees described it as "*My main problem is the weakness of my hands.*" (WS/2) and "*The strength in my hands is getting less and less.*" (IV05/1). Furthermore, reduced strength is affecting activities, such as holding, "*I don't have enough strength in my hands to hold something properly.*" (IV06/2), or lifting up, "*I experience the loss of strength in my hands when I am trying to lift up something.*" (FK01-1/60).

6.1.1.3 Deformity

Concerns about the deformation of the fingers were widespread within the subject group. Deformity appears as thickening, "*You can see it at my finger joints. They are thicker as normal.*" (IV02/1), "*Look here, at my two little fingers, they are thicker than the others.*" (IV05/1), or swelling “*The pain is gone, but the swelling stays.*” (WS/9). Another identified issue is the worsening progress, “*The thickness has come, gets thicker and stays. It is getting more and more.*” (IV05/10). After a high workload, deformation sets in “*After heavy building construction tasks my hands got very deformed.*” (IV01/1) and tends to progress “*When I have worked too much, everything got swollen.*” (FK01-1/46).

6.1.1.4 Stiffness

Stiffness is one more shared experienced disorder. One described it as an early symptom, “*First, there is this stiffness.*” (IV05/4), another patient pointed out its continuous progress “*My fingers are stiff. First it was one, now the second finger is stiff.*” (WS/9). Rigidity reduces the mobility of hands and fingers, “*The fingers, and the joints, for example this one, is not mobile anymore. This other joint is nearly immobile.*” (IV04/9), and limits hand functioning like bending “*I can’t easily make fists anymore, when I have to.*” (IV06/12). Participants experience stiffness in the morning after getting up from bed, as “*In the morning I have this stiffness quiet long.*” (IV03/1) and the habituation to it, as “*In the morning, I partly have this stiffness, but I am somehow used to it.*” (IV04/4).

6.1.1.5 Reduced dexterity

Participants reported a number of issues about reduced dexterity. One commented it as “*I am less dexterous with my fingers.*” (IV04/2), others described the cutback by a comparison with the past, as “*It is exhausting, that I am not that dexterous anymore like in old times.*” (IV03/7) and “*I am less dexterous than in old times.*” (IV06/18). A lower dexterity leads to low fine motoric skills, “*Activities that need fine motoric skills are much harder to do.*” (FK01-1/379), and problems when grasping fine objects. “*Dealing with small, fine objects like coins is much harder when using fine motoric skills as the pinch grip.*” (FK01-1/45).

6.1.1.6 Losing control

Another common view amongst interviewees was the loss of control in their hands and fingers. The loss of control manifests in unexpected hand motions, “*I wanted to take my glass of water, but overturned it, because my finger or hand do not opened properly in time.*” (IV01/7), issues when releasing an object out of the hand, “*I wanted to put an object out of my hand, but I did not get my hand open anymore.*” (IV01/5), and problems reopening the hand after closing it to a fist, “*When I am making a fist and I afterwards reopen my hand, one finger hangs.*” (FK01-1/82).

In addition, spontaneous retractions, “*Sometimes I have the problem in my left hand that it retracts and I can’t open it anymore without help.*” (IV03/8), and seizures, “*There are these flashing seizures, and afterwards I can’t do anything more. I want to drop my tool, but can’t get the hand open anymore.*” (IV01/3) may appear.

6.1.1.7 Insensitiveness

Another reported problem was the change of sensitiveness. One participant described it as the loss of fine sensitiveness, "*I have no more fine sensitiveness in my hands.*" (WS/3), leading to problems when doing fine activities, as another stated, "*That fine activities became very hard to do for me, because I don't have the sensitiveness for that kind of fine activity anymore.*" (IV06/5). Interestingly, the experience of insensitiveness lead to starting countermeasures against the condition at whole, as one interviewee commented on it, "*Yes, there is this kind of insensitiveness. I am asking myself, why I have dropped this object unintentionally. That was the reason, when I talked to myself, that I have to start doing something against it now.*" (IV01/3).

6.1.2 Burden on life

The sum of experienced disorders puts a high burden on the life of each individual. Performing activities in general becomes aggravated and limited, the progress of the disease continuously worsens, appearance of the hands and fingers leads to aesthetic discomfort and environmental conditions have an increased impact.

6.1.2.1 Aggravating and limiting activities

Suffering various disorders aggravates and limits doing activities. The condition appears while doing activities, as one participant commented on it, "*When I am working or doing something, I start feeling it.*" (IV02/10), whereas another interviewee just experienced the condition after exhaustive work, "*I think, the effect of osteoarthritis is more related to exhausting activities. If I am just walking or cycling, I do not feel anything. However, if I am doing constructional work, I start feeling it.*" (IV01/3). Longer lasting activities become troublesome, as one described it, as "*Yes, of course. The longer I use my hands, the more it hurts.*" (IV04/2), and another reported it, "*If I am doing, for example some long lasting handicraft activities at my home, of course, my hands are hurting afterwards in the evening.*" (IV05/08). One experienced it as a disturbance, expressed as "*It is disturbing me by a lot of little activities.*" (IV06/7), and tasks requiring strength in hand and fingers are aggravated too, "*Activities that require strength in hands are hard to do.*" (IV05/3).

Those effects of aggravation lead to a need of more time for accomplishing, as one interviewee argued, "*When my hands hurt, I need more time.*" (IV05/7), or another described it, as "*I am trying so long, until I successfully accomplish the activity.*" (FK01-2/282). If hands do not function anymore as intended, exhaustion may set in, "*It gets on my nerves that I can't use my hands anymore as I used to.*" (FK01-1/54), workload must be reduced, "*Nowadays I am working less.*" (IV01/1), and resting is required, "*When I am working a lot with my hands it gets very painful for me, so that I don't want to take anything anymore in my hands. It takes about*

1 or 2 hours until the pain disappears, and in the meanwhile I drink a cup of coffee and eat some snacks.” (IV02/10).

In addition, the disease limits social interactions. For example, shaking hands leads to pain, described as “*When I am shaking hands, and the other is putting too much pressure on it, it hurts.*” (IV03/11) or “*If someone touches one of my hurting fingers when shaking hands, it hurts me even more.*” (IV05/7). Even touching gets painful, “*When I touch it softly, it hurts.*” (IV06/18).

Furthermore, activities cannot be done anymore, “*I can’t do specific activities anymore, and I have to ask for help. That is something that concerns me.*” (FK01-1/314), or the usual way of doing them must be adapted, “*You can’t do things anymore as you want to do them, it is hindering me.*” (IV02/11). For example, doing fine activities is limited, “*These fine, exhausting activities, where you need your fingertips, are not possible anymore.*” (IV04/7), and helping others with their work is not possible, “*A friend of my son was asking me if I could help him with some constructional work at his house. But this kind of work is not possible anymore for me.*” (IV01/5).

6.1.2.2 Worsening progress

A common experience amongst participants was that they are suffering a continuously worsening condition. One interviewee felt that the disease is evolving badly, “*In the last years it was worsening. The more things I do, the worse it gets. It becomes worse over time and it is not stagnating.*” (IV04/1), another one described it as a continuous process, “*For me it is always progressing and it never stops.*” (WS/10). This situation leads to frustration, “*The main thing that is frustrating me is the progress. It started with my little fingers, afterwards spread to the ring finger, then to the joints. And it is still progressing.*” (WS/13), and fear of spreading over to healthy fingers, “*Nowadays I am afraid that it is spreading to the other healthy fingers.*” (WS/4), or body parts, “*It is somehow a sneaky process. I hope that it stops at my hands and it doesn´t affect any other body parts, because in my hands it is already awkward enough.*” (FK01-1/67).

Furthermore, the effect of the progress scares affected people, like the case of one interviewee, who reported to be afraid of losing hand functioning skills, as “*It scares me. I am scared of losing functions related to my hands, for example, writing. Will I always be able to write? Will I always be able to do this or that? Those are my fears.*” (FK01-1/369). Others are pessimistic looking towards their future without being able to move, “*Someday it will happen that I cannot move anymore.*” (IV04/8), they have accepted their helpless situation, “*I have accepted it, as it is, because I think to myself that you can’t change it anyway.*” (IV03/5), or they have stopped hoping for any improvements, “*I have stopped hoping for improvement that my fingers won’t change anymore.*” (IV06/17).

6.1.2.3 Aesthetic discomfort

Opinions differed as to whether the changed appearance of the hands and fingers has a major influence on their lifes. Participants described the look of their hands as less beautiful, "*You recognize that your hands are less beautiful than before, and that is constraining you.*" (IV06/19), and ugly, "*It is very painful and ugly.*" (IV04/11). This is true for men too, as one argued, "*For me, as a man too, I am considering it as ugly, and it is affecting my vanity. I am not that vain, but indeed, it is not very beautiful.*" (FK01-1/391). Feeling uncomfortable leads to hiding the problem, as one put it, "*And so I am trying to avoid that someone else can see my hands.*" (FK01-1/393), and another one commented, "*Sure, just look at my gestures, I try to hide my hands automatically. I realized that my hands are not that beautiful anymore, and that constrains me.*" (IV06/19). Hand gestures are adapted to feel comfortable within society, "*I have developed my own gestures, how to hold my hands, so that not everyone sees my problem immediately.*" (FK01-1/110). However, others considered this concern as a minor problem, "*To be honest, the appearance is my smallest problem.*" (FK01-1/385), or easy to live with, "*I have always been honest about it. What I have, I have, and everyone else needs to accept that too. And it is not that bad, I have already seen worse.*" (IV02/12).

6.1.2.4 Environmental impact

Another shared problem is the increased impact of environmental conditions. This impact manifests in higher weather sensitivity leading to pain, as one participant commented it, "*Depending on the weather, my hands are hurting and I need more time for doing activities.*" (IV05/7). Cold, "*Yes, when it is cold, it hurts and stabs more.*" (IV03/6), and wet conditions, "*Now in the winter, around autumn and winter, this wetness is very, very bad.*" (IV06/3), worsen the individuals' situation. Particularly, the mixture of cold and wet has a strong impact, "*For me, my condition is depending on the climate. If it is wet and cold, my condition is extremely adverse.*" (WS/2). In addition, strong wind has adverse effects, as one interviewee argued, "*If there is wind, it is extreme, and I can't move my fingers anymore.*" (WS/5).

6.1.3 Affecting daily activities

Beside the higher burden on life, hand osteoarthritis affects activities of individual's daily routines. Four subthemes emerged, describing and gathering the found concerning tasks, namely handling objects, household chores, personal duties and mobility.

6.1.3.1 Handling objects

A number of issues emerged regarding the handling of objects with hands and fingers.

6.1.3.1.1 Heavy objects

Participants reported troubles when dealing with heavy objects. One felt that holding a heavier object is painful, "*When I am holding a heavier object, it hurts me.*" (IV02/2), others described problems lifting up a heavier object, “*Holding or lifting up something heavy, just by using your fingers, hurts me.*” (IV04/5) and “*I have problems lifting up heaving objects, and partly I have also problems holding such objects.*” (WS/3). As an example, carrying a bucket of water is troublesome, “*Lifting up a bucket of water for cleaning hurts me. And this is an activity I have to do daily.*” (IV06/3). For mitigation, people try to use their second hand as help, as one put it, “*Holding heavy objects is only possible with both hands.*” (WS/1), and another commented, “*Holding something heavier than 2 or 3 kilos is painful. So I try to avoid holding it, if it is possible, or I use both hands, that also works sometimes.*” (IV02/2).

Figure 11: Holding heavy water cooker (IV06)

6.1.3.1.2 Small and fine objects

Another reported concern pointed to the handling of small and fine objects. As one interviewee put it, “*I can’t work with fine, small objects anymore.*” (IV04/2), because dexterity is gone, “*I am too unhandy for handling fine, small objects. It is not that I am handicapped. I can grasp them. I can grasp them quickly, but my dexterity is gone.*” (IV04/9). Especially grasping small objects become harder, “*It is already hard for me to grasp something that has no wider surface or handle to grasp with.*” (IV06/10), for example preparing pills, as one participants argued, “*When I am handling small objects, like preparing my medication pills, I have problems grasping them, and sometimes they are falling out of my hand.*” (IV03/7). Moreover, lifting up thin things gets more difficult, “*When I am trying to lift up something thin, I am working hard.*” (FK01-2/73). One participant described an example when cleaning up small and fine objects from the floor, saying “*When I have to lift up or grasp pieces of broken glass, such fine or small objects, like grasping coffee beans on the floor when I have dropped them, lifting up those small things is hard for me.*” (IV04/9).

6.1.3.1.3 Pressing buttons

Pressing the expected button on a remote control or smartphone becomes burdensome too. As one interviewee said, "*I can only use the remote control when the buttons are bigger. If they are small, my fine motoric skills are not good enough. Also my fingers are bigger today, and you don't have the grasp anymore.*" (IV06/12). Furthermore, if a button is hard to press on like on a steam iron, that may be painful, "*Ironing painfully hurts me. I have an iron, where you have to press a button for releasing the steam. I feel that and it hurts extremely.*" (IV06/5)

6.1.3.1.4 Dropping objects

A recurrent theme was a sense amongst participants that they unintentionally drop objects. As one put it, "*I realized it myself, I am letting things drop a lot.*" (FK01-2/383). Opinions differed on the cause, for example, one explained it based on reduced dexterity, "*Because of my reduced dexterity, wet things are slipping from my hands more often.*" (IV04/3), whereas another one feels a stabbing pain before, "*I feel a stabbing pain, so I need to open my fingers for a short time, and then it drops.*" (IV03/3). Even knowing the problem doesn´t prevent it from happening, as one interviewee said, "*My fingers just release the object I am holding. Even if you concentrate to keep holding it, it drops from my hand anyway.*" (IV06/8), and another suggested that holding something tighter is painful, "*To avoid dropping things I hold them more tightly. Indeed, the pain increases, but it keeps at a specific limit and does not exceed it.*" (IV03/2). Furthermore, dropping things may damage them, "*It is quite hard for me to let things drop occasionally. I am always hoping that they do not get damaged, and sometimes I manage to catch them at least.*" (IV03/10), and possibly gets you in awkward situations, "*Dropping things is embarrassing enough, when it happens. It happens occasionally and it makes me feel uncomfortable.*" (IV03/4). As examples, people mentioned dropping plates when carrying them, "*It happened already to me that sometimes in the evening, something dropped from my hand. I was not able to hold it longer anymore. A plate or something like that.*" (IV03/2), or glasses while cleaning them, "*For example, when I am washing glasses. The last time when I was drying a glass, it just dropped from my hand. Back then, I never dropped something and my plates were complete. It is just happing now. Moreover, I get angry by that, although it is not my fault. That's a big issue for me.*" (WS/3).

6.1.3.2 Household chores

A number of problematic issues were related to tasks in the own household. As one interviewee put it, "*When doing my daily household chores I am always feeling my osteoarthritis.*" (IV06/13). Additionally, the time for completing responsible task extends, as one described it, *"I am doing the household chores, and nowadays I have less time for the same work than back in days when I had a regular job. Everything works slower and I am at full capacity."* (IV02/6). Doing household chores includes several daily routines that put a load on hands and so, it become troublesome for people suffering hand osteoarthritis. As one participant summed it up, "*I am very ambitious and just like most people, who like to have everything cleaned up, I am struggling with my household chores. For example, those activities in the household, like cleaning the car, rearranging things and putting in or taking out stuff or lifting up stuff in the supermarket. All these activities happen very often each day, and I am mainly doing them first. And that keeps my hands under load.*" (IV04/3). The following subthemes of kitchen work, opening packaging and screw plugs, tidying up, shopping, gardening and handicraft gather found issues of specific activities in the household.

6.1.3.2.1 Kitchen work

Participants shared concerns regarding activities related to kitchen work, as one reported, the increased effort on it, "*It really makes me angry. I like to cook, but it is too laborious nowadays.*" (FK01-1/48), and another described troublesome cake baking nowadays, "*Last Sunday I baked a cake, and while stirring and holding the mixer for a longer period, I felt the pain. Back then, I was able to prepare the pastry with my hands, but that is difficult today.*" (IV06/11). One interviewee summed up the burden of activities in the kitchen, especially when preparing for many people, "*In the past I organized a lot of parties, but today I am trying to avoid that, as long as possible, because it hurts me and it is no fun anymore. Just the thought of taking about 20 plates in my hands and bring them from A to B already hurts me. Preparing dinner for about 40 people, cooking, carrying stuff around, preparing the table, those activities are painful to me. Still I do them sometimes, but with pain.*" (IV04/6).

Another one reported lifting up a pot of water, "*I realize it when I fill a pot with water and try to place it from the sink to the stove. That is hard for me to do.*" (IV06/7), and taking out the baking tray, "*Taking out a baking tray, especially if there is more stuff on it, I really have to give attention that I am using my left hand properly, like the right hand, so that I have less trouble.*" (IV06/11), as problematic. Cutting food like hard vegetables, "*Cutting vegetables is an agony. I don't like to do that.*" (IV04/7), or hard fruits, "*It is very hard for me to cut fruits.*" (FK01-2/359) becomes troublesome too. Carrots or melons are an example of this, "*Cutting. Cutting something hard brings me trouble, like a carrot or a melon.*" (IV06/8). Problems when eating soup with a spoon were reported as an issue by one participant, "*I am very limited. I can't hold the spoon and eat the soup with it.*" (WS/9).

6.1.3.2.2 Packaging

Other issues focused on the opening of packaging and screw plugs. An interviewee reported sticky packaging as problematic, "*All those packaging that sticks together, opening them is nearly impossible. Allegedly, they should be easy to open, but I do not get it open. I do not have the strength and it is exhausting. I have to use a scissor or knife.*" (IV02/2), and another one has trouble when pulling an opening flap, "*There are some milk cartons where you have* *just to twist their cap to open it. However, others have such a flap inside that is quite hard to open. I am struggling with that flap.*" (IV05/11). Especially opening screw plugs gets difficult, as one participant said it, "*Today on public transport I had a bottle of water with me, but I was not able to open it.*" (FK01-1/321), and another explained, that "*Already the opening of a bottle of milk or mineral water is difficult for me.*" (IV02/2). As a possible solution, one interviewee switches to tap water, "*I have to drink tap water, if I cannot open the mineral water bottle.*" (IV04/11). The disorders of pain and reduced strength in the hands cause the problems. One described the reduced strength saying that "*Opening screw plugs is painful for me. It is very difficult. The smaller the cap, the harder it is to open it, because you need more strength.*" (IV06/9), and another reported the pain as an underlying issue, "*When I opened a bottle last time, I felt the pain. When I am holding it in my hand, and twist the cap with the other one, it hurts in both hands.*" (IV03/6).

6.1.3.2.3 Tidying up

Interviewees described concerns regarding tidying up and cleaning, as one put it, "*Tidying up is awful for me. But nevertheless I have to it.*" (IV04/7). Especially cleaning windows, "*Yes, I can't clean our windows anymore.*" (WS/10), polishing cutlery, "*Polishing cutlery is impossible for me. I really cannot do that anymore. It is not laziness. It is the thought of polishing 30 forks with a special cleaning powder. No way, that is impossible for me.*" (IV04/7), or cleaning fine things are problematic, "*I try to avoid uncomfortable activities, like cleaning fine things, but still someone has to do it, and that is me.*" (IV04/7).

6.1.3.2.4 Shopping

Participants mentioned problems regarding activities related to doing the shopping. One felt that lifting up products is difficult, "*It is difficult for me to lift up or take out products from the shelf when shopping.*" (IV04/4), another one has problems dealing with coins, "*I always have some coins with me, but they must be bigger than 10 cent coins, otherwise it is too difficult to handle them.*" (FK01-2/44). Furthermore, bringing home the bought products raises its own issues. A trolley may be useful, as one commented, "*I know it looks a bit awkward in the beginning, but I take a trolley to carry my shopping bag home. You get used to it.*" (WS/2), but another participant described hand problems after pulling the trolley, "*I use a trolley to carry my stuff from shopping back home. Then I stand in front of my entrance, but my fingers feel that strange, and I cannot open my hand anymore for unlocking the door. Then I have to wait, do some exercises, and then it is fine again.*" (WS/3). Another interviewee feels the pain when carrying the shopping bag home, "*I realized that when I am carrying home my shopping bag from the supermarket, I used to do it with one hand in the past. However, today I have to change hands about 20 times. Otherwise, my fingers would start hurting. When one hand starts hurting, I change to the other hand, and vice versa.*" (IV03/3).

6.1.3.2.5 Handicraft

More shared concerns amongst the interviewees were handicraft related activities. Issues varied from putting together furniture and hanging up pictures, “*For example, putting together a new office desk is a difficult task for me, or hanging up a picture, that is also painful. Just lifting the picture up with my fingers is already really painful.*” (IV04/5), to hammering in a nail, “*Yesterday, I tried to hammer in a nail on top of the door. Already holding the nail with two fingers was difficult. And then the hammering was even more difficult.*” (IV06/10) and screwing, “*In the past, for example, it was easy for me to screw or unscrew, when I have to do some handicraft or repair work at home. But today I can’t do that anymore with my bare hands.*” (WS/2). Especially after a long handicraft work, problems occur, “*When I am doing some handicraft work for a longer time I get problems and one of my fingers retracts and doesn’t move anymore. I can’t even hold the tool in my hand anymore, because my hand is cramped.*” (IV01/1). Furthermore, fine handicraft tasks become burdensome, like sewing, “*I have problems when doing fine handicraft tasks, as sewing.*” (IV04/2), grasping for a needle, “*When I want to grasp a sewing needle, and I start trying, I already feel the pain.*” (IV05/5), and dealing with improper scissors, “*Using a simple scissor is difficult for me. The smaller the scissor, the harder it is to use it. I am working in the kindergarten, and there I have to handle scissors for kids. If the handle does not fit my fingers, it is a big agony for me, what I have to go through. If I get stuck in the handle, and cannot put my fingers out again, the pain increases.*” (FK01-1/382).

6.1.3.2.6 Gardening

Gardening activities was another problematic household chore mentioned by the interviewees. One felt that pain occurs after some time, “*Yes, my hands hurt after I work in the garden for a while. Then I have to stop, because of the pain, it is impossible to continue.*” (WS/13), whereas another has general problems working outside in the garden, “*Gardening, for example, is impossible today. No way, forget it. I tried it with gloves, but I still do not like to do it. All these activities with wetness, coldness, soil, and leaves are very bad.*” (IV04/8). Particularly, digging holes, “*In the garden some activities are impossible today. For example planting flowers, if you have to dig a hole, especially a bigger hole, forget it. It is too difficult.*” (IV06/12), or pulling out weed, *“I cannot pull out weed anymore, because it is just too painful for me.*” (IV02/3), were mentioned.

6.1.3.3 Personal duties

Participants reported problems within activities regarding their personal duties, comprising personal hygiene, clothing, writing and paperwork.

6.1.3.3.1 Hygiene

Personal hygiene was a wider topic consisting of various issues, namely washing hands, brushing teeth, putting on make-up and shaving the beard. One participant commented that washing hands with cold water is painful, "*Usually the water out of the pipe at my home is really cold in the first moments, and I need to let it flow a bit. And when I am trying to wash my hands with such cold water, it is very painful.*" (FK01-2/270). Another one even preferred to stay dirty, instead of washing his hands with cold water, "*When I need to clean my dirty hands with cold water I cannot do that and prefer to stay dirty. For example, I am somewhere and I have to wash my hands with cold water. That is horrific for me.*" (IV04/6). Another problem was about brushing teeth, as one interviewee put it, "*My problems start in the morning, when I am trying to brush my teeth.*" (WS/4). Using an electric toothbrush may be helpful, whereas using a normal one can be painful, "*Last time my electric toothbrush went out of battery, and I took the normal one. I nearly was not able to brush my teeth. It was stressful and painful.*" (IV02/8). Women described putting on make-up as problematic, as one put it, "*I have problems when putting make-up on. I have problems holding the tissues or brush, and I realize about my clumsiness.*" (IV04/2), and another stated, "*Yes, with these fingers, putting on my mascara is nearly impossible in the morning.*" (IV06/5), whereas one man described shaving his beard as an issue, "*In the morning, when I have to shave my beard with the electric razor and don't know how to hold it, then I have to do my exercises first. Even when it is possible nowadays to stay unshaved some days, I need to shave my beard sometimes. And when I do, my electric shaver is too heavy.*" (WS/2).

6.1.3.3.2 Clothing

Clothing was another issue expressed regarding personal duties. Interviewees described tying shoelaces as problematic. One felt that it is more difficult to tie shoes, "*It is hard to tie my shoes.*" (IV06/19), whereas another one reported it as painful, "*Yes, tying shoes is painful. This is such kind of activity, when you have to tie something tightly together that gets quite painful. It is hard to keep the pressure in your fingers, have the fine motoric skills, hold it and make a bow.*" (FK01-2/306). Furthermore, putting on clothes with buttons or zipper is troublesome. One experienced problems with buttons, "*I have problems when dressing up, like closing buttons or tying shoes laces.*" (WS/4), whereas another one struggles with the zipper, "*I am also struggling when pulling the zipper.*" (FK01-1/376). One more interesting finding was about wearing rings. As one interviewee put it, "*Oh yes my rings. I got them as a present last December, but because of my deformations they don't fit anymore today.*" (IV06/3). Another participant reported problems putting on gloves, "*My fingers are already so deformed that I cannot even put on my gloves.*" (FK01-2/209).

6.1.3.3.3 Writing

Writing was an additional issue that was mentioned by the participants. Some interviewees reported typical writing with a pen as painful. As one put it, "*Writing with the pen is usually painful and restricts me. Although I am still able to write, it is painful.*" (IV04/2). Especially writing over an extended period is troublesome, as one described it, "*It is restricting me when writing, and I am afraid that once a day, I will not be able to do my signature properly anymore. But also writing over an extended time is a problem.*" (IV06/1), and another participant said, "*But when I have to write over an extended period of time, for example, if I want to write a letter, then it is getting painful. If it is taking more time, I feel it strongly.*" (IV02/3). As mitigation, the right grip of the pen is important, "*Before I start writing I figure out the right position of the pen in my hand.*" (IV06/2). Even electronic devices for writing have their issues. One felt that, "*I can't write on a normal keyboard over an extended period.*" (IV05/3), and another interviewee had problems with the hand gesture for writing, "*I have problems when writing with the computer keyboard, because I can't hold my finger up long enough.*" (IV03/2). Furthermore, writing with the small keyboard of a smartphone is burdensome, as one put it, "*Yes, I often miss the letters when writing on a small keyboard like on my smartphone. Some letters that are close to each other are hard to point on with my fingers.*" (IV03/7).

6.1.3.3.4 Paperwork

As last subtheme, interviewees mentioned diverse activities concerning paperwork and office work as troublesome. One participant reported difficulties when dealing with paperclips, "*Using paperclips is hard for me. All such small things are hard for me.*" (IV06/10), or using a computer mouse, "*Using a computer mouse, after a specific amount of time, I start to feel it. When I try to click on the button with my finger, it is hard.*" (IV06/12). Another interviewee experienced problems reading the newspaper, "*Back then I was able to grab the sheets of the newspaper. That is not possible anymore. I realized it last time when using public transportation, I took the newspaper and wanted to read it, but paging forward did not work.*" (FK01-2/75).

6.1.3.4 Mobility

As last impacted area of specific activities, participants brought up issues regarding their mobility, comprising opening doors, driving a car, using public transport and doing sports. Opening doors becomes hard in two ways. First, turning the handle or knob gets difficult, as one put it, "*I am lacking the strength in my hands, and sometimes I cannot even turn the door handle.*" (IV04/2), and another one felt that "*It is very difficult for me to open doors, especially with a turning knob. Doors or windows that are already harder to open, doing the twisting gesture is difficult and gets more difficult over time. In the past it was easy, but now it gets more and more difficult.*" (IV06/9). Second, using and turning the key is not that easy anymore, as one participant said, "*I have problems turning the key to open a door.*" (IV03/7), and another one described the problem of holding the key properly, "*Yesterday, at our letter box, we have a small key for it, it was very difficult to open it, already holding the small key in my hand, if there is no proper wide surface for holding, is very difficult.*" (IV06/10).

Additionally, the condition affects getting from A to B. When driving a car, a participant reported problems when turning the wheel or changing gear, "*When I am trying to reverse out my car from the parking lot, I have to move the wheel faster, and I feel it in my right hand. And sometimes, I feel it when changing gears too.*" (IV06/13). Another describes the air condition and driving for a longer period as issues, "*I realized it when I drive my car and the air from the AC streams directly on my hand. That is bad. Also when driving my car, if I am driving a lot, up to 3 hours a day, after such a long time you end up holding the wheel very cramped, and that hurts. So I often try to drive with one hand only because my hands hurt.*" (IV04/3). Using public transport can be burdensome too, as one put it, "*It is impossible for me to hold on in the tram or subway, especially when it is braking hard. Sometimes the handles are also too high for elderly women, like in the old trams. Once, I was stuck in the entrance, and two people pulled me in. That frightened me. So I am only taking the tram if it has a lower entrance, otherwise I have to wait for one.*" (WS/3).

Furthermore, interviewees mentioned concerns regarding sport activities. One mentioned problems using the brakes of the bike, "*I don't want to stop doing sports, but especially when riding my bike or doing mountain biking is hard to use the brakes. After 3 hours my hands hurt a lot, I cannot undress myself anymore.*" (WS/4). Another one has trouble holding the Nordic walking sticks, "*I am doing Nordic walking, but holding the sticks got difficult. The left hand is fine, but with the right hand I cannot hold the stick properly.*" (IV06/12)

6.2 COPING STRATEGIES

The second broad theme emerged from discussions about counter measures and coping strategies interviewees conduct to deal with their condition. Those coping strategies consist of self-care practices, use of additive tools and professional help.

Participants shared the perspective that counter measures should start as soon as possible, as one put it, "*You should start coping with it before you experience difficulties.*" (FK01-1/274), and another one recommended, "*I just can recommend everyone that in the very beginning - which is earlier then I started - you better visit a doctor, otherwise it will get bad soon. By starting to deal with it early, you maybe can delay it or it even never starts to be painful.*" (IV02/11). Indeed, early coping happens rarely, as one experienced, "*As long as you are doing quite well and everything works, you don't even think about that, that you cannot do some activities anymore, and so you don't start coping with it. That is our problem.*" (IV02/7), and others underrated the occurring issues, as one said it, "*In the beginning, when you recognize* *some problems, you think to yourself, that hurts a little bit, but it will pass away anyway.*" (FK01-2/164), and another commented, "*In the beginning, it started with some constraints in activities in the morning; your fingers aren´t properly mobile. However, I really underestimated it, and thought to myself that it will go away, that this is nothing, and that it is no problem. But today, if I did not start coping with it, back then, it would have been much worse.*" (IV01/10). An obstacle to start early coping is the difficulty to recognize osteoarthritis, as one described it, "*Osteoarthritis develops sneaky, you will not recognize it.*" (IV01/2). Others described the problem of relating the effects in the beginning to the condition itself, as one put it "*You will not recognize it properly. Sometimes you get an awkward feeling in your hands but you do not relate it to the osteoarthritis. It is painful, but in the next moment it is gone, and then it vanishes from your mind.*" (IV02/12), and another one explained, "*In the beginning I didn´t recognized it. First, I saw that my finger became deformed and I thought to myself that something was wrong. Later on, I also felt some kind of pain. But in the beginning there was just the changed appearance of the finger that made me thoughtful.*" (IV02/4).

Opinions differed on the reasons why interviewees started with counter measures. One started because of the insensitiveness in the hand, "*Yes, there was some insensitiveness, and I asked myself why this thing just dropped from my hand. That was the reason why I talked to myself and decided to do something against it.*" (IV01/3), another one because of the pain, "*I started coping with it by myself because the pain in my hands increased more and more.*" (IV05/9). Furthermore, to cope with osteoarthritis properly, you need a high level of motivation and ambition, as one put it, "*When you believe in something, that it will help you, you should not be too lazy to do it. I want to try it and I want to help myself. That is - you know it - that is ambition. You need ambition to cope with our disease.*" (FK01-2/208).

Interestingly, the discussions showed that coping strategies and their results vary and depend on the individual. On one hand, every person needs to find the proper practices and tools, as an interviewee put it, "*I believe that if the curd works fine for you, that doesn´t mean that it works fine for someone else. So sometimes, a medication works fine for someone, but not for the other one. People react differently to different aids, maybe for someone even both aids work fine. But, I guess, everyone must try and find it out for himself.*" (FK01-2/191). On the other hand, individuals must believe in their coping strategies and have a positive attitude towards it, as one suggested, "*It is very important to have a positive attitude towards your coping strategy or tool. You must believe that it can help you. You should not decline it instantly and tell yourself that it will not help you. You have to think positively.*" (WS/12).

Nevertheless, even trying out the many possible counter measures cannot fulfill the hoped expectations or stop the progress, as one put it, "*To be honest, until now, nothing helped me.*" (WS/9), and another one described, "*Yes, I tried galvanic baths, I tried everything, ultrasound,* *paraffin, medications for my joints, expensive stuff you can buy in the pharmacy. Moreover, you have to buy it all with your private money, like various crèmes, or a smooth ball for exercising. I tried applying cold packs too, but still, my finger got stiff.*" (WS/9).

6.2.1 Self-care approaches

Participants mentioned various practices of self-care activities to mitigate and cope with their condition. They change their behavior, do exercises, research and increase their knowledge, ask others for support, adapt their nutrition and apply ointments and curd.

6.2.1.1 Behavioral changes

As osteoarthritis sets in and shows its first disorders, participants reported changing their behavior to mitigate upcoming problems. Those changes manifest in various approaches, such as habituation, adapt handling, self-protection and changing their environment.

Participants shared perspectives on getting used or not recognizing their condition anymore, as one put it, "*In my opinion, I am already used to the problems.*" (IV04/4), and another one mentioned, "*Most problems I do not recognize anymore.*" (IV02/8). Other interviewees suppress upcoming problems, "*Somehow, I managed to suppress the pain in my head.*" (IV03/6), or distract from them, "*I am only a human and I have to do a lot of things every day. I try not to give too much attention to the pain in my hands, so that I can do all things. That keeps me mobile and helps me compensate my problems.*" (FK01-1/292).

Shared approaches to reduce problems are reducing workload, "*Since I started doing exercises and reduced daily work load my hands are doing much better.*" (IV01/9), having breaks, "*I simply started having more breaks, and that works fine.*" (FK01-1/14), and stopping tasks before troubles occur, "*When I get the feeling that an activity will become painful, I stop it earlier.*" (FK01-1/14). A participant mentioned giving hands a regular rest or else switching to easier tasks, "*Usually I stop working with my hands after half an hour to give them a rest. There is no other possibility for me how to handle it, only making breaks. In my occupation, it is rarely possible to stop working and have a break. Therefore, I switch to activities with less hands involvement, but still there are a lot of activities that can be painful.*" (IV06/5). Another behavioral adaption is doing activities more thoughtfully, as one put it, "*I have to do activities more thoughtfully. Just before starting, I think about how I will do that now, what is the best way for me to do it, and what will be the easiest way for me.*" (IV06/14), and added, "*I have to think and try a lot before doing activities like writing. Generally, before most activities, I have to think about how I can do them, and that is a big restriction and strain for me.*" (IV06/2). Others try to be more careful, "*I try to treat and use my hands with care as much as possible.*" (IV04/8), and do tasks slower, "*I keep going on with my activities as before, just doing them a bit slower, more carefully, and indeed with a bit of pain.*" (IV03/9). Activities that are uncomfortable to do or lead to problems may be avoided, as one interviewee described it, "*Some activities are uncomfortable to do nowadays. I don't want to say that it is painful, but uncomfortable, and usually you avoid uncomfortable activities.*" (IV02/11), and another one commented, "*I automatically avoid some activities. Maybe because I know what will lead to difficulties or will be painful, so I avoid them automatically.*" (IV03/9).

Another reported behavioral change is that participants adapt the way how they are doing activities, as one described it, "*Yes, you manage it yourself. You help yourself, and you are doing your activities somehow different and you do that automatically.*" (IV06/9). For example, one interviewee reordered stuff to have easier access, "*Rearranging things helped me a lot. Putting things you often need to the top, and things your rarely need to the bottom.*" (WS/10). Furthermore, adapting to new hand gestures is common to relieve known problems, as one said, "*I try to relieve painful fingers when doing activities.*" (IV06/14). As examples, participants accommodate their gestures for holding a key, "*You adapt proper grasping techniques immediately. I do not know how I did it in the past, but now I hold the key differently with my whole fingers, and not just the fingertips.*" (IV04/5), or carrying a stack of plates, "*I grasp and use things differently today. For example, you would take the stack of plates like this, but I take it differently using my whole hands, not only the fingers. I am adapting the handling when grasping to relieve my fingers. Otherwise, I would feel the pain in my outer joints immediately.*" (IV06/6). Instead of using only the fingers for getting grip on something, people try to use their whole hand. Participants mentioned examples when holding a cleaning tissue, "*I try to hold the cleaning tissue with the whole surface of my hand, so that my fingers are relieved.*" (IV04/6), cutting vegetables, "*Holding a carrot while cutting it can be painful. Instead of holding it with my fingers, I use my whole hand, but then I need much more time.*" (IV05/7), and opening a can, "*When opening a can, I try to use the full surface of my hand instead of my fingers. I try to put on pressure with my hand surface, because otherwise I would have to twist it with my fingers, and they are too weak for doing that.*" (FK01-2/304).

Figure 12: Lifting up a pot with both whole hands (IV06)

Interviewees try to avoid troublesome gestures, "*There are some gestures I try to avoid, if possible.*" (IV02/8), and avoid involving problematic fingers, "*If a single finger hurts, I try not to use it and skip it for a specific activity. I try to move it away and not use for grasping.*" (IV06/14).

Figure 13: Relieving problematic fingers when holding plates (IV06)

If one hand is still healthy, participants use it as support for doing their tasks, as one said, "*I realized that my left hand automatically supports my right one.*" (IV06/11), and another commented, "*If I cannot open something with my right hand, I try to do it with my left one.*" (FK01-2/294). One tries to load balance on both hands, "*For specific activities that are automated with my right hand, I try to use my left hand to achieve a better distribution of load. For example, when I am grasping something or lifting up something, I try to avoid using always the same hand and do it with my left hand.* " (IV01/13), and another relearns several activities from the main to the second hand, "*Relearning activities, like writing or sewing, from one hand to the other is very hard. I have been good at handicraft tasks, and relearned a lot from my left* *to the right hand. However, specific activities, like cutting out something or holding a spoon properly, are still not possible for me.*" (WS/10).

Another behavioral adaption is to change for a more comfortable environment. That includes warm rooms at home, "*It should just be warm, warmness makes it comfortable. Warm rooms, if you are going from room to room, carrying a heavy ladder around, it would be much more comfortable if it is warm rather than if it is cold.*" (IV04/10), warm climate, "*Last time in America the climate was much hotter, and I had no problems with my joints. I guess the temperature plays its role.*" (IV03/6), and for example having more holidays in the warm south, "*If I am on holidays in the south, wetness is no problem. If it is warm, I feel better. The deformities are still there, but the pain is reduced and I have fewer or no problems at all.*" (IV05/2).

6.2.1.2 Exercising

A widespread coping strategy of the participants is staying active, keeping your hands active and doing exercises or sports in various forms, as one put it, "*I just can repeat it, keep on moving and stay active, that is the best you can do for yourself.*" (FK01-2/461).

Participants shared the practices of keeping their hands active, stretching them or warming them up. One interviewee just keeps the hands active, instead of doing exercises, "*I don't do specific exercises, but I try to keep my hands active.*" (FK01-2/145), for example while watching television, "*While watching TV I try to keep my hands active and stretch them.*" (FK01-1/151), whereas another one see is as continuous action, "*I am trying to keep my hands active and move them as long as possible.*" (IV05/1). Stretching the fingers is also beneficial, as one put it, "*I stretch my fingers to relax my joints. An occupational therapist showed me how that works. It hurts for a short time, but afterwards it is better.*" (IV05/2).

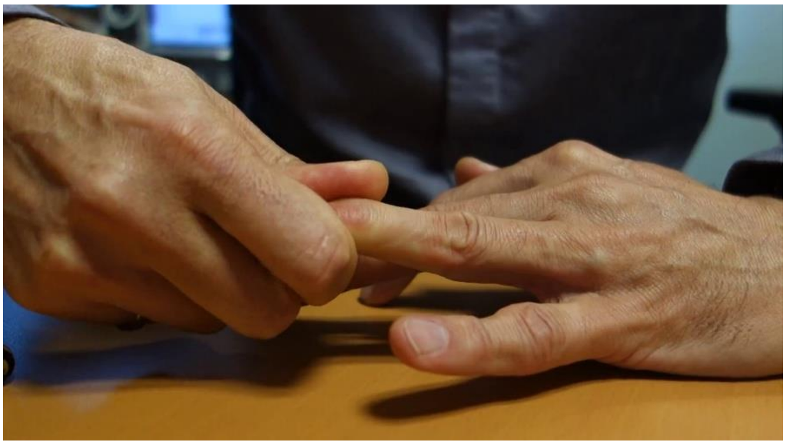


Figure 14: Stretching fingers (IV05)

Others mentioned the importance of warming up their hands in the morning, as one described it, "*Against the stiffness of my hand in the morning I need to keep my fingers active or do some exercises to warm them up. Then my hands are fine and relaxed again.*" (IV01/2), and another one had to do it before going to work, “*Every day in the morning I have to warm up my hands, like you do before doing sports. Yesterday, my work began early, around six, and my hands were not warmed up. That was more painful.*” (IV06/13). One individual used a spiky ball for activating hands and fingers, *“I am also using a spiky ball and play around with it the whole time and always put a bit of pressure on it with my fingers and hands. When I am pressing the spikes softly it feels good, and it seems to promote my blood circulation. That cannot be bad.*” (FK01-2/20).

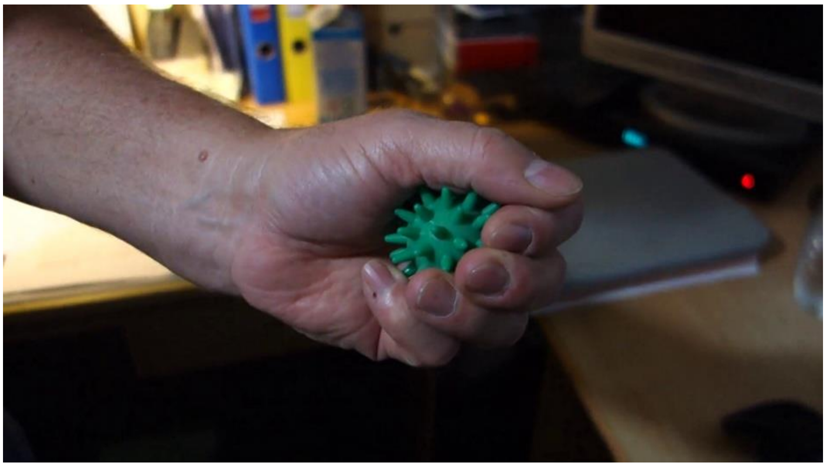


Figure 15: Spiky ball for activating fingers (IV03)

Doing hand specific exercises was one more common and beneficial behavior of participants, as one put it, “*I just can recommend everyone to do hand exercises.*” (IV05/13), and another reported, “*Doing hand exercises works fine for me.*” (FK01-2/136). An interviewee described the benefit of it as maintaining the mobility of the hands, “*Since I do hand exercises my fingers are much more mobile. I do not have any problems anymore and can do everything. I know some people who do nothing and have problems with the mobility of their hands. Consequently, they can’t even move their hand, which I can.*” (IV02/9). Especially against stiffness, “*When I feel the stiffness in my hands, I am forced to do hand exercises to relief my hands. And that works instantly.*” (FK01-2/121), or pain, “*Sometimes I do my hand exercises regularly, but that varies. For example, when I am on summer holidays in the south and I do not have any problems, I also do not do any exercises. But another time, if it hurts a lot in the evening or morning, then I have to do them.*” (IV05/9), it is helpful. Interviewees highlighted the importance of doing regular hand exercises because when they interrupt them, problems come back. One reported that, “*Last time, when we moved into our new house, I had less time and did not do my hand exercises regularly. I instantly felt the worsening of my condition.*” (FK01-2/27), and another one felt, “*Doing my hand exercises less regularly punishes me instantly with the worsening of my condition.*” (FK01-1/18). Some participants utilize special tools for exercises, as soft balls or a putty, as one put it, “*Doing hand exercises with a putty or a soft ball helps me.*” (IV05/9). Using a soft ball helps them train the strength of the fingers, “*I got a* *soft ball which you can press for increasing strength in your fingers.*" (IV03/6), and a putty allows several more exercise techniques, even it is too sticky in the summer, "*After my regular hand exercises, I use a putty. I knead, roll, and press it. Afterwards, I form it into a circle around my hand and try to open my fingers. However, just this summer, on hot days, the putty got so sticky that I did not get it off my hands, I could not do my exercises properly and now I have to buy a new one.*" (IV02/7).

Figure 16: Exercising with putty (IV06)

As a trick for putting ease on doing exercises, one interviewee mentioned warming up the hands before, "*My hand exercises are much easier to do if I warm up my hands before. So over time, I realized that it is much easier for me to do the exercises when my hands are warmed up under warm water.*" (IV06/14).

Moreover, beside the positive effects of hand exercises, participants reported problems too. First, doing them regularly and incorporating them into daily life was a reported concern. For example, one described the need to get up earlier, "*I have to schedule more time to get my hands ready. In the morning, I have to get up at least 15 minutes earlier. That is still harder when you regularly have to get up at 5 o'clock just to get my hands ready. That really concerns me.*" (FK01-1/314), which results in a more exhausting and constraining life, "*It is exhausting and it constrains your daily life if you have to prepare your hands to function well. If you have to get up early just to prepare your hands, that constrains you and it is exhausting.*" (FK01-1/319). One interviewee mentioned the time needed to accomplish a set of exercises as an issue, "*For doing all exercises I need about half an hour, no matter if I try to hurry up, I need about half an hour. So I changed from doing exercises with one hand after the other, to doing the exercises with both hands at a time, to save at least a bit of time.*" (IV02/7). Another person had no access to proper instructions, "*I got an instruction sheet for doing the hand exercises, but I already lost it.*" (FK01-2/154), just no motivation, "*I am too lazy to do the hand exercises.*"

(IV03/10), or reported a lack of proper exercises for their specific condition, "*In the hospital they prescribed me a set of hand exercises, but I never do them. I think the given exercises do not affect the right joints. They focus on the base and middle joint, but not the end joints. So, sometimes I do them and I know what muscles I have to train, but I do not do it regularly.*" (IV04/7).

Doing various kinds of sports is an important way of coping. Besides it is beneficial for the hands, "*What helps me is a mix of western and eastern gymnastic exercises, including Tai Chi. That works really well for my hands and I have way less pain afterwards. There are many stretching exercises included, but not everyone has the attitude and motivation to do such exercises.*" (FK01-2/196), it also improves the overall condition, "*Nearly every day I do my exercises at the next park, with sticks, and I am walking that way there and back. That helps me a lot, and my mood is much better afterwards. Forcing myself to do such kind of morning activity helps me a lot.*" (FK01-1/296). Participants doing sports on their own visit gyms, "*Two times a week I go to the gym to do my exercises there. But I am just using the machines I know or my doctor recommended me.*" (WS/14), watch exercising television programs, "*There is, for example, a very good sport program in the television every morning, where various exercises are presented by different trainers. They show very good exercises to actively take part in it.*" (FK01-2/87), or go to specialized institutes, "*I am going to the Kieser-Training. There, I am doing exercises with my hands with low weights. I feel that this works well for me. I do this two times a week, and there are doctors and good trainers that support me and make sure that I am doing all exercises the right way.*" (WS/10).

Concerns regarding doing sports focused on the costs of professional support, "*The difference between a normal and a good gym is that in a good one there is trainer that helps you to do the exercises in the right way, especially if you don't know how to do them. So you have to give some extra money to get professional support, but you can't go there for less money to do the exercises wrong, that makes no sense.*" (WS/14), what kind of sport is appropriate related to the condition, "*I did a lot of muscle training with an expander, but that really took it out of me. How stupid can you be, to worsen your condition that much? I just wanted to get strength back in my hands.*" (WS/13), and how often they should do sports, "*That is the question, how much sport you should do. I guess sport is always healthy, but if you get pain afterwards, I don't know if stressing your joints through those activities is good or bad.*" (FK01-1/424).

6.2.1.3 Research

Another common self-care practice amongst participants was the interest, need and the obtaining of information, as one put it, "*Regarding the pain in my hands, I started coping by gathering information about my condition.*" (IV06/16), another argued, "*If I had been properly* *informed about osteoarthritis, I would have visited a doctor earlier.*" (FK01-2/161), and another one reported, "*I started getting informed immediately, and today I am really studying it, mostly through information from the Internet.*" (IV04/9). Interviewees brought up a number of areas they are interested in, starting from disease-related information, "*I am very interested in specific information about osteoarthritis.*" (IV03/11), to counter measures in daily life, "*I am interested in different tips about how to adjust my behavior, what you can do against it, how to relieve it and where to put your attention.*" (IV01/13), and new medical research outcomes, "*I guess we are all interested in new outcomes from actual research, for example, new therapies. I know that the disease is unstoppable, but no one wants to live with the pain, that's all about it.*" (FK01-2/445). The sources for knowledge retrieval vary, as one participant described, "*I informed myself through health-related books, via the Internet, and other books.*" (WS/6), and others mentioned the participation in a medical study as beneficial, as one put it, "*I feel well informed and enlightened since I took part in a study.*" (FK01-2/177), and another commented, "*All the information from the study I participated in was very helpful for me.*" (FK01-2/209).

Interviewees also brought up the interest in knowledge exchange with other patients, as one argued, "*I would be thankful for every advice someone can give. Maybe other people, suffering osteoarthritis have good tips, for example, a specific diet or medication, I would be really thankful if you can provide me with such information.*" (IV04/11). Another one suggested gathering in small groups for exchanging experience, "*I am very interested in something like a self-help group, where you can meet others having the same problems as I have, where everyone can share experiences, like I am doing that and that helps me, or trying this thing.*" (IV06/18), with the benefit to be surrounded by one's own kind, "*I would like the idea of a group about ten people with the same condition and having conversations with them. That would really strengthen my self-confidence.*" (IV06/19).

Especially the internet is a common source and allows research on your own, as interviewee reported, "*I decided to gather information about osteoarthritis on my own because the pain in my hands increased over time, and I informed myself using the Internet.*" (IV05/9). However, participants had concerns about looking up information on the Internet. A concern was about misleading information, as one said it, "*That is the problem with the Internet. There is too much information that may mislead you.*" (FK01-2/188). Other interviewees experienced that they end up with wrong conditions, as one put it, "*I honestly have to admit that not everything that is written in the Internet is okay. I won't start informing myself using the Internet again about any disease because you will end up with cancer.*" (IV06/16), and another one felt, "*I don't like to inform myself using the Internet because I end up sicker than I am.*" (FK01-2/413). Furthermore, the reliability and correctness of information is important, as a participant reported, "*The main issue with information on the Internet is that you cannot be sure if the provided information is correct and safe.*" (FK01-2/412), and another one added, "*I am very* *interested in getting information from a trustworthy person that provides me with 2 or 3 web sites with reliable content.*" (FK01-2/465).

A main concern on doing research is that is hard to get proper information, as one described it, "*It is hard to receive helpful information.*" (IV05/12). Interviewees missed proper information about counter measures, "*No one ever told me about possible preventive measures, so I hardly can do anything. Everyone tells me that I should try to keep my joints flexible. They do not know where it comes from, why it is there and what it is. That is the problem that makes it hard for me to do something preventive.*" (IV05/9), and often hear that there is nothing they can do, "*Sometimes I hear that actually there is nothing you can do, which makes me a bit depressed. That is basically the main issue I hear again and again.*" (FK01-1/210). Therefore, interviewees need holistic elucidation from the beginning, "*There should be much more elucidation. People should be informed well and in detail, already at the early stages of the disease.*" (FK01-2/161).

6.2.1.4 Support from others

Asking other people for support and help is another common used self-care approach, as one described it as "*Taking and accepting help from others.*" (WS/6). A participant reported this practice as workaround and delegation, "*I am trying to solve my problems until I make it or if it is really not possible, I try to ask someone else, to see if he may be so kind to open that for me or he may be so kind to take care of it. I am simply delegating it.*" (FK01-2/282), and another interviewee only asks others on problematic tasks, "*If I have to do troublesome and difficult activities I ask someone else to help me.*" (IV06/15). Close relatives are very important for giving such support, as one interviewee said, "*At home I have my husband, and for troublesome activities I ask him.*" (IV06/8). Others reported to pay for support in the household, "*I have a charwoman helping me with my household chores.*" (WS/10) or other duties, "*For about 3 weeks I had a driver and I really enjoyed it. However, having a personal driver, kitchen assistant or a chambermaid is not the regular case, but that would help a lot. The only problem is that my husband has still not won the lottery jackpot.*" (IV04/8).

However, participants shared also concerns about this kind of help, as one put it, "*Something that really concerns me is that I just need a lot more help from others. There are specific activities that I cannot do anymore and I have to ask for help. That really concerns me.*" (FK01-1/314), and another added the awkwardness of asking others for help, "*Last time, I had to walk over and ask my neighbor for opening some packaging. He was very surprised and looked at me with puzzled eyes.*" (FK01-1/325). Furthermore, delegation of difficult tasks is not always possible, "*I cannot delegate specific activities that usually a man does at home to my wife. Some activities you have to take care on your own. You cannot delegate everything.*" (FK01-2/288), for example opening a bottle, "*If I ask my wife if she could please open a water bottle, she won't be able to do it, she does not have the strength.*" (FK01-2/297).

6.2.1.5 Nutrition

Another self-care practice reported by the interviewees was changing their nutrition to benefit their condition, as one applied it, "*I had to change my daily nutrition, because there are many things you should not eat anymore. I researched that in the Internet, printed it out, and used the list as an orientation for my change, not one-to-one, but I reduced some things or removed them entirely from my daily nutrition.*" (IV02/12). One participant manifested a high interest in proper nutrition, but lack of knowledge, "*Maybe my change is extreme, but I try to live as vegan. For me it is very important to know what I should eat, and what I should not eat. For other diseases, like cholesterol, you know that you should not eat fat. But for osteoarthritis you don't know anything, and that would be interesting for me.*" (IV05/14). Getting proper information may be difficult, as one mentioned, "*When I asked the doctor during my visit for nutrition plans or changes, he told me that there is nothing I can do, and he only recommended me to take prescribed medication.*" (FK01-2/168).

Changing nutrition consists of two parts, eating good food, and avoiding bad food. Participants mentioned avoiding meat, "*I changed my nutrition. I am eating less meat and sausages. I try to avoid sugar, or at least take as less sugar as possible.*" (06/15), wheat and sugar, "*Changing nutrition, for example no wheat flour and no white sugar, helped me.*" (WS/6). By contrast, interviewees reported eating fish, "*Eating a lot of fish works well.*" (FK01-2/417), gummy bears, "*Instead of medication you have to eat a packet of gummy bears every day. The gelatin inside them helps.*" (FK01-1/177), omega-3-fatty acids, "*I recommend omega-3-fatty acids, which are important for cleaning your blood vessels, and may also help you with your fingers.*" (FK01-1/269), and using supplements, "*By taking daily dietary supplements, e.g. with vitamins, magnesium or calcium, I got the feeling that it neither improved the condition in my hands, nor did it worsen it. And not worsening is already something good.*" (FK01-1/233) as beneficial.

However, opinions differed as to whether changing nutrition is helpful at all. One participant tried a special diet cure, "*I did a detox cure over 7 weeks, and that helped me a lot, for my whole body, but I cannot tell that my osteoarthritis has gone away afterwards, not a bit.*" (IV04/10), and another one tried to eat healthier food, "*They told me to change my nutrition. I should eat more vegetables, and I started to eat more vegetable variations and afterwards I started a fruit therapy. However, nothing helped me. Really nothing.*" (WS/7), but both approaches showed no beneficial effect on their condition. Furthermore, living as a vegan has no potential to stop the condition, as one experienced, "*I reduced eating meat and in the last years I lived as a vegan. However, it did not help, everything is progressing, and you cannot stop it.*" (WS/14). Besides having no benefits, changing eating lifestyle is not that easy, as one interviewee put it, "*It is hard for me to go on a diet.*" (IV03/11).

6.2.1.6 Ointments

A common view amongst interviewees was the benefits of applying specific ointments on their hands. One reported using it after experiencing work-related pain, "*As long as I am working, no matter if in the household or in the garden, I don't feel any problems, but when I am finished everything hurts. Then I have to do something against it and therefore I apply the horse ointment on my hands. It is like an ointment against pain and it works like such one by making the pain tolerable.*" (IV02/1), another described applying it over night to mitigate morning problems, "*I am applying calendula ointment over night and I put on gloves. It works during the night and I am completely free of pain in the morning.*" (FK01-1/35). However, ointments only reduce pain, as one put it, "*At the moment the application of pain ointments works fine. It is for the joint, it does not improve the condition of my joints, but it palliates the pain. It works best if you keep the ointment in the fridge and apply it ice-cold. I got to know it from an advertisement in the television.*" (WS/7), but nevertheless, show their advantages over other aids as painkillers, "*It is better to take a pain ointment instead of painkillers, because it has an immediate effect and it doesn´t affect your stomach.*" (WS/8). Another possible benefit is its easy and quick application saving time, as one positively echoed, "*I want to try out the calendula ointment over night too. Because if it extends my sleep for 15 minutes every day, that will be a difference for me. That is quality of life for me, if you have to get up at 5 o'clock or at half past 4.*" (FK01-2/464). Participants highlighted only one issue, as some ointments are harder to get, "*Back then you got the calendula ointment in the drugstore, but nowadays you have to order it in the pharmacy.*" (FK01-2/462).

A more controversial discussed self-care approach was the application of curd on hands. Some participants shared their opinions of its helpfulness, as one put it, "*I apply my ointments and curd, that works fine for me.*" (FK01-1/214), and another commented, "*Once this finger was very deformed, but today it is straight again. It is not that beautiful as before, but it was looking much worse. Although every doctor told me that I will not get the finger back to normal, only applying curd worked fine.*" (FK01-1/119). One individual highlighted its easy self-made application compared to professional treatments, "*I prefer curd over paraffin. Although paraffin is helpful for my hands too, you have to make the effort to go to a physical institute to apply it, but curd you can do it yourself at home.*" (FK01-1/340). However, others did not perceive any effect, "*For example, something that did not help me was putting my hands into cheese or curd.*" (IV05/5), or did not even take the idea seriously, "*They told me to put my hands into warm curd, but I answered that I prefer to eat the curd to applying it.*" (IV03/8).

6.2.2 Additive tools

Another widespread coping strategy brought up by the interviewees was the usage of additive tools. The mentioned themes of additive tools encompass proper ergonomics of tools and objects used in daily life, enhancements through technology, opening aids, thermal applications and proper clothing.

6.2.2.1 Ergonomics

Besides using specific helpful tools, participants mentioned the importance of proper handles and shapes of tools and objects used in daily life, as one described it, "*The difficulty of working with various objects depends on their handle.*" (IV06/12), and another mentioned pain as a consequence of non-proper handles, "*If the handle of the scissor doesn´t fit my fingers, it will be painful working with it.*" (FK01-1/382). Therefore, replacing tools and objects by ones that are easier to work with may be helpful, as an interviewee explained, "*I help myself by substituting things with things that are easier to handle for me. Just exchanging them. So, I am always trying out different things for a while, then decide which one works better for me, and take it home.*" (IV06/15).

Attributes of proper objects include bails, "*Objects having a bail are easier to use, because it is easier to hold it.*" (IV03/3), handles, "*It would be very important to produce cans and glasses with handles that are easier to use and you can get a good grip at the handle. For example, adapting caps can be an opening aid. Some ointments have bigger caps, not just only such small ones, and so you can open them properly.*" (IV05/11), low weight, "*It is much easier to deal with lightweight stuff. For example, I am using small chopping boards.*" (IV06/11), and bigger size, "*A bigger key is much easier to use than a smaller one.*" (IV06/9). Especially thicker or bigger handles put ease on work, as one put it, "*If I am cooking, for example heating onions, I help myself by choosing a thicker wooden spoon over a thinner one, because a thicker spoon fits comfortably for my hand. A thicker handle, a bit broader one, makes it much easier for me.*" (IV06/11), and another argued, "*If I have to work with a screw driver, I need to take one with a bigger handle in order to hold it properly. And you have also more force, a bigger lever, when using it.*" (IV03/8).

Furthermore, the shape of handles is important when using them. Comfortable handles are round, "*I always choose the knife with the best handle, because I already know which handle works best for me, and it is a lot easier for me afterwards. The best handle for a knife is round, not angular, not edgy, just round. That fits comfortably for my hand.*" (IV06/8), not angular but soft, "*A pen must not be angular. That would make it difficult for me. It is much easier for me if I have a pencil that is round and soft with a gumming.*" (IV06/2), thick, "*When I am writing, I prefer thicker pens over very thin ones. I do not even have such thin pencils anymore. Back then you were able to buy enhancement that made pens thicker.*" (IV05/12), not thin, "*Yes I am struggling when writing with a pencil, especially if it is very thin. The thinner, the worse.*" (FK01-2/365), and not slippery, "*My writing problems depend on the shape of the pencil. If it is a thicker or smooth one, I am struggling. I need one that is not slippery.*" (IV06/1).

Figure 17: Proper knife handle (IV06)

6.2.2.2 Technology

Technologic progress enables and provides additive tools. Participants reported several activities they accomplish much easier by electronic substitutes, namely screwing, "*Today everything is easier as you have electric, cordless screwdrivers. Back then, we did everything by hand. That would be too hard nowadays.*" (IV01/7), stirring, "*When I have to stir with a usual spoon it is normally no problem. But if I have to stir over a longer period, I have to take an electric mixer.*" (IV02/8), cutting, "*I use an electric bread cutter as an aid.*" (WS/6), and tooth brushing, "*For brushing my teeth I have an electric brush because using a normal toothbrush hurts. With normal toothbrush I have to hold it a bit cramped, and somehow my whole hand hurts. Not just only some fingers, my whole hand hurts. That is why I am using an electric one. You just have to hold it. Sometimes it is a bit too heavy, especially if you brush for a longer period, but it still works.*" (IV02/8).

Especially when facing problems with handwriting, electronic devices are helpful, as one interviewee argued, "*He told us that he is afraid of losing writing skills. I am not afraid regarding my writing skills because nowadays you are usually writing with an electronic device.*" (FK01-1/397), and another mentioned the smartphone as a helpful example, "*It hurts when I have to write something with my hand, for example when I write down some notes for shopping. Therefore, I usually write short notes on my smartphone.*" (IV03/7). Furthermore, touching interfaces, as on mobile phones or tablets, are easier to use than pressing buttons, as one put it, "*On my mobile phone I don't have to press any buttons anymore, and this is much easier to handle than having keys to press. You just have to wipe.*" (IV06/12), and another one commented, "*It is much easier to write with my tablet, than to write with a usual keyboard. There you don't have to hit the keys so hard.*" (IV04/4). Beside touchscreens, which are not available everywhere, writing on electronic devices may be improved by using special ergonomic keyboards, as participants reported, "*I have an ergonomic keyboard because with a normal one I can't work that long. Using the ergonomic keyboard keeps my hands in a more* *comfortable position. Additionally, I have an ergonomic mouse that is much easier to handle. My employer provides me with these devices. First, you have to get used to it, but afterwards it is much better.*" (IV05/3). However, such keyboards are rarely available on the market, "*Good ergonomic keyboards are rare on the market. Last time I searched for one in a common electronic store, there were only one or two different keyboards available, and even they were not very usable. There should be much more types available, not just varying in color.*" (IV05/11), and more expensive than others, "*For elderly people, who are already receiving pension, and who want to work on the computer, specific ergonomic devices like an ergonomic mouse and keyboard are already about 100 to 120 €. They have to think carefully if they should buy them or just a cheap mouse for a couple of euros.*" (IV05/12).

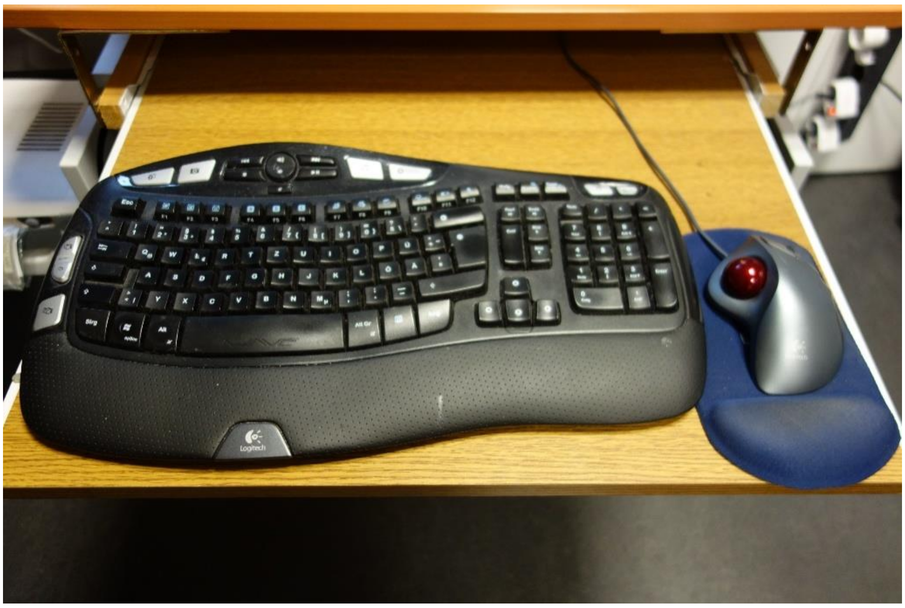


Figure 18: Ergonomic keyboard and mouse (IV05)

Opinions differed whether modern technologies as smartphone applications are beneficial. One interviewee stated new opportunities, "*I think such smartphone applications may be useful if someone can get some ideas or exercises out of it then, its purpose is already fulfilled.*" (FK01-2/439), whereas others fear such technology, "*I did not want to download an application for my mobile phone. First, those applications are very annoying and interruptive, and second, you do not know what will be there in the next 3, 5 or 10 years. Maybe the public health insurance has access to your smartphone and knows what kind of disease I have and drugs I take. I am afraid of that.*" (FK01-2/435), or they do not even have a smartphone, "*I can't use a smartphone application, because I don't have a smartphone.*" (FK01-2/435).

6.2.2.3 Opening aids

Another widespread coping strategy is the use of opening aids. Regarding the lack of strength and presence of pain, participants use such aids as help, as one described it, "*I have the opening aid in my hotchpotch chest of drawers. Without it I won't open any cucumber glass, or* *any other glass, because it's my strength and my pain.*" (FK01-2/324). Those tools help to open bottles, "*I have opening aids for opening bottles or glasses.*" (IV05/1), or glasses, "*I already need a tool to open a glass of marmalade.*" (FK01-2/286). A special opening tool reported by the participants are plastic foils. One reported its helpfulness, "*That is really great. It is a plastic, like a sticky foil, you place it on the top of the container and then you open it. That is much easier.*" (IV06/8), and another its easy application, "*I use blue plastic foils that I got from my doctor if I cannot open it anymore. You have two parts, one sticks on the kitchen workspace and you put the other on the screw cap of the glass. This works quite well, it is very sticky and I do not slip anymore. However, I got 5 liter glasses of cucumber from my sister-in-law that are very big, and you cannot use the plastic anymore.*" (IV02/6).

Figure 19: Plastic foil opening aid (IV02)

Besides special opening aids, interviewees used other tools, encompassing nippers, "*For glasses, like these normal salad or cucumber glasses, I have to use a nipper to open it. I had to buy a nipper and I am still able to open it.*" (IV05/3), and knifes or forks, "*Some packaging is so difficult to open that you give up or use a knife, fork or something similar that enables you to open it.*" (IV02/2).

However, participants reported disadvantages regarding opening aids. There is an additional effort to search and apply it, as one put it, "*If I want to open a bottle of water, indeed it is painful, but before I start searching for an opening aid and use it, I simply suppress the pain and open it.*" (FK01-2/297), and another commented, "*Usually an opening aid lies somewhere in a chest of drawers beside a lot of other stuff. So, if you take out a glass you want to open, you forget about it. You open it with pain and it requires some force, and most times, it is open immediately. So there is no purpose for the opening aid.*" (FK01-2/323). Furthermore, those tools are available at specific locations and not everywhere, when needed, as an interviewee argued, "*I cannot bring my additive tools everywhere. I have one at home and at my workplace.*

Nevertheless, last time I was sitting in public transport and I was unable to open a bottle of water." (FK01-1/320).

6.2.2.4 Thermal applications

Some commonly used helpful additive tools are thermal, i.e. warm and cold, applications. Participants reported warmness in its various kinds and forms as beneficial, as one put it, "*Warmness helped me a lot.*" (WS/11), and one commented, "*Warmness, warmness in every kind and types helps. No matter if it is warm water or warm wax, both are very comfortable.*" (WS/8). Another person emphasized the importance of keeping his hands warm, "*It's an important issue for me to keep my hands warm, even in the summer.*" (IV06/14), for example against pain, "*If my hands hurt, I just warm them up.*" (FK01-1/175). Warmness improves the condition of the hands, "*Usually I go to the bathroom each morning, let some warm water flow over my hands, do some exercises, and afterwards my hands are doing better.*" (IV06/4), and gets fingers more flexible, "*Warm water is good for me. My fingers get more flexible and more mobile, so that it is easier for me to grasp things.*" (IV06/3).

Participants mentioned several hand-warming applications. Applying warm water is therefore, one easy helpful way, as one put it, "*I found out that warm water works fine for me.*" (IV05/13). Interviewees mentioned using hand baths, as one said, "*I put my hands in lukewarm water, keep them a while in it, and then it is fine again.*" (IV03/4), and another commented using vibrating hand baths, "*I take the small vibrating pan, usually used for foot, put some warm water inside, put my hands and start the vibration. Usually that is for feet, but I use it for my hands and it helps me. It´s like a bath for hands that is vibrating.*" (IV05/4). Other hand-warming tools are warming pads, "*I also apply a warming pad. When I have pain in the evening, I take the warming pad, put it in the microwave and apply it on my hand. Then I stay under a blanket until it feels more comfortable.*" (IV06/4), massage rolls, "*Getting my hands warm with warming pads and massage rolls has helped me.*" (WS/11), heating beds, "*I have a water bed you can heat and it is adjusted at 30°C, that is quite hot, but when I go to bed my whole body feels well, not just only my fingers. That helps a lot, when you are going to bed and it is warm, and your blanket is warm, this is much more comfortable.*" (IV06/4), and heating handles, "*For my motor bike I have heating handles.*" (IV05/2).

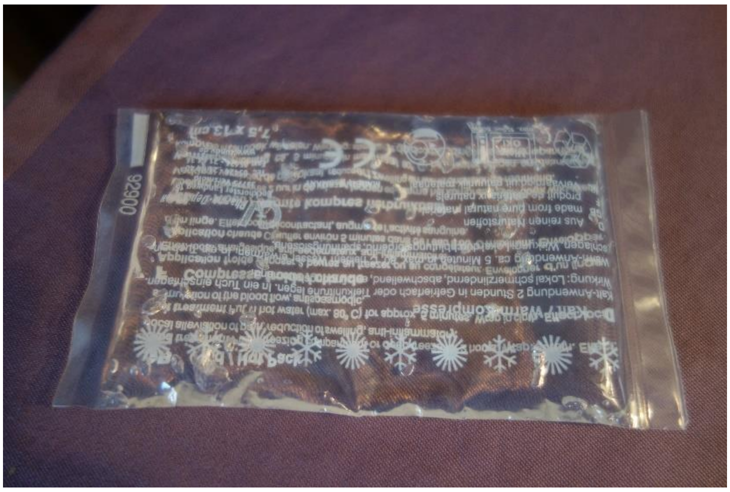


Figure 20: Warming and cooling pad (IV02)

Besides the benefits of warm application, also cooling may be helpful for others, as one put it, "*Back then, I always had cold hands, but since the osteoarthritis started, my hands are warm all the time, sometimes too warm and that is quite uncomfortable. So I apply a cooling pad that is not too cold, but that makes it comfortable for me.*" (IV02/12). Whichever kind of thermal application is helpful depends on the individual and kind of application, as an interviewee said, "*I take the curd from the freezer and it is cold, but that works well for me. However, I had paraffin baths with warm water about 37°C that worked well for me too. So I believe that there are not just only 2 (warm and cold) types of people, because the curd works as cold and the paraffin works as hot and both are fine.*" (FK01-2/266).

6.2.2.5 Proper clothing

Participants reported proper clothing as a helpful tool to mitigate their problems. Gloves are beneficial against coldness, as one put it, "*If it is getting cold, below 7-8°C, I always wear gloves.*" (IV05/2), and another added, "*The only thing I do that relieves my problems a bit is wearing gloves when it is cold. Back then, I have never done this, because there was no need for it. But nowadays, when I go out, I put my gloves on.*" (IV03/9). Additionally, one interviewee reported more comfortability putting on gloves while working, "*If I am wearing gloves, real gloves, not such rubber gloves, then I have less pain, because it is softer. However, I don´t usually do it. For example, if you have to clear out a chest of drawers, you usually do not put on gloves. But if I did that, that would be much more comfortable.*" (IV04/7). One more example for proper clothing are shoes without shoelaces, as one put it, "*Nearly all my shoes are without shoelaces, so that you can slip in easily. However, the disadvantage is that you will never get a good grip in such shoes.*" (FK01-2/307).

6.2.3 Professional aid

Besides doing self-care activities and using helpful tools, people utilize a number of provided professional aids. Those aids include visiting health professionals, taking painkillers, joint injections therapy, application of ointments, doing paraffin hand baths, using splints and getting massage. As there are many potential positive effects, participants mentioned various accompanying issues coming along.

6.2.3.1 Health professionals

For individuals suffering from osteoarthritis, searching for and visiting proper health professionals is the first step to get help. Approaching for professional help yields useful tips and prescriptions, but it also includes several issues, as adherence, no help provided at all, getting the correct diagnosis, and finding appropriate professionals.

Visiting doctors is a widespread coping strategy and the first access to professional treatment. One interviewee reported it as the only way for getting help, "*In any case you should visit a doctor for doing examinations, because there is nothing else you can do.*" (IV02/11), and others gave examples for the proper help and information they got, as a first elucidation, "*My disease-related knowledge derives from the medical study I participated in. The doctors there explained me what the disease really is, what I may do and what I should not do. That was enough proper information for me and so I did not ask for any more.*" (IV06/16), doing exercises, "*The doctor told me that it is enough to do the exercises twenty times every second day, and I am following that advice.*" (IV02/7), handling pain, "*I have regular occupational therapy sessions. My doctor showed me how to handle the pain in my finger. I just take my painful fingers with the other hand and stretch them. You can hear the cracking, but the pain stops.*" (WS/13), and other suggestions, "*Back then, I informed myself by asking doctors what I should do. They advised me to have warm and cold baths, general warmness and move to Polynesia.*" (IV04/9).

However, getting proper help and adhere to it is another challenge. One reported not following the suggestions after some time, "*The doctors advised me after my accident to avoid lifting up things above 15kg and that I shouldn't work with my hands over my head. But after half a year had passed, I continued doings such things, for example preparing the ceiling on a ladder.*" (IV01/9), another person did not even consider to adhere, "*I am too lazy to follow the prescriptions of my doctor.*" (IV03/9), and one described frustration by all the provided constraining suggestions, "*After my 50th birthday I experienced it for the first time. People told me it is like that when you are working on construction sites your whole life, but I laughed at them. Now I know how it works. The doctors told me to stop with this, stop doing that and avoid this. So what is left for me to do?*" (WS/8). An interviewee reported this issue as getting good tips on treatments, but the challenge to continue afterwards and incorporate them in regular life, "*I have been in a rehabilitation program for several times and it was very helpful. However, you should continue the exercises at home, but who is really doing that? You keep on doing them for maybe 2 weeks, but then you get lazy and forget about it. After the cure program, you* *have the intention to keep on going because it was helpful. But afterwards, when you are back in your regular life, it becomes very hard to continue.*" (FK01-2/225).

Indeed, experiences on getting useful help differed within participants, as one interviewee put it, "*The doctor told me that there is nothing I can do to heal my fingers.*" (FK01-2/209), and another commented, *"I was at the hospital, and I believe that everything they told me, that there is not much more I can do, may be true.*" (IV06/17). One individual didn´t get a suggested path to follow and had to pay a big amount of money without getting proper help, "*There are a lot of doctors around, where you have to pay a lot of money but get little relieve and they can't tell you something new. You go to the doctor and tell him that you want to do something, and the doctor says, yes, we can try this and that, but you will not get proper help. I think for every disease there is a suggested path you have to follow, but you don't get this with my condition.*" (IV05/12). Such negative experiences make people to exclusively follow an approach on their own, as one put it, "*The doctor explained how the disease develops and progresses over time, but that there is no help and that I just have to deal with it. I have to deal with it, that is how he explained it to me. Therefore, I thought to myself, I just help myself and ease my tasks, and some specific activities I just cannot do them anymore.*" (IV06/16).

Another reported problem was getting to the correct diagnosis, especially in the beginning. As an example, one described the long way for getting the right diagnosis, "*It took a long time until I knew what kind of disease I have because most people told me that it is arthritis, but only a few knew the difference with osteoarthritis. First, they told me I have the gout. Therefore, I changed my nutrition, but my condition did not improve. Then, they told me it is rheumatism, so I did a blood test, but it showed me that I do not have any rheumatism indicators. Finally, they told that it is osteoarthritis. So it takes quite some time to find out which disease you have.*" (IV05/12), and another one commented it as a big issue not knowing what the problem is, "*That is our biggest problem. Usually you visit a doctor and he will find something, for example, if you have problems with your lever they will find a related indicating marker. But with our condition it hurts, your hands get stiff, but no one can tell you what is going on.*" (WS/14).

Besides the provided help, finding a proper professional may be a challenge, as one interviewee reported, "*During my last rehabilitation I was treated by an occupational therapist specialized on fingers and I asked her for someone like her in Vienna. However, she did not know anyone. If I look up such therapist in the Internet, you will find many occupational therapists who do everything, but you have to try out 6 to 7 different ones to find someone who is really specialized in osteoarthritis. It is very hard to search for a specific doctor or therapist.*" (IV05/13).

Additionally, one interviewee stated a request for receiving regular assessments to track his disease progress and adjust coping strategies, as "*I would prefer it to have regular* *examinations and assessments to evaluate and track disease progress, and the speed of progress. For example, by comparing the year 2012 with 2014. Those tests for hand functionality with paper clips and rubber bands would be a possibility to repeat every year so I can see how far and in which stage I am, and what other things I can do against it.*” (IV06/17).

6.2.3.2 Painkillers

A controversial reported professional aid was taking painkillers. Some participants described it as very helpful, as one put it, “*The best help for me are pain killers. One in the morning, one in the evening and everything is fine. This way, I can open and close my fingers without problem, at least until today.*” (WS/10), another commented it as the only help, “*The only thing that helped me were painkillers. They vanished my pain completely from my mind.*” (FK01-1/209), and another person takes it in case of severe problems, “*On some days I cannot stand my condition without taking painkillers, so there is no other way than taking my medication.*” (FK01-1/18).

However, participants brought up a number of issues when taking painkillers. Some described adherence to continuously and regularly taking them as a challenge, “*I am not a good pill taker regarding my lack of consequence. I do it well for one or two weeks, but afterwards I discontinue. I am living a very irregular lifestyle and I travel a lot, so it is not so easy for me to do something at 8 or 12 o'clock.*” (FK01-1/69), and another commented, “*It is hard to keep on taking pills over a longer period of time.*” (FK01-1/171). Others reported some side effects, which affected the body, “*Taking pain killers affects my stomach badly.*” (FK01-1/99), or changed perception, “*I felt like surfing a small wave when I took pain killers.*” (FK01-1/87). Additionally, medications may be expensive to buy, and do not show the expected effect, as one put it, “*You can buy a lot of different and very expensive pills and crèmes in the pharmacy that are of no help and you have to buy that with your own money.*” (WS/9).

A recurrent issue in the discussions was a sense amongst individuals that they were not in favor of taking medication at all, as one explained it, “*Something I am really curious about, and it gets on my nerves is that I have to take pills to be able to work without pain.*” (FK01-1/319). Others try to find workarounds instead of using medication, “*I am trying to avoid drugs as much as possible and always look for a workaround.*” (WS/12), replace it with homeopathy, “*I try to reduce the drugs I have to take, because I prefer the homeopathy way. Therefore, I will look for something that possibly can replace the drugs. To be honest, I am against drugs.*” (IV06/16), or apply other coping strategies if possible, “*Instead of taking drugs I try to keep my hands in motion as much as possible because I don't want take too much drugs. I have my drugs at home just in case of intense pain.*” (WS/12).

6.2.3.3 Joint injections

A variety of perspectives were expressed, whether injections into the hand joints are proper and helpful or not. One interviewee reported that getting injections improved the condition, "*I got an injection therapy in my hand root joints. 4 or 5 times, once a week, I had to go there and it improved my condition a bit.*" (IV03/5), whereas another described no perceivable effect, "*The injection therapy from my rheumatic doctor was really no help. I had to go there every 14 days, and I am sure the public health insurance had to pay a lot of money for it, but there was no visible positive effect.*" (WS/11). Additionally, participants brought up more issues of this therapy, such as uncomfortable conduction, "*Injections are painful and bloody. I got some bleeding on all hands and joints after the injections.*" (FK01-1/205), and the time limited effect and expensiveness, "*One of my working colleagues visits a doctor for injecting something into her joints. That improves her condition for 2 or 3 months, but then the pain comes back, and that is not very funny. I did that once, somewhere in the south of Vienna there is a specialist where you have to pay a lot of money, but except from the expensiveness it was no help at all.*" (IV05/10). Even professionals share varying opinions on this theme, as one interviewee reported, "*In one hospital they told me that usually you should not do any injections, but they cannot forbid it to all doctors. So there are some doctors left doing injections, but it is extremely dangerous.*" (FK01-1/199), what may let to confusion for affected people, "*Sometimes I feel helpless, because you hear a lot of different opinions regarding injections for your hand joints.*" (FK01-1/210).

6.2.3.4 Paraffin baths

Participants expressed varying concerns regarding effect and application of paraffin bath treatments. Whereas some highlighted its helpfulness, like "*Paraffin was very helpful for me and very comfortable too.*" (FK01-1/140) or "*Physical treatments worked really well for me. I do them regularly. For example, paraffin baths, and in general I always had a very good feeling afterwards.*" (WS/12), others perceived its application yielding the same results as wearing gloves, "*I tried paraffin baths but that showed the same results as, for example, wearing gloves inside your flat. Like a paraffin bath, it warms and calms your hands.*" (IV04/7) or no proper effect at all from very few prescribed treatments, as one put it, "*Most times you get physical therapies prescribed, but nowadays the public health insurance only approves about 10 treatments, and the second time only 6. That is it. There you put your hands for 7 to 8 minutes in warm water. That is all a joke. It is too few and you do not have an effect. You have to do that every day, and not just once or twice a week.*" (WS/11).

Instead of professional care providers, an interviewee explained the practice of self-made paraffin baths, as "*I have bought a paraffin bath to do it at home. But I am not a regular person, so it is hard for me to do things regularly, and it is also a bit laborious to do it at home.*" (FK01-1/137), bought via an online marketplace, "*I got my personal paraffin bath at home via an online* *marketplace because new ones are about 100 to 200€. It was very easy to get it over this marketplace from a private person, who is also suffering arthritis, but who told me that those baths did not work for her. So she sold it.*” (FK01-2/460). However, another participant commented on this idea to stick to professional treatments, if affordable, as those are more comfortable, “*Once a year, in January, I am doing paraffin baths and electric treatments. That works well for my osteoarthritis. Doing paraffin baths at home would be too complicated, because you have to do it for both hands and that is very time consuming. It is not difficult to do it at home, but it is easier to go to a physical institute. Although the public health insurance does not pay for it anymore, 10 treatments are about 160€ and that is affordable, at least for me.*” (IV02/3).

6.2.3.5 Splints

Another professional aid mentioned was the usage of splints. Although they are helpful, participants brought up some issues. One interviewee reported splints as reducing pain, but quickly get worn and there are problems of adherence over a longer period, as “*For my thumb I used a kind of splint. Back then, my left hand was more painful, because my right hand was injured and I did everything with my left one. However, I did not use it for a long time and I forgot how to apply it. You can immobilize your thumb with it and so you can do many activities without pain. But now it cannot be used anymore, it is already stiff and worn.*” (IV02/11). Another one described splints as uncomfortable to wear, “*I have a splint against the numbness of my hand. I got it prescribed and they adjusted it specifically for my hand. It keeps my hand in a specific position over night and that is very helpful. However, it is awkward to go to bed with such a tool on your hand.*” (IV03/10). Instead of professional adjusted and more expensive splints, cheap alternatives are available and show relieving effects, as an interviewee mentioned, “*I bought some aid from an orthopedic catalog, a bandage for my hand for around 25€. If you go to an orthopedic store you have to pay much more. It reaches from my thumb over to my pointing finger and it stabilizes my fingers. I saw them and bought several. It is a real relief for doing my work. The tighter ones are the better ones. Unfortunately, you have to change and wash them every day.*” (IV06/6).

Figure 21: Hand splint (IV03)

6.2.3.6 Massage

Participants reported massages as a beneficial treatment, but still mentioned a number of issues. One individual described getting massages from a specialist as very helpful for reducing pain, but that those specialists are hard to find, "*I would like to find a good physiotherapist. However, the only one I know, I visit on my holidays in Italy 2 times a year, because our hotel includes a rehabilitation center. She is pretty good and she uses special massage techniques. It is fantastic, the treatment is about 50 minutes, she massages every joint very gently and afterwards you are a bit taller and completely free of pain. You feel like a new born afterwards and it lasts for half a year.*" (FK01-2/213). Another one described the problematic situation that prescribed massages provided by the public health insurance are often very few and non-qualitative to show proper effects, as "*The problem for people here in Vienna and Austria is that you go to a physical treatment that your doctor prescribed you. Therefore, you visit a physical institute, they put you on a bed, and a masseur comes in, does his job, and after 10 minutes you can leave. That makes no sense and is not helpful. One reason is that the public health insurance is still reducing the times. You will not get the qualitative massages you can get at cures. It is a fact that the public health insurance will not pay for it in regular.*" (FK01-2/219). Additionally, taking private massage sessions is expensive, as one participant put it, "*As a typical Viennese you just get about 1000€ per month in your pension. If you want to go to a massage therapy of 10 treatments about 50€, that is impossible. That is the problem.*" (FK01-2/221).

6.3 SUMMARY

The thematic analysis applied on the outcomes of the user research provides a range of themes and subthemes that are categorized in two broad main themes and six more specific subthemes giving insight into the problems caused by HOA and coping measures against HOA. The content of the first main theme, namely problems and impacts, covers issues participants experience regarding their disease, ranging from the disorders, to the burden on their life and the affection of their daily activities. The second main theme, namely coping strategies, provides a range of counter measures to handle the condition, comprising self-care approaches, additive tools, professional aid and their accompanying issues. Every single issue is supported by at least one corresponding extract from the transcripts, to provide evidence and highlight the participant's voice and context. Because of the high amount of identified topics a summarizing story about life with osteoarthritis is provided in the following chapter 7.

7 LIVING WITH HAND OSTEOARTHRITIS

The previous chapter provided a structured form of the identified themes and issues reported by the participants. Within this chapter, the outcome of the analysis is put into a story to summarize what living with hand osteoarthritis means to individuals. Based on the findings, the story answers the related research questions RQ1 about which problems and challenges people experience, how they cope with those issues and which issues accompany those coping strategies.

7.1 DEVELOPING OSTEOARTHRITIS

Having osteoarthritis is a sneaky process and therefore hard to recognize in the beginning. Occasionally, soft pain in specific hand gestures, a bit of stiffness after waking up in the morning, and here and there, and a somehow awkward feeling shows presence in the hand. However, all of those symptoms are quickly gone and vanished from mind until their next appearance. Although counter measures should start as early as possible in the beginning, people underrate their disorders and rarely visit a doctor for clarification, since within daily life those events come and go, and are seen as part of the normal aging process, not related to the oncoming chronic disease. Letting the disease evolve its worsening progress over the years and in absence of treatment, make the frequency and intensity of those symptoms rise. Pain increases, stiffness reduces mobility of joints, hand and fingers lose their strength, fingers thicken and get swollen, and dexterity and control decrease.

As the condition is continuously worsening, individuals have to face more and more challenges. Hands and fingers that usually are unconsciously involved in many daily routines request for attention and are getting now into focus, as they aren't function anymore as they are expected to. People start struggling when holding or lifting up heavy objects, and grasping small or fine things without a proper handle or wider surface gets difficult. Objects unintentionally drop from their hands regarding the reduced dexterity or pain, and pressing a button hurts. The situation of the hands affects the performance of daily activities, thereby limiting and frustrating individuals. In general, tasks are harder to accomplish, more exhausting and longer lasting than before, especially if strength is required or load is on the fingers. At worst, specific activities cannot be done anymore. The effect of deformation shows up, making the appearance of fingers less beautiful. Individuals experience it as aesthetic discomfort making them feel uncomfortable in social interactions. Therefore, they try to hide their hands, and avoid shaking hands, which may be painful. Furthermore, the condition promotes people sensitivity under environmental influences. Especially, cold or wet conditions bring them more problems and even causes pain.

This continuously worsening progress leads to frustration and resignation. Individuals fear the spreading of the disease over to the healthy hand or fingers, and they are afraid of losing important hand functioning skills as writing. So, people end up with a pessimistic look towards their future having a non-functioning hand and being unable to move their hands and fingers at all.

7.2 EVERY DAY CHALLENGES

Days start with getting up from bed in the morning and stiffness in the hands. To be ready for a day with fewer difficulties, hands need to be prepared, the so called warm-up. People do some movements, concrete hand exercises, they put their hands under warm water, or a combination of these practices. All of them are helpful, but time-consuming tasks. In the bathroom people face various problematic activities of personal hygiene. They struggle with the hand motion while brushing their teeth, putting on make-up is hard regarding reduced dexterity, and even a heavy electric razor can be painful to hold over time. Furthermore, cold water on hands is a no-go. However, brushing teeth with an electric toothbrush puts some relieve on this activity. As elderly people regularly have to in-take their daily medication, handling small pills is another daily burden with non-functioning hands. Another morning activity is getting dressed. Closing buttons require dexterity, pulling a zipper puts load on fingers, and tying shoes laces is painfully laborious. Regarding deformities, rings may do not fit anymore and putting on gloves becomes difficult. Therefore, people buy clothes that are easier to put on, for example shoes without shoelaces.

After being washed and dressed, preparing food in the kitchen offers more challenges and cooking related activities become laborious. Heavy things, such as a pot of water or a filled water heater, are burdensome to lift up, and cutting hard food like carrots or melons gets painful. Baking a cake is nearly impossible, as preparing pastry gets troublesome, and stirring, as holding a mixer over a longer period, becomes painful. Taking out the laden baking tray when the cake or meal is finished from the oven is even harder to do. Finally, when preparing dishes for the table, carrying a stack of plates is painful too, and things may unintentionally drop from hands. Dropped items may be damaged, need to be bought again, and lead to embarrassing situations for individuals, especially when guests are around. People ease those tasks by using electronic tools, such as a slicer or mixer, or use tools that are easier to handle for their hands, as spoons with thicker handles or chopping boards of lower weight. Another challenge at the kitchen area is packaging. Lacking of strength and having pain in hands, packaging that tightly sticks together or includes pull flaps like with milk cartons, or have screw plugs, as mineral water bottles or cucumber glasses, are all very hard to open with bare hands. Therefore, people try to look for packaging that is easier to open like bottles with broader caps or use opening aids, like sticky plastic foils, nippers, knives, forks or special opening aids from an orthopedic store. However, such tools must be instantly available when needed and easy to apply, which is not always the case, and so their application is perceived as an additional effort. After cooking is done and food is finished, the working area must be tidied up. However, carrying a bucket of water for wiping up the floor or cleaning up small objects from the floor, like pieces of broken glass, is problematic. Furthermore, holding a cleaning tissue properly, for example for cleaning windows or polishing cutlery, is rather exhausting.

Another household chore offering more challenges is shopping. First of all, traditional shopping requires getting from A to B, and people experience reduced mobility starting in their homes. Regarding the lack of strength in hands, turning the handles of doors gets more difficult, and holding a key adequately between fingers and turning it is even harder without proper dexterity. Out of home, each kind of transport vehicle is accompanied by its own problems. Driving a car works well in short time, but over time turning the wheel and changing the gear becomes burdensome. Furthermore, after holding the wheel for a while, hands get cramped and they need to have some rest or be switched. On public transport like trams, the condition of hands makes it harder to find proper hold, especially on abrupt breaking. When using a bicycle, a cold wind will be hard to stand and pulling the brakes is painful. Finally, arriving at the supermarket new issues arise. Products may be too heavy to lift up from the shelf and dealing with coins for paying the bill or getting exchange is burdensome. Afterwards, the purchased products must be brought home. When walking carrying food, shopping bags may be too heavy to carry home and pain in hands sets in. Therefore, hands can be switched or a trolley can be used. However, taking a trolley is also perceived as looking awkward, and so taking the car is more comfortable.

Handicraft and gardening activities may be either a necessary household chore or a leisure time activity. However, individuals face several problems. Assembling furniture as a new office desk or hanging up a picture becomes hard to accomplish, especially involved tasks as holding a nail with two fingers or screwing something tight with bare hands are burdensome. After longer lasting handicraft work, as renewing a floor or wall, disorders show up with high intensity. As relieve, electronic tools, as screwdrivers, are used. Furthermore, fine handicraft activities become difficult. Sewing, holding a needle or using scissors with non-proper handles become harder to do, as the required dexterity has disappeared. Another location of problematic activities is the garden. Longer lasting gardening tasks lead to pain and must be stopped after a while. Especially, digging holes or pulling out weed is troublesome. For doing handicraft or gardening activities wearing gloves is beneficial and puts some relieve on work.

Besides daily household chores, paperwork activities provide their issues. A daily task getting more and more difficult over time is writing, either by hand or with an electronic device. Writing by hand becomes harder and painful, especially when writing over an extended period of time or holding an uncomfortable pen. As writing is a very personal task, people are afraid of losing this ability in the future, for example as doing their own signature. To put ease on writing, individuals choose pens with comfortable handles and figure out how to hold them properly to get a relieving grip on them. Additionally, electronic devices, such as computers and smartphones, are more and more preferably used for writing. Keyboards are helpful and modern interfaces as touchscreens are much more comfortable to use, compared to pressing keys. However, using such devices brings up other issues, as writing on a keyboard over a longer period is still burdensome for hands, and matching the right letter on a small smartphone display keyboard is difficult. In the case of keyboards, specialized ergonomic keyboards may bring relieve, but are harder to get and more expensive. Besides writing, reading newspapers or books is also troublesome, because when switching and browsing through the thin pages are hard to grasp. Also other paperwork tasks, such as dealing with small items, like paperclips, get difficult or doing clicks with the computer mouse may be painful after a while.

7.3 SELF-CARE PRACTICES

In the early stage of the condition, people do not even recognize the upcoming problems. After the first times experiencing the disorders, they try to suppress them or distract themselves from them, and they get used to it over time. When the intensity and frequency of problems increase, people start with first behavioral changes to accommodate their life and lifestyle to the new circumstances. They reduce their amount of workload, do more resting breaks to give their hands more relieve, especially when performing exhausting tasks, stop activities before problems occur, try to switch to easier tasks, do their work slower and more thoughtfully and carefully. If possible, individuals avoid activities that lead to problems or adapt the way how they do things. For example, rearranging stuff for easier accessibility or substituting tools by those that are easier to handle. People avoid troublesome hand gestures or try not to involve problematic fingers. Therefore, they try to figure out the best grip on a tool to handle it more comfortably. An example of this is that instead of only using the fingers, the whole hand is used for getting a better grip of an object, as when holding a key, using a cleaning tissue or opening the cap of a can. Additionally, the healthier hand is used for support and heavy load is balanced on both hands, for example, when carrying a stack of plates. Having still one healthier hand left, people try to relearn doing tasks with that one. Undeniably, all these adaptations put a higher burden on daily activities and individuals need more time to accomplish activities.

Good ergonomics of tools individuals work with is critical, as bad ergonomics cause problems. Therefore, people try out several tools and replace non-proper objects by their more comfortable and easier to use substitutes. Better ergonomics are described as proper handles and shapes, for example bigger caps on bottles, a can with an opening handle, or a glass with a bail. In general, objects should be of lower weight to reduce load on hands and of bigger size to be easier to grasp. Comfortable handles are round, soft, thick, but not angular, not thin and not slippery.

Regarding the higher weather and environment sensitivity, bad weather and climate conditions are avoided, especially cold and wet ones, and ubiquitous warmness is important as it improves the condition of the hands. Keeping hands warm helps against pain and fingers stay more flexible. People start to have warmer rooms at their homes, seek for warm environments everywhere they are, dress for colder weather than necessary as putting on gloves in autumn, and travel to the warm south on holidays. As daily practices they apply warm water or warming pads and do hand baths. Furthermore, a heating bed brings relieve for problems over night and in the morning and heating handles on the bike allow them do their desired leisure time activity.

When people start struggling with activities as those are getting more and more difficult to do, they request for help and ask other people for support. Therefore, if possible, they delegate problematic tasks to their partners, relatives or working colleagues. However, asking people who are not familiar with them or their condition for help may be uncomfortable and lead to awkward situations, as asking your neighbor or a foreign person in public transport to open a bottle. Additionally, not every task can be delegated to others, as an elderly woman may not have the strength to open a tight closed can. Another approach is paying for help, such as hiring a charwoman for doing household chores or having a chauffeur.

Individuals require proper and holistic elucidation about the condition as early as possible to better understand what is going on. They often hear that they cannot do anything about their situation, and retrieving helpful information is not as easy as it should be. Therefore, they start increasing their knowledge on their own by gathering information about disease-related issues, coping strategies, lifestyle and behavior adjustments, and new medical outcomes. They search for information in books or in the Internet, take part in medical studies, or exchange experiences with other patients. A common and easy accessible way for information retrieval is via the Internet. However, nowadays the Internet is wide and full of unfiltered information. People easily get on the wrong track ending up with some other disease, and determining correctness, reliability and trustworthiness is hard to do for non-experts. Additionally, smartphone applications may be helpful, as for getting tutorials for doing exercises. However, individuals are not in favor of such apps, which are perceived as annoying and interruptive, and furthermore trustworthiness, such as what happens to their personal data, cannot be determined.

Another self-care approach is keeping hands active and doing exercises. People achieve this by keeping hands and fingers moving, by stretching them, or by doing hand specific exercises. This approach helps against stiffness and pain, and maintains mobility of the hand. For alternation, people utilize tools, as soft balls or putties. For best effect, doing regular exercises is important, as otherwise problems will come back. However, incorporating regular, time-consuming exercises in daily life is difficult to do as it puts a higher burden on the individual’s life. They have to get up earlier and need some time every day to complete a proper set of exercises, which is perceived as exhausting and constraining life. Furthermore, individuals are lacking of proper set of instructions to know how to do exercises correctly, or are not motivated to do them at all. Additionally, doing sports improves the overall condition and people perceive it as beneficial for the hand. They visit gyms, watch exercising television programs or go to specialized institutes, like Kieser. However, financial costs for professional support are an issue, and individuals are uncertain about what kind of sport fits properly to their condition and how frequent they should do it.

Another lifestyle adaption is changing nutrition. People try to eat good food as fish, omega-3-fatty acids, gummy bears, and use vitamin or mineral supplements. On the other side, they try to avoid bad food, as meat, sugar or wheat. However, opinions if this approach is helpful or not and how to do it right differ between individuals. They lack of information about the correct nutrition for their condition, and they don´t know how to do it right. Furthermore, changing eating behavior is a hard challenge itself.

Another self-care practice is the application of ointments. A diverse range of pain ointments is available, they are easy and quick to apply, and often used after pain occurs, such as after work, or applied over night to mitigate problems in the morning. Indeed, ointments only reduce pain, but since there are no perceived side effects, they are preferred over painkillers. A special form of natural ointment is curd. Although it may be helpful and shows comparing effects as professional treatments, some people will not take the idea seriously to apply something that is considered as food.

Different aids work for different people, so a one fits all solution is not given, and everyone needs to find the coping strategies that work best. However, if several aids do not help, or even nothing helped, besides the financial costs, it leads to frustration and resignation. Therefore, osteoarthritis patients require helpful guiding information, a lot of ambition and patience to cope with it properly, and a positive attitude towards coping strategies or used tools.

7.4 PROFESSIONAL TREATMENT

Professional treatment usually starts by visiting a doctor for a first professional examination, but helpfulness and experience vary. At best, their physician provides an understandable explanation and elucidation about the disease itself, and creates an easy to follow, individualized care plan consisting of professional therapies, like painkillers, joint injections, paraffin baths, splints and massages, accompanied with a range of tips regarding self-care practices, like exercises, warmness and baths. However, individuals experience the opposite. Often general practitioners are not the right experts on such a specific disease as individuals expect them to be and finding the right professional providing appropriate help is exhausting. People end up with the wrong diagnosis for a related disease, like gout or rheumatic arthritis, or their consulted doctor could not provide any help and tips at all, resulting in inappropriate care actions and lacking of a concrete path to follow. People left alone without help, at best, try to figure out a way by themselves or, at worst, just let the condition worsen over time until more adverse effects appear. That makes it an important issue, to find the right professional help on the first encounter. Besides helpful treatment, people still miss the possibility for continuously monitoring their condition for reassessment and adapting or extending the current care actions. Another recurring issue of prescriptions and advices from health professionals is that individuals often decline them after a while. The reasons for this are a lack of motivation, no perceived effect, or difficulties to incorporate those in their daily life.

Another issue is that professionals tend to prescribe professional treatments only. Physicians prescribe painkillers or suggest joint injections, which are both controversially discussed, leading to irritation for individuals. Although painkillers are beneficial for reducing the perceived pain, they show side effects, as stomachache or a changed perception. People struggle with the required continuous and regular in-take, take them on demand only, stop taking them after a while, or even refuse to take medication at all. Joint injections are able to reduce the pain for some months, but must be repeated to prolong the positive effect. However, individuals do not always perceive the desired effect, and the treatment is expensive and uncomfortably painful. Other professional prescribed treatments are paraffin baths, splints and massages. Paraffin baths put relieve on hands and give a good feeling, but those effects are not satisfying everyone. Although home application is possible, it is laborious to arrange and conduct it, so people prefer to do it at physical institutes. Splints are beneficial for immobilizing problematic joints and therefore reducing the pain, but are often uncomfortable to wear and wear off over time. Individualized orthotics are superior, but more expensive, compared to their general ones from the catalog. Finally, massages are beneficial for individuals, but specialized professionals are hard to find, and the costs are an issue for individuals. A recurring problem of professional prescribed treatments are their expensiveness, as the public health system is continuously reducing financial support and amount of applications, so people have to pay it on their own, as long as they can afford it.

7.5 Summary

This chapter summarizes the thematic analysis by telling the story about living with hand osteoarthritis. From the individual perspective, it explains the evolving process of HOA, shows the daily challenges, and mentions the used self-care practices and professional treatments.

8 PROTOTYPING

The user research and analysis conducted within the previous chapters identified the problems and challenges of people with HOA. This chapter is dedicated to the second part of the research question RQ2 to answer how a self-care technology can provide help in this case. To answer this question, a design process is conducted, involving the creation of a persona to identify the target user, describing potential user scenarios, defining design principles and creating a conceptual prototype according to the findings. The persona represents a typical user with HOA and is based on the outcomes of chapters 6 and 7. The following design steps are based on the persona and consecutively build on each other, as illustrated in the following figure.

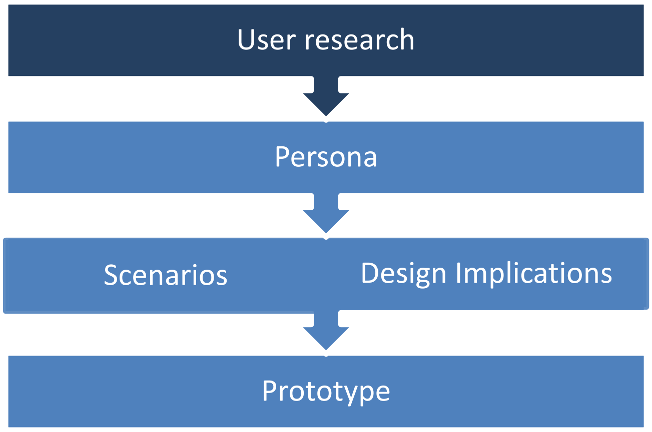


Figure 22: Consecutive prototype process

8.1 PERSONA "MATHILDA"

Mathilda is 60 years old and lives with her husband in a small row house with garden in the suburbs of Vienna. Her two children are already grown up and they live with their own families. Regarding her health situation, she had to stop her occupation and is now retired.

In her mid-40's, for the first time she felt that something was changing in her hands. There was this kind of awkwardness in her hands. Occasionally she woke up with stiffness in her fingers, and sometimes, lifting up a heavy object was painful. However, all those symptoms were short lived, and so for years, she ignored the signs, until a special event changed her attitude. Mathilda loved to cook and to host parties for her family and friends. As her husband's birthday was approaching, she decided to prepare his favorite meal and invite their children with their families for lunch. She was really looking forward to it, but it came differently than she expected. It was a cold, rainy winter Sunday and Mathilda woke up in the morning with stiffness in the fingers of her right hand. After taking a warm shower, the stiffness was gone, but an awkward presence stayed in her hand. As a lot of work needed to be done, she decided to suppress her problems. During cooking, the pain set in several times, once while cutting carrots, then when opening the cucumber glass, another time when putting the pot of water on the stove, or when taking the plates to the table. She got really exhausted, and had to stop her work, giving her hands a rest, before she continued. Despite the worsening condition of her hands and the fatiguing work, she finally made it, and the dish was ready to serve when her guests arrived. As last step, she had to bring the finished meal from the oven to the table. She already struggled when taking the tray with the main dish out of the oven. Her daughter offered help, but Mathilda declined, as her guests should not do the work. When bringing the meal over to the table, on half way, it happened. A strong pain she could not stand set in her right hand and the pot fell to the ground. Even though her family helped her to clean up the mess and her husband invited them to a restaurant to save the day, for Mathilda it was one of her most embarrassing moments and several thoughts were preying on her mind. She knew that she completely underrated the problems. Indeed, she should have already started treating them carefully years ago, and at least, she should have asked for help. Now she wanted to change that.

As first step, she visited her family doctor for clarification. However, her doctor could not provide any diagnosis, and instead he prescribed her painkillers and told her to keep self-monitoring her condition and putting ease on her life. Mathilda was fine with that as she trusts her doctor, but after the first time taking the medication, she felt stomachache and had an awkwardly changed perception. Therefore, she declined regular in-take, and she only took her pills on severe pain.

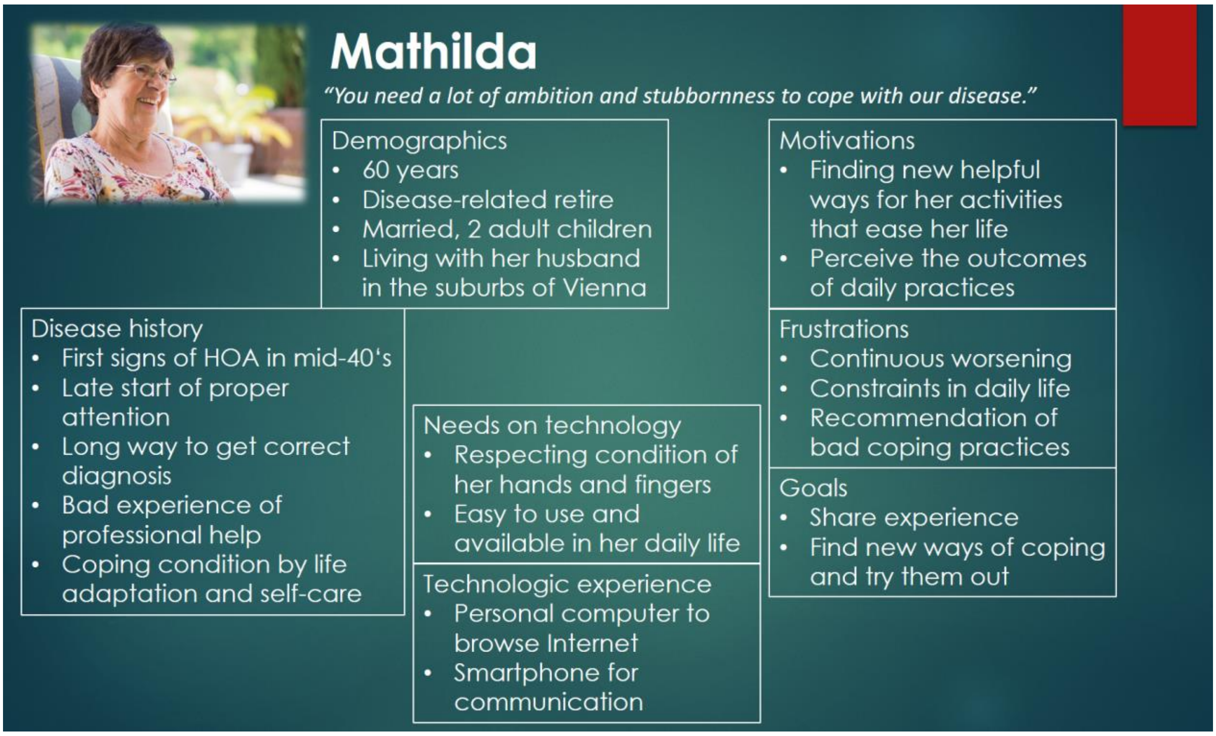
However, her condition continued worsening. Over time, Mathilda had to reduce her workload, both at her occupation and at home. At work, her colleagues supported her when tasks got too difficult, so she could switch to easier tasks that put less load on hands, and her boss let her do more resting pauses. However, at home she was responsible for doing most of the household chores and she got less capable to do them. Preparing the meal got more exhausting, and tidying up the household got harder to do. In her leisure time, Mathilda had to reduce some of her favorite activities, such as doing fine handicraft work and taking care of their garden. Although she was always interested in new technologies and she regularly used her computer and smartphone for communication and browsing the Internet, the condition of her hands made it sometimes difficult to use those devices. Even hosting parties for her family or friends was no more possible. In the morning, on bad days, she could not put on her make-up anymore, as dealing with fine objects and working with precision became tough. In addition, the appearance of her fingers changed, as they got slightly deformed and less beautiful. Subconsciously, she started hiding her hands when she was with other people, and tried to avoid shaking hands, as that could be painful for her. Furthermore, her writing skills worsened.

Facing all those challenges and being without control of the situation, she decided to ask other doctors for help. After two more consultations of other doctors, one recommended by a friend and one looked up via the Internet, she finally found a specialist. Doing some more examination, the correct diagnosis was determined: osteoarthritis. Her new doctor recommended her injections and paraffin paths, but also handed over a set of hand exercises she could perform at home. Still, she was missing a holistic approach to follow. Mathilda struggled to incorporate the time-consuming exercises in her daily life, and could not keep the motivation over a longer time. Once she lost the instruction sheet, so she could not determine correctness of her conduction, and she reduced doing them to a minimum. The application of injections was painful, but reduced problems to minimum for half a year. Afterwards, problems came back. In addition, paraffin baths brought some relieve, but must be repeated several times a year. However, both treatments were expensive and their effect unsatisfying. When her public health insurance reduced taking over the costs, she stopped it. Mathilda understood that she had to cope with it herself.

She started by revising every problematic activity of her daily life, thinking about how to facilitate them easier. Mathilda figured out more comfortable hand gestures and tried to use her healthier left hand as support. She replaced tools that were painful to work with proper substitutes. For the kitchen, she bought an electric cutting machine and a new set of knives and spoons with good handles. At the supermarket, she tries to buy the products with packaging that is easier to open, and uses a trolley to bring the stuff home. When doing her household chores or gardening and thereby having a difficult task, she asked her husband for support. As he is not always at home, they decided to hire a charwoman. For writing, she bought some special pens with comfortable handles, but mostly she uses her smartphone, which provides the relieving user interface of a touchscreen. Step by step she achieved more relieve in her daily activities, but still the condition was present. So she managed to incorporate the hand exercises in her daily life, and found some ointments at her local pharmacy that reduced the pain. By visiting an orthopedic store, she found other helpful tools. Besides an opening aid for bottles, she bought some bandages that put ease on hands while working, and a warming pad. However, the opening aid is mostly not available when needed, and so she is going for the short pain, or asks her husband to take care. Warmness got new importance. Mathilda found out that under warm conditions her hands are doing much better, whereas when winter is coming she even avoids going out for a walk. As she convinced her husband, nowadays they have a mandatory holiday in southern Europe every year, the rooms at home are well heated, and when going out she wear gloves that even others would consider as strange looking on warm autumn or winter days. She applies warmness, as a warming pad or does a warm hand bath, which both bring relieve. If today, major problems occur she is able to cope with it. Apart from the additional financial burden on her life, all these mitigations came along with constraints and limitations in her daily life, as time, ambition and motivation is needed.

Besides all these actions, she was still searching for new information about helpful tools, practices, new medical outcomes, and experiences of others to further improve her condition. Every treatment or tool will get its chance to state helpfulness, and if so, it will be integrated in her life. Therefore, self-research became important. She started reading books, but also searching the Internet. In the beginning, she quickly ended up at wrong diseases and followed wrong recommendations. In addition, correctness and trustworthiness of information was hard to determine for her, and sometimes provided information was even contradictory. Although such negative experiences frustrated her, she also found some promising information about proper nutrition and new hand exercises. Nevertheless, her high expectations were not fulfilled. She missed opportunities to exchange experience with other patients, to retrieve new outcomes in an easy understandable way, or even to have easy access to helpful, disease-related information and coping practices.

Although her diseases progress is continuing and Mathilda still hopes for a cure, she nowadays feels to be capable of keeping her condition under control and knows about the necessary amount of ambition and motivation to achieve it. Looking back on all her experienced problems and mistakes, she would like to share those, so that others don´t repeat them. Still, she misses a holistic approach and support, including explanation and guidance how to treat her condition and its accompanied problems accordingly.



Mathilda

“You need a lot of ambition and stubbornness to cope with our disease.”

Demographics
- 60 years
- Disease-related retire
- Married, 2 adult children
- Living with her husband in the suburbs of Vienna

Motivations
- Finding new helpful ways for her activities that ease her life
- Perceive the outcomes of daily practices

Disease history
- First signs of HOA in mid-40‘s
- Late start of proper attention
- Long way to get correct diagnosis
- Bad experience of professional help
- Coping condition by life adaptation and self-care

Needs on technology
- Respecting condition of her hands and fingers
- Easy to use and available in her daily life

Technologic experience
- Personal computer to browse Internet
- Smartphone for communication

Frustrations
- Continuous worsening
- Constraints in daily life
- Recommendation of bad coping practices

Goals
- Share experience
- Find new ways of coping and try them out

Figure 23: Persona "Mathilda"

8.2 SCENARIOS

Based on the outcomes of the thematic analysis and the created persona, six scenarios providing areas of implementation of self-care technologies were identified.

8.2.1 Providing personal assistance

On a daily base, individuals with HOA face challenges they can't solve on their own. Those situations may happen within their own home, at occupation or when being mobile and getting around. Therefore, they are in need of support. Technology can provide two possible solutions in this case. First, technology like robotic can take over tasks from individuals. A heavy pot of water can be moved onto the stove, hard packaging can be opened, doors and windows can be opened, closed and (un-)locked, or vegetables can be cut automatically. Second, technology can provide access to support. For example, individuals can ask for help on specific tasks via a social platform when they need support, for example for doing household chores, and the participating, helping people are rewarded.

8.2.2 Finding HOA health professionals

A reoccurring issue of HOA patients is that they struggle to find a helpful health professional on the first time, who is knowledgeable and experienced on the diagnosis and treatment of hand osteoarthritis. This leads to the frustrating situation that individuals have to try out several professionals until proper help can be provided. Furthermore, people get wrong diagnosis involving the wrong treatment for years. Via technology a list of known experts experienced with HOA in the close area can be provided. Patients may recommend experts, from general-practitioners to occupational therapist that were knowledgeable and helpful to them. The goal of this application is to make much easier to find the right professional in the first time.

8.2.3 Understanding of and awareness for hand osteoarthritis

Health literacy about hand osteoarthritis is low in population. This circumstance leads to the ignorance of the first signs and symptoms of the sneaky HOA development process and affected individuals visit a doctor or start coping on a late stage. Via technology, a platform can be provided that helps individuals to understand HOA, helps them to determine if their problems are HOA related and guides them to first coping strategies, e.g. visiting a specialized doctor or self-care advices. The provided information must fulfill the criteria to be easy to access, correct, easy to understand and trustworthy. Furthermore, information for non-affected individuals should be provided, e.g. with suggestions on how to support their relatives with such a condition.

8.2.4 Providing coping strategies

Nowadays a wide range of coping strategies is known for HOA patients. But in reality, less are known by the individuals, who are mostly dependent on the recommendations from their health professionals that may not provide a holistic approach or what they found out on their own. So, they are lacking of ideas about what to do and a general “path” to follow. Therefore, technology can show the range of possible coping strategies, from professional treatments, to self-care practices and lifestyle or behavioral changes. Descriptions and outcomes of coping practices can be provided, including where to get them or how to apply them. For specific practices, a motivational guidance and easy to follow instructions can be offered. Self-care practices may be delivered on a daily basis, as tip of the day, supported by multi-media or a communication channel between individuals to teach and learn those practices. Furthermore, HOA patients showed interest to keep up to date with disease-related news, as new therapies and practices. Nevertheless, such information is hard for them to find and understand. Therefore, an application can search for HOA related news, and sum them up in an easy way.

8.2.5 Exchange individuals experience

Patients show high interest in exchanging their experiences with others about their condition, helpful tools and practices. Although nowadays available technology offers a wide range of communication tools, none was used by the interviewed subject group. Therefore, a specialized platform for HOA patients can be provided, where they can exchange their experience related to coping strategies and organize personal meetings with other patients living next to them. Each user can share their used treatments, therapies, tools and practices, provide tutorials for those or where to find them, and those can also be rated or commented by others. Thereby the platform should provide a space and create a community of HOA patients where they can get in contact and exchange their knowledge.

8.2.6 Disease monitoring and assessment

Hand osteoarthritis is a continuously worsening progress. Therefore, patients want to know how their condition develops, accompanied with proper counter measures. Nevertheless, continuous monitoring and assessing of the HOA progress is missing. An application can be helpful for self-monitoring and assessing the state of the condition. For example, the strength in the hands can be measured, and the application provides positive feedback, if new applied counter measures work.

8.3 DESIGN IMPLICATIONS

Besides common design principles as easy to use, easy to understand, effectiveness, and efficiency, individuals suffering hand osteoarthritis have their very own needs on technology. Before creating the prototype, the design implications for this target user group are clarified and described. Therefore, the given literature and the outcomes of the user research are used for deriving definitions of design principles. The found principles are described in the following sections.

8.3.1 Minimum load on hand and fingers

HOA individuals experience several disorders in their hands and fingers of varying frequency and intensity, such as pain, stiffness, deformation, and reduced strength, dexterity and control. If a technology doesn´t reflect on these specific needs and requires any problematic hand gestures on use, it becomes a visible reminder of one's disability, is perceived as barrier and will be abandoned. Therefore, the involvement of hands and fingers, and the load on them, must be kept to a minimum, and even within worst conditions the device or application must be usable. On the device and interface, buttons that have to be pressed and may cause pain should be avoided. Any interface element must be of proper size to be easy to touch with low dexterity. Touchscreens are preferred as they can be used with less strength in fingers. User input via typing should be reduced to a minimum, as the activity of writing is an elaborate task for hands and fingers. Even on touchscreens small letters will be hard to match with low dexterity. Instead, other input methods, as voice control should be considered. Furthermore, the device itself should be of low weight.

8.3.2 Proper ergonomics of handle and grip

Due to the disorders in hands and fingers any device must fulfill proper ergonomics for HOA individuals, or else it will be replaced and abandoned. Because of the reduced strength, the device must be of low weight, and as a consequence of the low dexterity, its shape must provide a wider surface that is easy to grasp and have a proper handle. Preferred handles are round, soft, thick, but not angular, not thin and not slippery.

8.3.3 Non-stigmatizing appearance

People avoid devices whose appearance expose their special needs and remind them on their condition. Therefore, any device must not challenge the identity of their users to avoid stigmatization by look. By making use of typical technologies, people won't perceive such awkwardness.

8.3.4 Robustness

Occasionally people lose control over their hands and unintentionally drop objects they are holding. Therefore, the device and application must be robust enough to survive such drop undamaged so that the user is able to continue using it.

8.3.5 Warmness

Individuals are on the steady search for warm and dry environments. Holding a cold or wet device would feel awkward and painful in their hands. Therefore, any device and its materials must be a keeper and provider of warmness, or at least it mustn't get cold or wet.

8.3.6 Availability

Even if a tool is helpful, people will stop using it if it isn't available when needed. For example, a helpful opening aid is no good when lying hidden in a kitchen cupboard. Any application must be ubiquitous accessible in the changing environments of the user. Therefore, it must be easy to carry around, e.g. in your pocket, or have at least access to it on demand independent of the current context.

8.3.7 Time efficiency

People with HOA perceive an additional burden on their life and are timely constrained, as depending on the condition of their hands activities need more time or special activities for their hands are time consuming. Therefore, they have the need to accomplish activities in little time. If individuals perceive the usage of a tool as additional burden or its requesting time takes too much of their daily life that is not related to the help it provides, it won't be used. Any used tool must accomplish its promised goal in as few steps and as less time as possible.

8.4 PROTOTYPE "MY HELPING HAND"

Based on the outcome of the persona, the user scenarios and the defined design principles, a prototype is created and described in the following sections. This prototype represents the concept of a self-care technology potentially helpful for people with HOA.

8.4.1 Concept

On a daily basis, Mathilda faces various problems depending on the condition of her hands. For some issues she already found proper, easy to apply solutions and she would like to recommend them to others. However, there are still a lot of challenges which she doesn´t know how to overcome and she would like to share them with others and ask for help, instead of further constraining her daily life.

The goal of the smartphone application named "My Helping Hand" is to provide a platform, where users can report issues they face within their daily life, and help others to cope with their reported issues. Nowadays ubiquitous availability and functionality of mobile phones, i.e. having integrated cameras makes such an application feasible. A user facing a problem describes it by recording it within a short video and posts it on the platform. To enable categorization and identification of reported problems tags will be assigned manually and automatically by the system after analysis. At the platform, other users are able to browse through the requests for help, and provide a solution, if they are knowledgeable. If a potential solution was provided, the requesting user will be notified, and the answer can be watched. If the provided help was useful the solution can be rated and the topic will be considered as solved. If it was not useful or unclear, the answer can be discussed. If both users are online, a video chat can be started to clarify the solution. Furthermore, when the video is processed at the platform, the conducted analysis looks for similar reported issues that are already solved. Existing helpful answers to those videos will then be provided to the requesting user to browse through. If the user finds a helpful solution, the issue will be considered as solved and the solution is rated. To better understand the idea of the prototype the following illustration represents a sketch of the basic workflow.

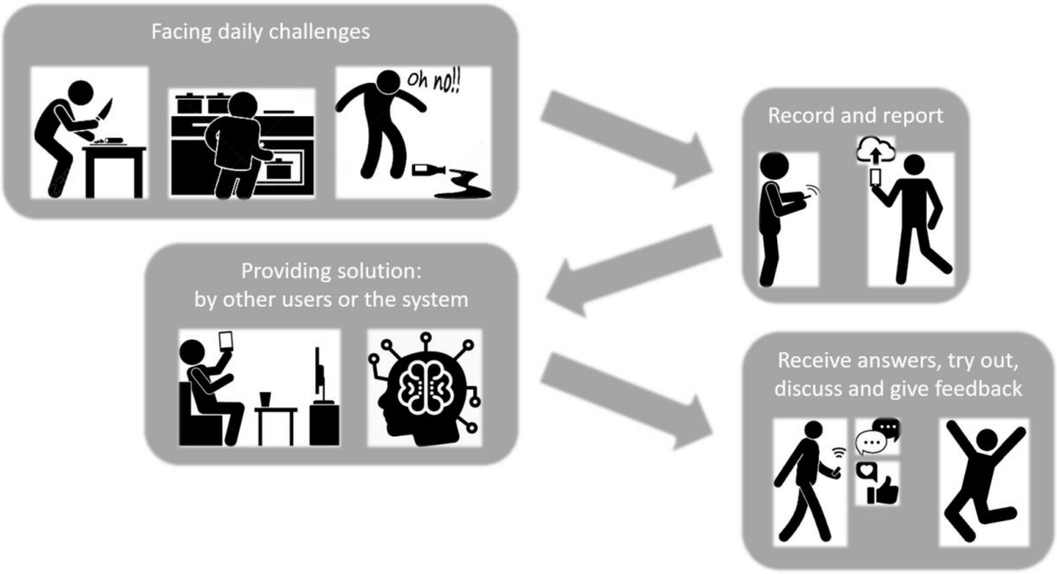


Figure 24: Prototype sketch "My Helping Hand"

8.4.1.1 Considerations of scenarios and design principles

“My Helping Hand” covers the identified scenarios of the sections 8.2.4 Providing coping strategies and 8.2.5 Exchange individuals experience, by providing a social platform for finding and providing help.

Furthermore, the defined design principles are considered. To ensure a minimum load on fingers and proper ergonomics, the smartphone is used as device. Smartphones provide round handles, wide surfaces, and touchscreens for comfortable user input. A wide range of smartphones with varying features as size and robustness are available, which makes it easier for individuals to find their proper fitting tool. Smartphones are nowadays wide-spread and part of daily life, and therefore they are available to the user continuously and they don’t appear medical stigmatizing. To further reduce the load on fingers, the application follows a video-first and voice-control approach. Problems are described within video records and reported to the platform when finished. Navigation and control can be done by voice control. Besides starting the application on the phone, no further input typing is mandatory. Time efficiency will be ensured through reducing workflow actions and steps. For example, reporting an issue must be done within three user actions, such as starting the application, selecting reporting an issue, and finishing the record.

8.4.2 Workflows

The following descriptions and illustrations show the basic workflows of the “My Helping Hand” application.

8.4.2.1 Recording problems and providing help

1. Start the application “My Helping Hand” within the menu of your smartphone
2. On the initial start two menu options are available “Facing a problem?” and “Share your experience”. Both menu entries can by invoked via voice or on click.
    a. After invoking “Facing a problem?” the video recording starts and the user can describe the issue. When the recording is finished, the system auto assigns a name and tags to categorize the problem and make it easily identifiable. Those can be changed by the user. Afterwards, the video is submitted to the platform.
    b. After invoking “Share your experience” a gallery of existing problems is displayed. The user can browse through it, listen to the issues and, if knowledgeable, provide an answer as video record.

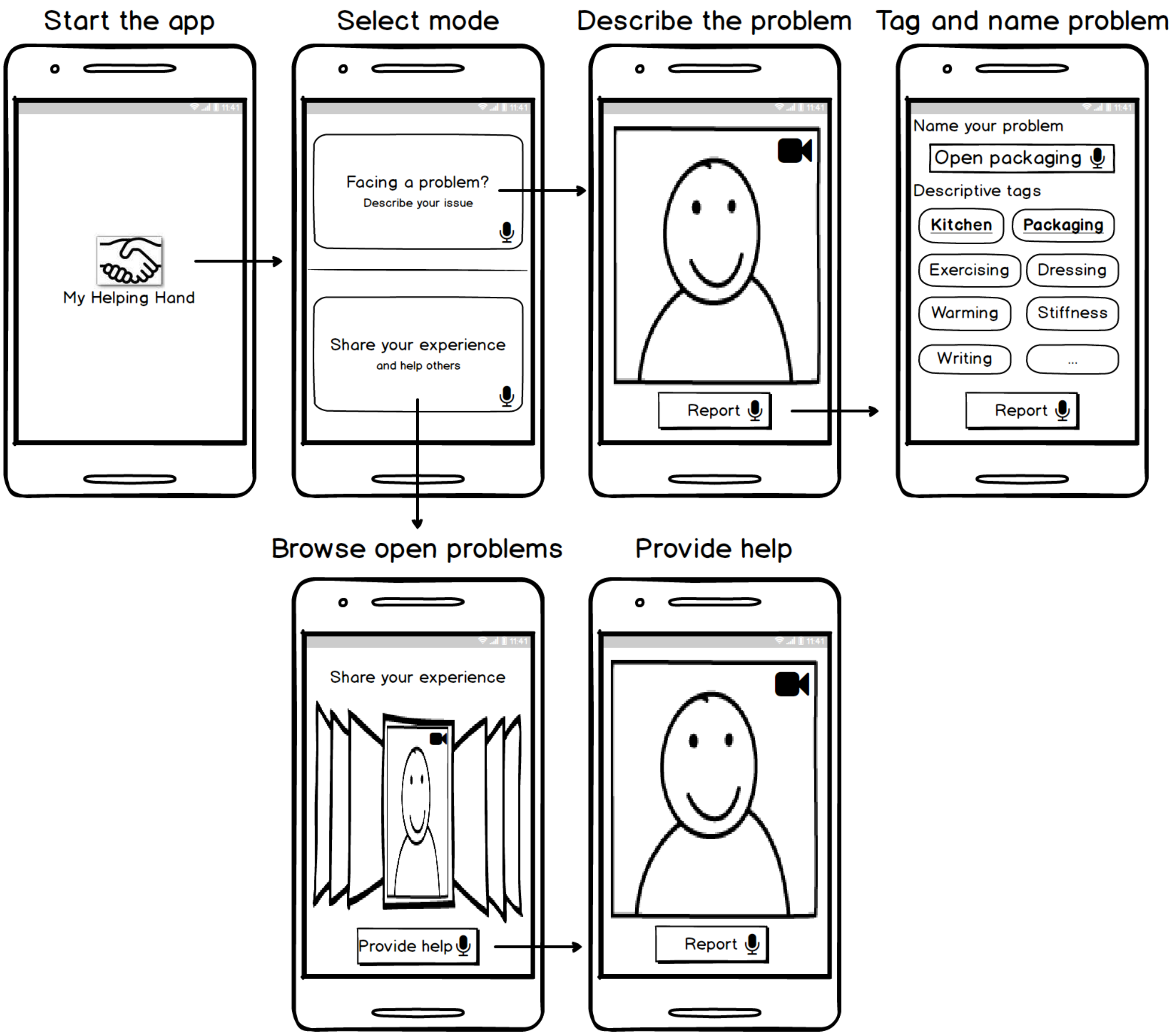


Figure 25: Prototype mock-up of reporting problems and provide help

8.4.2.2 Watch answers and give feedback

1. After you have submitted a problem to the platform, the application sends a notification if an answer was provided by another user or the system found a proper answer to a similar problem. The notification is displayed as a message and symbol at the application icon.
2. From the notification message the user can directly access the answer, see step 4. Additionally, when starting the application a new menu entry “Your reported problems” is available, which gives access to the users’ reported problems, and displays if new answers or updates are available on one of those.
3. When entering “Your reported problems” a gallery of submitted problems is displayed, ranking problems with new answers or updates first. The user can browse through, and go to the provided answers.
4. After selecting a reported problem, the available answers to a problem are listed and can be watched. If something is unclear a discussion can be started, using the comment function. If an answer was helpful and solved the problem, it can be rated.

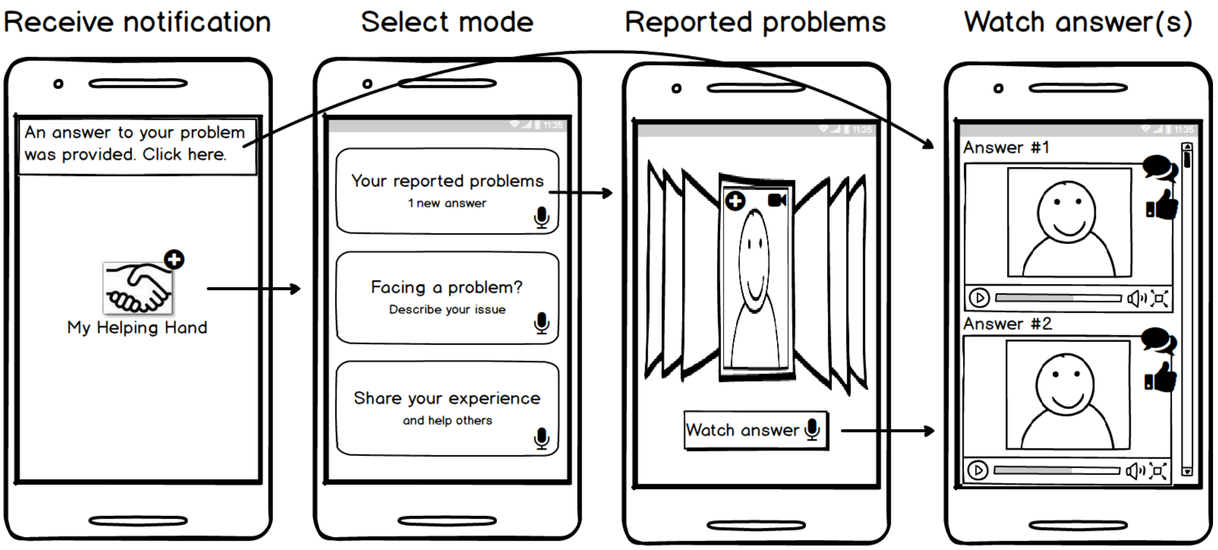


Figure 26: Prototype mock-up of watching answers

8.4.2.3 Receive feedback and discuss

1. After feedback to a given answer has been provided, the corresponding user will be notified. Therefore, the user gets a notification, either the answer was helpful or a discussion was started on it. Additionally, a notification symbol is displayed on the application icon. If a discussion was started, the user can directly access it within the notification message, see step 4. Otherwise, the application can be started as usual.
2. If a user already provided answers, a new menu item “Your answers” is provided. Within this item new updates on ongoing discussion are highlighted.

3. When entering “Your answers” a gallery of all provided answers is shown, listing open discussion with new updates first. Open discussions with new updates are highlighted by a notification symbol. The user can browse through the open discussion and enter the discussion on a selected one.
4. Within the discussion the provided original answer is displayed first. On top there are status symbols, displaying the number of new comments and the number users considered this answer as helpful. Furthermore, a menu is provided, e.g. to review the original problem. Below the answer all comments on it are listed, which can be answered by the user.

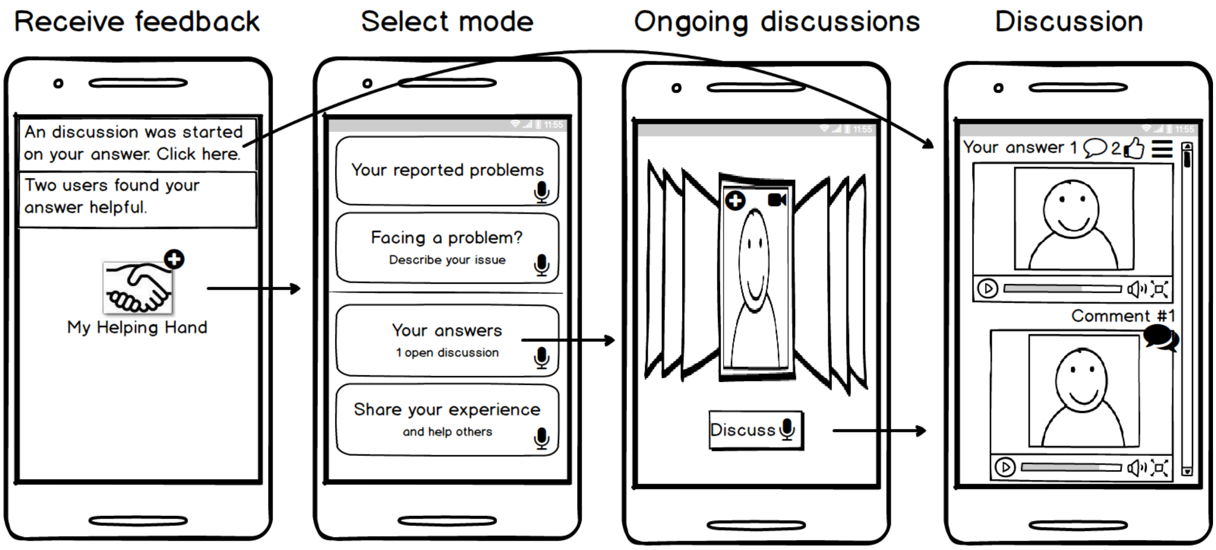


Figure 27: Prototype mock-up of feedback and discussion

9 DISCUSSION

This chapter goes back to the initial research question of this thesis and discusses how the results of the conducted research answer it. Therefore, the key findings are named and the results are compared with the given literature to draw out what is new and what restates or differs from existing research. Furthermore, the limitations of this study and potential future work are described.

9.1 KEY FINDINGS

9.1.1 Challenges for people living with HOA

The first research question RQ1 addressed daily challenges of individuals with hand osteoarthritis. The conduction of qualitative user research and its analysis brought up several problem areas, namely the development of osteoarthritis, every day challenges, self-care practices, and professional treatment. Thus, our starting assumption was met, which was that individuals are experts on their condition-related domain, and their problems are taken as opportunities for self-care technologies. Overall, the results build upon the given literature on HOA symptoms (see section 2.1.3), the impact on people’s life (see section 2.2), and coping practices (see section 2.3), but they further contribute with new challenges to the existing evidence. The outcomes provide a better understanding of the daily life with HOA from the individuals’ perspective, give new insights into the relationship between symptoms, activities and coping, and show people’s limitations, capabilities and accompanying problems on coping practices.

9.1.1.1 Difficulties to start coping

Literature states the importance of an early awareness and an early start of coping to attenuate and control the effects of the condition´s worsening progress [7]. Despite this necessity, individuals perceive their condition at an advanced stage, and start with proper counter measures even later. Individuals reported the challenge to notice their rare, short lived symptoms and signs, and do not relate those to the beginning of the chronic condition. Instead, such occurrences vanish quickly from their minds and they decide to ignore or suppress them, mentioned as bad coping techniques “keeping up” and “covering up” in literature [45]. With time they get used to those problems, thereby letting the disease evolve without any proper counter measures. As frequency and intensity of symptoms are continuously increasing, daily activities become harder to accomplish and at some time a trigger point is reached. This point is often perceived after a severe incidence, letting people realize their condition and taking up first counter actions. However, until this point time has gone by, which could have been used to establish adequate awareness and coping practices.

9.1.1.2 Impacts of HOA on daily life

The findings of the user research confirm and further detail the stated literature (see section 2.2). Results build upon the existing evidence on hands impaired motoric function [37], [10], [27], i.e. handling heavy or small objects and writing, impacted areas of daily living [34], [31], [36], i.e. household chores and mobility, and named impacts from individuals with rheumatic arthritis [30], i.e. opening a new milk carton or jars, cutting, washing, tying shoe laces and doing buttons. Although the stated evidence on the changing appearance of hands mentioned as major concern [22], [35] was partly confirmed by individuals attributing their hands as ugly and trying to hide them in social interactions, others provided a different opinion on it, not seeing it as a major concern and accepting it as it is.

In general, tasks that are done using hands and fingers become difficult to do, and thereby need more time to do them, leading to a reduced work load people with HOA can manage within a day. Handling heavy objects was related to pain and loss of strength, especially affecting household chores. Tasks as carrying a stack of plates when preparing dishes, bringing food from the kitchen to the dinner table, putting a pot of water on the oven when cooking, carrying a bucket of water around when wiping up the floor, or taking a heavy product from the shelf when shopping, are all considered as troublesome. Dealing with small or flat objects was related to reduced dexterity and control, affecting tasks as cleaning up small pieces of glass, picking up medication pills, or turning pages of a newspaper. Furthermore, heavy or small objects are predestined to get out of control and being dropped unintentionally, leading to embarrassment when other people are around, or costs if things got damaged.

Besides the challenges regarding the attributes of objects, the movements of pressing or pulling with hands and fingers, especially if dexterity is required and only few fingers are involved, are burdensome and related to pain. Troublesome tasks involving pressing are cutting hard food as carrots or melons, doing buttons, either when dressing up or using a remote control, or using a mechanical interface of an iron. Pulling tasks are pulling the flap to open a milk carton or tying show laces.

Additionally, impacts on other areas of daily living were found. Activities related to doing handicraft, either when assembling furniture, screwing, using a needle for sewing or holding a nail between two fingers are problematic. Also, gardening tasks, like pulling out weed, harvesting food, or digging holes when planting become burdensome. Furthermore, personal activities as putting on make-up, holding a razor or brushing teeth are considered as painful.

Several new insights were reported on the limitations in the area of mobility. First, keys are harder to hold and use, especially if they are small, making it more difficult to open or lock doors. Second, doors and windows that are already hard to open and require additional strength in hands and fingers are even harder to deal with and painful to open when affected by HOA. Using transport vehicles such as cars, bikes or public transport bring their own difficulties. Hands get cramped when holding the wheel while driving a car, or using a manual gear change is painful. Pulling the brakes on a bicycle was also reported as troublesome. Within public transport getting proper hold is more difficult. Moreover, mobility is also restricted by weather and climate [31]. As individuals are more sensitive to cold and wet conditions, they try to avoid them, for example by not going out on cold and rainy days.

More details were provided on the task of writing. Thereby, the challenges on writing depend on the ergonomic of the used writing utensil and the duration of the activity. Hand writing gets problematic when using an uncomfortable pen, it is painful to type on conventional mechanical keyboards when doing it over an extended period, and when using touchscreen keyboards such as on smartphones, letters are harder to press because of the reduced dexterity

Besides the physical impacts, individuals shared new aspects on the perceived psychological impact of their condition. Overall, the condition requires a high level of motivation and ambition to go on and keep coping with it, and creates a high amount of frustration and fear on individuals. People confirmed the stated evidence on frustration [24]regarding the available controls for their condition. Furthermore, frustration was derived from the unstoppable continuous progress increasing limitations on daily activities and life, dealing with the health system, which lacks proper support and adequate guidance, and non-working or non-effective coping practices. Regardless of this challenge, individuals reported the need to maintain a high level of ambition and motivation to keep coping with the ongoing progress and the importance of adopting a positive attitude regarding their coping practices. Nevertheless, they lack support, and they don’t experience the recommended cognitive strategies, as positive thinking, communication and pushing oneself [29], [99], [100]. This contributes to further negative experiences and leads to resignation. Thereby people fear the future and share a pessimistic look towards it, especially the fact that their condition takes over other still healthy body parts and that they will lose important skills and functioning, like when they have to give a hand signature.

9.1.1.3 Challenges of the health system

The ongoing demographic shift brings the healthcare system to its limits, especially regarding the treatment of chronic conditions as HOA [1]. Therefore, provision of adequate help and the transition to the self-care paradigm is of importance in state of the art care [1]. Although literature states and recommends what is required[1], [46], [55], [56], [92], for example individualization of treatment regarding patient needs [43] and providing mixed treatment programs with guidance [48], the results of this thesis indicate that individuals experience quite the opposite when dealing with the actual health system, which is not yet capable of delivering a holistic care approach focusing on individual empowerment and self-care. Moreover, individuals face various challenges with professional treatment, which requires them to not only tackle the burden of their condition on their own, but also to get experts when dealing with the health system, adding one more burden to their life.

Consulting a trusted doctor is part of the first counter measures that people start with. Thereby individuals experience that doctors are not knowledgeable in HOA and not capable of providing any help or not able to tell them what to do. Moreover, identifying the condition and getting the correct diagnosis may require several attempts and years, leading to improper care actions. Furthermore, doctors fail to provide a holistic approach, a guiding path to follow, and tend to prescribe professional treatments only, which is conflicted with recommendations in literature [49], as patient education [46], and focusing on non-pharmacologic treatments over pharmacologic ones [44], [45].The prescription and advice for taking pain medication was controversially discussed. When some used it as their preferred coping strategy against pain, others reported problems with adherence, and took it only in cases of severe pain or even refused to take it regarding its impacting side effects.

The outcomes of user research confirm the needs of individuals, such as having an individualized relationship with a practitioner knowledgeable in OA who provides a holistic approach [49], and restate the problems of lack of help and information, lack of understanding the impact of HOA, and dealing with contradictory pieces of advice, even after consulting professional care providers [50], for example as seen on joint injection therapy. As a result, individuals lack self-care practices, guiding information and accompanying support to perform them. As a consequence of these challenges, at best, individuals try out several care providers until knowledgeable professionals and proper help are found, take part in medical studies to receive helpful information, and do self-research to figure out a way on their own. In the worst case scenario, frustration with the system leads to a reduced utilization of it and its members, leaving people with improper support and guidance.

Another aspect of the problems in the health system is the increased economic impact. Not only costs for medication and special equipment must be taken [41], but also the public health system is reducing cost coverage on available therapies and treatments. This situation gets even worse when professional care providers tend to prescribe costly treatments, which only brings people to their finical limits following their care suggestions.

9.1.1.4 Difficulties on coping

Overall, the outcomes of this study confirm that the recommendations on non-pharmacologic coping practices, i.e. exercising, splinting, physical modalities, and assistive devices were known and conducted by the individuals [43], [46]. However, the knowledge about them and the experience on those practices varied, as they depend on the capability, knowledge, teaching skills, and the guidance and support of their consulted health professional (see section 7.1.1.3).

The fundaments about the condition, knowing coping practices and how to deal with the condition is an adequate patient education in the beginning (see section 2.3.1.1). Nevertheless, when consulting health professionals, for example general practitioners, people heard that there is nothing they can do about their condition and that they have to take it as it is. In the worst case, people got frustrated and let the disease worsen, and in the best case, they tried other ways to gain knowledge, for example through self-research or taking part in medical studies. For self-research individuals used books or searched the Internet. Indeed, unguided self-research lead to other problems, as people end up with the wrong disease and derive incorrect information, leading to even more frustration.

Hand specific exercises as mentioned in the literature (see 2.3.1.2) were done by individuals. However, people lack continuous support and adaptable programs as recommended in the literature [70]. Instead of adequate support, they only got simple instructional sheets. Also, the incorporation of exercises in daily life [73] was confirmed as a problem, as exercises were considered as time consuming, exhausting tasks. Additionally, varying exercise belief [86], [87] could be restated, as for some it was the best coping practice they can do, others experienced it as too painful to do, perceiving no positive effect or were just too lazy to do it. Besides these specific exercises, people experienced that doing physical activities, for example going to the gym or Nordic walking, and just keeping their hands and fingers active were positive counter measures, but they didn´t possess the knowledge about what kind of activities are beneficial for their condition, and they lacked non-expensive professional support.

Although the provision of assistive devices (see 2.3.1.3) is recommended by the literature [59], [89], individuals had varying experiences. Whereas some received specific tools or recommendations from their health professionals, for example an opening aid or a cooling bag, others had to do self-research to find proper tools, for example in the Internet or visiting orthopedic shops. Recommendations of guidance or proper preselection was not seen [88], [89]. The usage of opening aids [99], [101] and thermal applications (see 11.1.6.3) was confirmed by participants. Moreover, a shared coping practice, which was mentioned in the literature [100] was changing the tools individuals used. People replaced tools or devices that were considered too uncomfortable or even painful to use. Important factors therefore were being of low weight to reduce load in hand and fingers, being of bigger size to be easier to grasp, being ergonomic, described as being round, soft, not slippery, and having a proper handle, having convenient interfaces, for example without buttons that must be pressed like touchscreens, and ease the task that is tried to be accomplished with the tool, for example through electrification, like in the case of a tooth brush. Issues regarding assistive devices were the need for ubiquitous availability, proper ergonomics and easy to apply, else they won't be used.

Another practice stated in the literature [31], [93], [96], [102], [98], [101]and confirmed by participants was the application of heat, e.g. through hot compresses or warm water. Furthermore, they use heating beds and heating handles. Besides local heat application, people generally need a warm surrounding. They prefer warmer environments, such as warmer climates and heated rooms and they dress with warmer clothes than usual, all with the goal to keep their bodies and hands warm, which reduces the problems and their intensity caused by the condition.

A common form of self-care practice mentioned in the literature [98], [99], [100] and confirmed by the individuals was changing and adapting the way activities are performed. People reduce their amount of workload, take more breaks within their activities, do their work slower and more carefully, or even try to avoid painful tasks. Besides the tasks themselves, troublesome hand gestures are changed or avoided. For example, individuals figure out the best grip of a tool before using it, try not to involve painful fingers, use their whole hand, or use their second hand as support. People figured out those working alternations mostly on their own, and the literature recommendation for professional guidance on how to alter working methods and movement patterns [97], [101] was not experienced. Although changing the way of doing activities makes people independent, applying it in their daily life was considered time-consuming, exhausting, and sometimes even frustrating, as they have to try it several times until a proper new way is found. If tasks get too painful or people can't do them anymore, they ask other people for help, confirming the existing evidence[29], [31], [100]. Therefore partners, relatives, working colleagues or even foreign people are asked for support to help them or to take over problematic activities. Indeed, not always are others around, not every task can be delegated to someone else who may not be capable of doing it, and asking foreign people may be perceived as awkward and embarrassing. Besides asking for help, paying for support, for example for supporting in household chores or driving the car was mentioned as useful, but also expensive.

Another form of self-care practice as stated in the literature was changing the diet [29], [93], [102]. In this regard, individuals faced the lack of knowledge and information about what is the proper nutrition for their condition and they struggled with the incorporation of new nutrition plans in their daily life.

9.1.2 Opportunities for and requirements of HOA self-care technologies

The second research question RQ2 required finding the opportunities and requirements of self-care technologies for people with HOA. Therefore, the applied prototyping design process provides a characterization of a typical user with HOA through the persona. As the literature lacks a representative description of HOA individuals, the results from user research allowed the realization of a descriptive and representative user characterization in form of a persona, which serves as an underlying base to build on when designing technologies for individuals with HOA. Furthermore, opportunities of needed application are identified through the description of scenarios, and design implications of self-care technologies for users with HOA are stated. Finally, a concrete prototype shows the possible implementation based upon the outcomes. In line with the hypothesis, the results state that derived information from user research is able to provide a technology design process focusing on user needs and their requirements.

9.1.2.1 Application scenarios for HOA self-care technologies

The identified application scenarios for HOA people build on the existing evidence for stated application areas of self-care technologies (see section 2.4.1), but further provide the underlying problems and needs that explain the reason, and additionally show a new area of application. The identified scenario of “Understanding of and awareness for HOA” (see section 6.2.3) fits into the application area of “Providing health-related information”. The scenario “Finding HOA health professionals” (see section 6.2.2) partly matches the area of “Collaboration of patients and health professional”, even before collaboration can be established, proper health professionals must be found. The scenario “Providing coping strategies” (see section 6.2.4) targets two areas, namely “Providing health-related information” and “Supporting, guiding and suggesting care activities”. For example, individuals experienced a knowledge gap and difficult access to coping practices, which causes the need for applications in the area of providing and suggesting activities (see section 2.4.1.3). The scenario “Exchange individuals’ experience” (see section 6.2.5) directly addresses the application area “Connecting patients”. The scenario “Disease monitoring and assessment” (see section 6.2.6) covers two stated areas, first “Collection of health-related data” and second “Collaboration of patients and health professionals”. The identified area of application “Providing personal assistance” (see section 6.2.1) is not mentioned by the stated literature and thereby offers a new area to consider by future development of self-care technologies of HOA individuals.

Overall, the results show that identified scenarios for HOA individuals overlap with the areas of application mentioned in the literature. Indeed, the identified scenarios show that it is not enough to focus on one single area of application, but on the underlying problem and reason that may connect these areas or focus on specific parts of these areas to provide a helpful technology. Furthermore, the stated areas should be extended by the area of personal assistance, offering possibilities for new applications.

9.1.2.2 *Design implications for HOA self-care technologies*

The identified design implications for self-care technologies of HOA individuals support the stated literature, but further detail and enhance demanded implications of HOA technology, providing new insights on what is necessary to create a proper technology for these people. Identified implications are the minimum load on hand and fingers, proper ergonomics of hand and grip, non-stigmatizing appearance, robustness, warmness, availability, and time efficiency.

The literature states that if technology is perceived as an enabler that solves present problems it is likely to be used, but if it is seen as a reminder of disability it will be abandoned [88]. Therefore, technology for individuals with HOA must recognize the impact of the condition on fingers and hands. The design of technology must enable people using it with as minimal involvement and load on hands and fingers as possible (see section 6.3.1).

Furthermore, the results confirm that usage depends also on device-related factors, such as technical and ergonomic features [89], but there is a lack of concrete information about what technical attributes are of importance and what makes a technology for HOA individuals ergonomic. The outcomes show that people with HOA have specific ergonomic needs on any device or tool. The results confirm the given literature that the device must be of low weight [89], [90], but further name features as a wider surface to get a good grip on it, and having its handle to be round, soft, thick, but not angular, not thin and not slippery (see section 6.3.2).As individuals have reduced control on their hands, any device is in risk of being dropped unintentionally. Therefore, robustness is one more important requirement (see section 6.3.4). Another feature that must be considered is that device or its material gives or provides warmness, as individuals feel uncomfortable with coldness in their hands (see section 6.3.5).

In accordance with the stated literature, design implications, such as non-stigmatizing appearance to avoid unwanted attention that challenges users identity [88], [113] (see section 6.3.3), ubiquitous availability when needed [89], [90] (see section 6.3.6), and having time efficient technology [121], [133]as having HOA is already perceived time-consuming in daily life and another time requiring task would make another burden, are important aspects for individuals (see section 6.3.7).

9.1.2.3 *Issues of existing technologies and applications*

The literature review gives an overview of implementations of self-care technology for chronic condition as osteoarthritis, their tackled use cases, and different kinds of used technology, i.e. web, mobile or wearable (see section 2.4.2).Despite the stated availability and helpfulness of mentioned applications, usage of such technologies was rarely reported by individuals within this study. Several factors contribute to this situation. First, people were not aware of the existence of such technologies, which is caused by the digital divide, i.e. as elderly people are not comfortable with new technologies, negative reservations, i.e. that such applications cannot be trusted, and negative experience, for example when using the Internet for self-research, are hindering people to explore and make use of new applications. Second, available applications are mostly targeting the English speaking area, which makes another barrier for elderly German-speaking people. Third, the mentioned implementations were designed for a more common purpose, i.e. dealing with a range of chronic conditions or arthritis in general, but they lack specific solutions for fulfilling the demands of HOA individuals. For example, user interfaces are designed to be used by hands, the application depends on text-based information, and it is designed for a specific device, e.g. only via computer or smartphone. Even though the given literature on available implementations focuses on possible scenarios and used technologies, it lacks the incorporation of design implication and misses the emphasis on the importance of a holistic concept for the development of self-care technologies for individuals for HOA. When designing technologies for HOA not only the requirements of a software application must be taken into account, but also the needs and demands on how it will be used and on which hardware device it will be accessible.

Therefore, the developed prototype demonstrates a concrete concept for a self-care technology respecting the individual’s needs on scenario and design, bringing the findings together. It provides a feasible solution to tackle the existing gap on coping practices combining the provision of such practices and experience exchange. The video-based approach allows the reduction of load on fingers and the smartphone as target device addresses the implications of ergonomics, non-stigmatizing appearance and availability.

9.2 LIMITATIONS

The overall study design of this thesis has two major limitations, which are the use of qualitative methods and an incomplete design process.

First, the applied qualitative methodologies within user research limit the generalization of the results. The chosen small sample size for the used qualitative methods doesn´t allow the generalization of outcomes. Furthermore, generality is limited by the shared characteristics of participants, i.e. living in Vienna or the suburbs of Vienna and being treated by the General Hospital of Vienna. Participants from other areas and with different treatment history may also show other results.

Second, the prototyping approach covers only parts of a complete user design process. Although the persona incorporates mixed individual perspectives, it can’t encompass the various experiences of the whole user research results. Therefore, descriptions of further representative user types are necessary. Furthermore, the completeness and relative importance of the defined scenarios and design implications can’t be stated, and must undergo further investigations, i.e. taking these results back to the individuals for evaluation. The same counts for the created prototype. It serves as an example concept in respect to the findings, but to establish the evidence it represents, a proper helpful self-care technology must be further evaluated and feedback from people with HOA integrated.

Despite the given limitations, the outcomes contribute to important insights into the life with hand osteoarthritis and the people's perspectives. The prototype represents a grounded example of opportunities and needs on self-care technologies used by HOA individuals.

9.3 FUTURE WORK

The outcomes of this study provide several starting points for future work. First, based upon the mentioned limitations, further research is needed to establish the reliability of identified user needs regarding scenarios and design implications. Second, as this study only covers the first parts of a user-centered design process, further work should go on, and take the developed prototype “My helping hand” back to the individuals for evaluation, iteratively incorporating feedback, until a first version can be implemented. Third, the identified user scenarios and design implication offer new ideas and opportunities for other kinds of technology that can be developed based upon these findings.

10 CONCLUSION

This thesis is based on the motivation to support people with hand osteoarthritis within the shift to a new self-care paradigm by utilizing nowadays technology. As a new self-care paradigm requires patient empowerment, technology should be an enabler to achieve and strengthen this empowerment, giving individuals more capabilities and opportunities to handle their condition and its accompanying challenges on their own. Regarding the existing burden derived from a chronic condition as HOA, any provided technology must be based on the needs of individuals and their requirements on such application to be considered as helpful and not another challenge to cope with. Any successful technology must be based on a concrete idea or demand. Therefore, this thesis focused on the fundamental stakeholder of any technology, its potential users, which are individuals suffering from HOA, to reveal their experiences, impacts and challenges in their daily life. This target was achieved by conducting a user-centered design approach. Through qualitative user research consisting of interviews, a focus group and a workshop, understanding of the individuals and insights on their daily life was gained, thereby identifying concrete challenges, derived either directly from the condition´s symptoms or when coping with those. The collections and analysis of individuals’ experiences built the proper fundament for the next steps within the design process. The outcomes informed the creation of a persona to describe the target user. Based upon this user description, possible application scenarios and design implication on a technology were identified. Finally, a concrete prototype tied all those findings together by giving an example concept for a helpful self-care technology. Although the results of this thesis confirm the literature regarding the impacts of HOA on daily life, problems of coping practices, application scenarios and design implications, new challenges, opportunities and requirements on technology could be identified. Besides issues on the areas of handicraft activities or mobility, also the difficulties to start coping in the early stages of HOA and the challenges faced when dealing with the given health system contributed to the existing evidence. Furthermore, individuals struggled when coping with their condition regarding the low quality of patient education and lack of support on coping practices. In terms of self-care technologies, people rarely reported experiences or did not know about their existence, and the stated implementations within the literature missed to incorporate the full requirements for HOA people, consisting of valid scenarios and demanded design implications. Overall, this thesis emphasizes the importance to respect user needs, especially when developing technologies for critical areas as chronic conditions. Therefore, building a technology based on an identified use case with the solely focus on the software is not enough, but the whole concept of how this application can be accessed, how the user interacts with it and what kind of hardware device is running in their hands, must be aligned towards the user.

11 GLOSSARY

Abbreviation	Explanation
AT	Assistive technology
ACR	American College of Rheumatology
ADL	Activities of daily life
CMC	Carpometacarpal joint of the hand Trapeziometacarpal joint of the hand
DIP	Distal interphalangeal joint of the hand
EULAR	European League Against Rheumatism
HOA	Hand osteoarthritis
MCP	Metacarpophalangeal joint of the hand
NSAID	Non-steroidal anti-inflammatory drug
OA	Osteoarthritis
UCD	User-centered design process
PIP	Proximal interphalangeal joint of the hand
RHOA	Radiographic hand osteoarthritis
SHOA	Symptomatic hand osteoarthritis

12 TABLE OF FIGURES

13 APPENDIX

13.1 EXTENDED LITERATURE

13.1.1 Pathogenesis

Traditionally osteoarthritis was seen as a disease, mainly degenerating the articular cartilage of synovial joints [7], [164]. Nowadays research established evidence, that also other parts of the joint as the subchondral bone, synovial fluid and ligaments are involved [7], [164].

To the beginning the superficial surface of the cartilage is intact, but uneven and can show little fibrillations [165]. The discontinuity of the surface starts by fibrillation extending through the superficial zone and later created vertical fissures extend and branch into the mid and deep zone of the cartilage [165]. The damage of the articular cartilage leads to a hypertrophic repair process lasting for years or decades, observable by swelling of the joint [166]. By progression of the disease, the repair process may stop causing the cartilage to soften and lose elasticity and thereby further compromising integrity of the joint surface [166]. The processes of the cartilage degradation are accompanied by cell death and proliferation, leading to the appearance of ulcerations and extensive erosion resulting in excavation and loss of matrix in the fissured domain [165], [167], [168]. Over time, these losses results in the loss of joint space [166]. With the erosion of the damaged cartilage, the articular surface left is consisting of calcified cartilage or the naked subchondral bone [165]. The mechanical, unmuted stress of the joint is now affecting directly the bone, causing fractures of the bone plate [165]. The bone responds with reparative processes, including vascular invasion, increased cellularity and filling the fracture gaps with fibrocartilage, getting the bone thicker and more dense at areas of physical pressure [165], [166]. These processes change the contour of the articular surface, leading to a growth of fibrocartilage along the unprotected surface and formation of new bone, so called osteophytes [165], [168]. The fragmentation of these osteophytes or of the articular cartilage itself results in the presence of intra-articular loose bodies [166]. Along with joint damage negative effects of associated ligaments and neuromuscular apparatus are possible [166]. The progress of osteoarthritis in the articular cartilage is illustrated in Figure 28 [165].

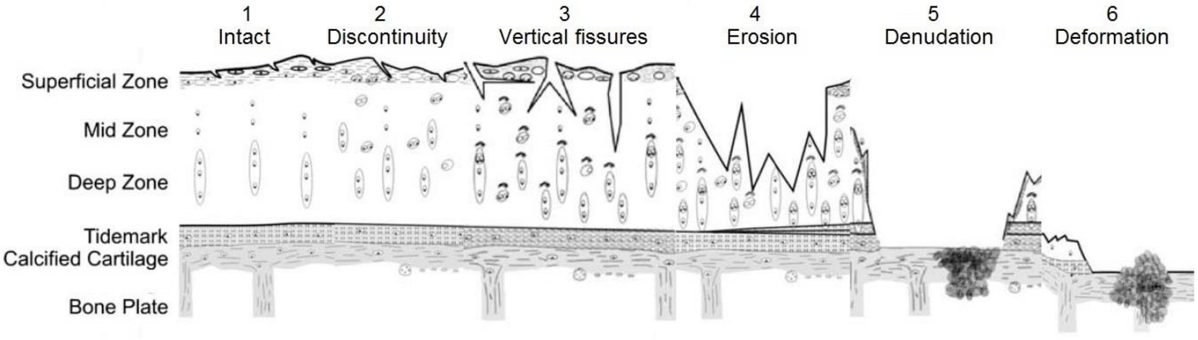


Figure 28: OARSI grades [165]

13.1.2 Epidemiology

Various studies focusing on the epidemiology, i.e. incidence and prevalence, of osteoarthritis were done, differing in the research method, the type of definition used for OA and the subject group.

13.1.2.1 Incidence

Research within participants of a health maintenance organization, show that the age- and sex-standardized incidence rate for symptomatic hand OA is about 100/100,000 person-years [9], [11]. Another longitudinal study with focus on different hand joints showed highest incidence for DIP joints, increased by age in all hand joints reaching a maximum of 106/1000 person days in those men aged 60 and above [169], [170].

The following Figure 29 illustrates incidence rate of female, male and different types of OA and its increasing by age.

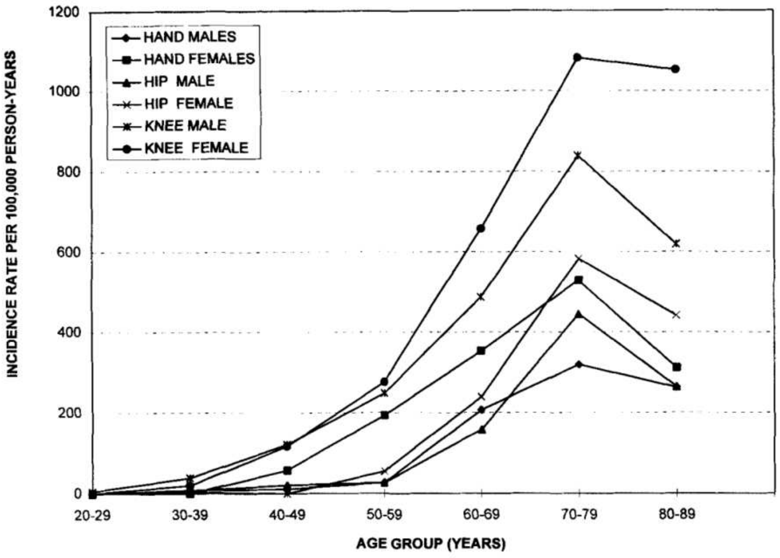


Figure 29: Incidence of OA among patients in a health maintenance organization [11]

13.1.2.2 Prevalence

Overall the prevalence of hand osteoarthritis is higher for women, than for men and increases with age [2], [12], [171], [37]. Another study suggests a lower prevalence of hand OA among elderly Chinese subjects compared with white subjects in the US [10]. Depending on the type of disease definition studies using the radiographic definition show much higher prevalence rates, than symptomatic ones, which takes also clinical findings into account [10], [3]. A study not differentiating between different diagnose definitions on a Norway subject group, comes up with a prevalence of 4,3% for hand OA [19].

13.1.2.2.1 Radiographic hand osteoarthritis (RHOA)

Taking the definition of RHOA several studies have been conducted, varying in the participant group and their results. The age-standardized prevalence of radiographic hand osteoarthritis was 27,2% among the US-placed Framingham study subjects [9]. Studies with age-specific target groups show 10-20% participants under 40 years showing the characteristics of RHOA of [3], a prevalence of 67% for women and 54.8% for men above the age of 55 [172], raising up to 90% for women and 80% for men in a European population sample above the 70s [10].

Using radiographs for the definition of disease prevalence makes it easy to take a closer look on different joints of the hand. Overall the DIP joints showed the highest prevalence rates, i.e. up to 75% for women above the 60 [3], while the PIP joints showed the lowest prevalence [169], [170], [3], [171]. In a majority of participants DIP and PIP OA was present in their dominant hand, whereas CMC OA had the tendency to be more present in the non-dominant hand [171].

13.1.2.2.2 Symptomatic hand osteoarthritis (SHOA)

Studies within samples of the US population show an age- and sex-standardized prevalence of 7% [2], [9], [3] to 8% [37]. As found within RHOA studies, symptomatic hand osteoarthritis shows same characteristics as an increased prevalence for women and age [3], [27], [37]. Among white US subjects SHOA occurs in 3% of men and 6% of women [10]. Data from the Framingham cohort demonstrated a prevalence of 13.2% in men and 26.2% in women aged above 70 [3], whereas an Iranian study showed a prevalence of 2.2% for people aged 40-50, rising to 22.5% for people older than 70 years [3].

13.1.3 Risk factors

13.1.3.1 Systemic risk factors

13.1.3.1.1 Age

Age is one of the strongest risk factors for all kinds of osteoarthritis [9]. Several population studies show, that within the elderly population, e.g. over 40 [15] or over 50 [11] there is an increased risk for developing osteoarthritis [2], [9], [4], [19], [8], [169], [170], [173]. Above the age of 60 OA progresses at a faster rate [174].

13.1.3.1.2 Gender and hormones

Another strong indicator for the risk of developing OA is female gender, shown in several studies that women are more affected than men [2], [9], [10], [4], [11], [19], [3], [169], [170], [12]. Within women, those in the menopause show higher incidence rates caused by the hormonal change [15], [9]. Further research focusing on sex hormones indicates that those hormones, especially estrogen, have an influence on the development of OA [175], [176].

13.1.3.1.3 Genetics

Research provides evidence for the genetic predisposition of OA [12]. OA may be inherited over generations within the families [15], [9], [10], [4], [177], [169], [170]. Estimates suggest a 50% heritability of OA [177].

13.1.3.1.4 Bone density

Studies of the bone structure and its association with osteoarthritis showed that a higher bone density increases the risk of hand OA [15], [9], [4].

13.1.3.2 Local risk factors

13.1.3.2.1 Obesity and overweight

Several studies show evidence that obesity and overweight increase the risk for developing osteoarthritis, especially for the joints of hip or knee [15], [9], [10], [4], [19], [8], [169], [170], [173], [3], [12]. Further investigations showed the association of obesity with the development of hand osteoarthritis, an increased risk per kg by the increase of body weight, and the severity of the disease correlating to the amount of weight [13], [14]. Reasons for the role of obesity in osteoarthritis development are the increased mechanical stress on joints and the altered lipid and glucose metabolism contributing to the joint destruction [178].

13.1.3.2.2 Injury

Injuries, traumas or deformity of the joint or parts of its composite structure are known as local factor increasing the risk for developing OA at the affected joint [15], [9], [10], [4], [3].

13.1.3.2.3 Mechanical factors

Investigations on the role of biomechanical factors for the health of joints identify altered joint loading caused by obesity, mal alignment, trauma or joint instability as a risk for OA [74], [69].

Special occupations, e.g. as cotton mill workers [9], requiring a special usage of the joints and a physical workload during heavy manual labor, are leading to an increased risk of developing OA [15], [10], [173], [3], [12]. Especially repetitive joint usage and excessive joint loading associated with mechanical stress during manual labor are linked to OA [15], [10], [169], [170], [3], [12]. An abnormal usage of joints can also be caused by sport participation, but is usually not seen for HOA [9], [4].

Further studies focused on hand osteoarthritis name higher grip strength [12], [179], greater forearm muscle strength [15] and handedness [12] as risk factors for developing the disease in specific hand sites and joints.

13.1.3.2.4 Laxity

Several paper indicate joint laxity as a risk factor for OA [15], [9], [12].

13.1.3.3 Socio-economic factors

Beside systemic and local factors groups within the society were detected, showing a higher risk for developing osteoarthritis. Those groups can be identified on socio-economic parameters, as less educated [19], out of work [19], rural-living [8] or deprived [180].

13.1.4 Diagnosis

For diagnosing the presence of osteoarthritis three approaches have been defined in literature, named clinical, radiographic and symptomatic definition [2]. The clinical definition is based on symptoms and findings from a physical examinations [2]. The radiographic definition is based on the assessment of features in images [2]. The symptomatic definition is based on the presence of pain and radiographic evidence [2].

13.1.4.1 Radiographic definition

Plain radiographs still provide the gold standard for morphological assessment of HOA [15]. Simple film radiography, and advanced technologies as MRI, are helpful to confirm the clinical diagnosis and rule out other conditions [6]. Imaging features as narrowing of the joint space width, osteophyte formation, the development of subchondral bone sclerosis, erosions and cysts can be detected and assessed via standardized scoring systems, as defined by Kellgren and Lawrence or the Osteoarthritis Research Society International [7], [15], illustrated in Figure 30.

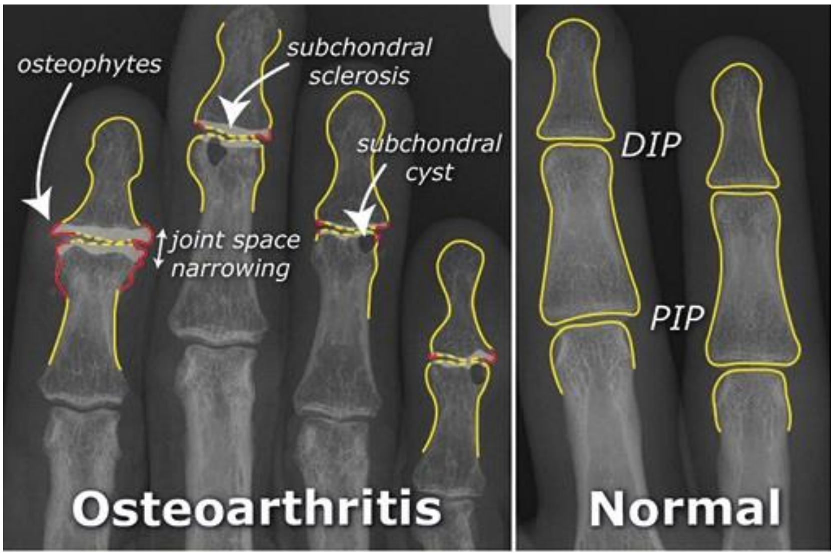


Figure 30: X-Ray of OA hand showing typical features [181]

Advanced, but more expensive are MRI technologies allowing the assessment of joint structures in three dimensions and with high resolution resulting in capabilities for early detection of structural changes in the joints [7]. Additionally ultrasonography can be used to assess changes in the synovium, especially in the hands [7].

13.1.4.2 Symptomatic definition

The symptomatic definition of osteoarthritis comprises the clinical and radiographic definition [2]. Patients have symptomatic OA if they have a frequent pain in a joint, e.g. on most days of the last months, and radiographic evidence of OA in that joint [2]. A problem of this approach is that the pain must not derive from the arthritis seen on the radiograph [2].

13.1.4.3 Structural definition

Furthermore there is the definition of structural osteoarthritis as an approach to detect osteoarthritis in early stages based on structural changes within the joint [7]. Taking into account the limited capabilities of clinical and radiographic diagnosis of osteoarthritis at an early stage, and alternative approach was defined [7]. The definition of structural osteoarthritis is based on the evidence of cartilage loss without inflammatory or crystal arthropathy, regardless of perceivable symptoms [7].

13.1.5 Activities of daily living

To investigate the impact of functional impairment the capability of patients to perform activities of daily life (ADL) is assessed [182]. Based on questionnaires, e.g. the Stanford Health Assessment Questionnaire, ADL categories as dressing, grooming, arising, eating, walking, hygiene, reaching, gripping and mobility are assessed by the participants regarding their difficulty to perform them [182].

13.1.6 Therapies

13.1.6.1 Splinting

Splints have been long time shown effective for other diseases and pathologies, and are increasingly utilized for patients with OA [44], [183]. Splinting of osteoarthritic joints is recommended by the ACR and EULAR, especially for thumb base OA, that is affecting the CMC joint [43], [59]. The goal of splinting is to limit and prevent excessive painful motion, e.g. lateral angulation, around a joint, and to prevent or correct flexion deformity [43], [44].

Various forms and designs of splints exists [85]. Custom-made splints seems to be more beneficial in outcomes, as reducing pain, but are more expensive, then prefabricated ones [183]. From the patients perspective short splints are preferred over long splints [184]. Other comparisons of splints don't show any significant difference within the improved outcomes [84], [185]. Figure 31 illustrates an example of a splint for base thumb OA.

Figure 31: Splint to stabilize the CMC joint [186]

The different effects of splinting dependents mainly on the length of application, i.e. therapy adherence. Main effects, shown already in the short-term, e.g. until 3 months, application of splints are reduced hand pain [44], [54], [85], [81], [186], [187], [184], [185] and lower disability [54]. Improvements for hand function [83], [81], [187], [185] pinch strength [83], [81], [187] and range of motion [81] are more likely seen on the long-term, e.g. 12-month, application of splints. Also radiographic changes, i.e. a reduced subluxation at the first CMC joint, could be seen [184]. Exercising is a common therapy to enhance outcomes for pain, stiffness, function and strength when splinting [84], [85], [66].

As splinting can have negative side effects as disuse atrophy of joint stabilizing muscles under splinting, also additional exercise programs are recommended [44]. Negative side effects are usually related to fitting and local reaction to the materials used in fabrication [44].

13.1.6.2 Physical modalities

Physical modalities are noninvasive and time-honored approaches, where various kinds of modalities are applied to create healing and relieving effects in disease affected body regions

[44]. Most common forms are thermal modalities, i.e. heating and cooling [44]. Heat increases the collagenase activity leading to a relaxation effect in the tissue and increased pain threshold, but can also lead to vasodilation and may worsen inflammation [44], [45]. Heat can be applied superficial, e.g. in forms of heat packs or compresses, or deep by going through the surface, e.g. in forms of ultrasound, diathermy, microwave or laser [44]. Cooling has an anti-inflammatory and primary analgesic effect, also slowing down the speed of nerve conduction [44]. As thermal modalities reduces pain and muscle spasm, application is recommended before doing exercises [43], [46]. For the user, thermal applications should be easy to access, use and effective for intermittent, short application [46].

For HOA thermal modalities are recommend by EULAR and ACR [43], [44], [54], [59]. HOA patients should be instructed and informed on the usage of local application of heat, e.g. with paraffin wax or a hot pack [43], [54], [59]. Local application of heat shows beneficial outcomes, as alleviating pain and stiffness, associated with OA [54]. For patients with painful Heberden’s nodes hand baths in hot paraffin wax or even in warm tap water can show soothing and analgesic effects [45]. Paraffin bath therapies are a common beneficial short-term therapy option, effective for a 12-week period, reducing pain, tenderness and maintained muscle strength in HOA [188]. Paraffin baths can be enhanced by addition of topical analgesic [189]. A special therapy, called the Berthollet technique, for hands was developed, consisting of a 15 minute local steam bath combined with a finger shower, and showed benefical effects as functional improvement and reduced pain of the hands [190]. Furthermore ultrasound is recommended [43], magneto therapy had shown beneficial outcomes in pain and function for patients with thumb CMC OA [83] and laser therapy improves hand range of motion in hand HOA [81].

13.1.6.3 Surgery

Surgeries are recommended when conservative pharmacologic and non-pharmacologic therapies have failed, and the patient is still marked by chronic pain and disability [6], [43]. Surgeries aim to relieve pain, and to restore shape and/or function of the hand [191]. For hip and knee OA surgeries are regularly conducted in high numbers [6], but figures of finger surgeries are low, regarding higher risks for complication, increased failure rates and hard trade-off between scarified mobility for pain relief [191].

The two main surgical interventions for HOA are fusion, also known as arthrodesis, and joint replacement, also known as arthroplasty [44], [191]. In arthrodesis the bones are fused together, creating a strong, stable, and pain-free joint, but with no or reduced motion range [44], [191]. In arthroplasty the joint is replaced by an artificial implant, maintaining essential joint functions, but not replicating full natural finger motion [192], [191]. In example silicone and pyrolytic carbon implants showed improved outcomes for function, when used to replace CMC or MCP joints [192]. Possible complications are the limited lifetime, implant loosening and persistent pain [192], [191]. Other adverse side effects from surgeries are scar tenderness and tendon damage [193].

Depending on the type of joint, person's age, activity level and amount of stiffness acceptable after surgery, the proper intervention should be chosen [191]. For PIP joints arthroplasty is preferred to maintain flexibility needed for griping, but regarding high usage, implants can wear out quickly [191]. Alternatively PIP joints can be fused, as regularly seen for DIP joints in the ends of the fingers, to gain a reliable, life-long, pain-free and reasonably functional solution [191]. For severe thumb base OA arthroplasty or arthrodesis of the CMC joint or trapeziectomy, i.e. removing the trapezium bone, are effective, regular treatments [43], [44], [47], [193].

13.1.6.4 Alternative therapies

A wide range of complementary alternative medicine and naturopathic pharmacotherapy exists, and are preferred by OA patients, that want to avoid conventional pharmaceuticals and interventional therapies [44]. A factor for choosing alternative therapies are low beliefs in efficacy of conventional treatments or experienced side-effects [50]. Examples for naturopathic pharmacotherapy are chondroitin, glucosamine, collagen, plant-derived substances, vitamins, antioxidants, Ayurveda medicine, traditional Chinese medicine, and homeopathic preparations, but there scientific evidence is rare [44].

Positive scientific evidence exists for acupuncture and leech therapy. Acupuncture is a common form within alternative therapies for OA patients, resulting in a modest pain-relieving effect up to 6 months [44]. Also a single course of leech therapy for OA of the CMC joint, was effective in relieving pain and improving disability up to 2 months [194].

13.1.6.5 Pharmacologic treatment

The ACR and EULAR recommend the use of oral and topical nonsteroidal anti-inflammatory drugs (NSAIDs), and topical capsaicin for a safe and effective pharmacologic management of HOA [43], [59]. Particularly oral medications have been important for pain control in OA and are nowadays used primarily for analgesia [44]. Topical and oral NSAIDs showed beneficial effects for patient, regarding alleviation of pain [47], [54]. For Patients with stomachache adding gastro-protective agents to NSAIDs should be considered [43]. Regular prescribed analgesics are tramadol [59] an opioid medication, and paracetamol also known as acetaminophen [43] a non-opioid medication. According to the ACR opioid analgesics, as tramadol, should be avoided [59]. Therefore Paracetamol is considered as safe and effective oral analgesic and should be used on the long term, if successful in the short [43]. Regular treatment should start with paracetamol and later changed to NSAIDs [6]. Supplements as glucosamine and chondroitin can be used additionally [6].

A major problem of prescribed pain medications is therapy adherence [195]. From the OA patient perspective, medications are required to achieve symptomatic relief, but adherence depends on adverse side effects and financial cost [49]. So patients are regular reluctant to take their medication, and if they do, they don't take it in the prescribed dose or frequency [195]. Depending on their perception and attitude to pain, e.g. by explaining that pain is ignored or they have a high tolerance level, patients are willing to adhere, or not [195].

13.1.6.5.1 Pharmacologic joint injections

Intra-articular joint injections, as corticosteroid or hyaluronic acid injections, are common and used to deliver medications directly into the joint space or to aspirate an acutely inflamed joint [44], [47]. Injections are beneficial in the symptomatic relief of pain in OA joints and reducing osteoarthritic flare-ups, but those improvements are limited in time [6], [44], [47]. While Corticosteroid is inexpensive and works on the short-term, hyaluronic acid injections are more expensive but can maintain symptom improvement for longer periods [6]. Aspiration and needle placement are done by a blind or anatomic approach, and can be enhanced with ultrasound or fluoroscopic guidance, e.g. for an obese patient [44]. Whereas EULAR is suggesting intra-articular corticosteroids [43], the ACR explicitly don't recommend the usage of intra-articular therapies [59]. In general, local treatments, specialized on specific body parts, are preferred over systemic treatments, especially if pain is low and few joints are involved [43].

13.1.7 Special forms of patient education

13.1.7.1 Self-management education

Self-management education enhances traditional patient education, i.e. providing information and technical skills, by addressing general skills, as problem solving, goal setting, decision making; social skills as social integration, social support; and disease specific skills, as self-monitoring, health-directed activity, coping and pain managing techniques [55], [1]. Teaching self-efficacy, which means increasing confidence to carry out a behavior for reaching desired and goals, plays an important role and increases when participants succeed in solving their disease-related problems [1]. With the knowledge about the disease, coping and managing skills, participants should be encouraged to take an active role in their treatment [55]. Deliverance is done by healthcare professionals or lay leaders in an unstructured form on various ways, e.g. face-to-face, Internet or telephone [55].

Educating patients about self-management is effective for pain and disability [54]. Compared with usual care programs or information-only education, self-management education show better outcomes, in improvements for skills, pain, function, symptoms and quality of life [55], [1].

13.1.7.2 Health coaching

Health coaching enhance educational programs by a close collaboration of participants with health professionals and utilizing techniques as motivational interviewing [56]. Adoption to healthy lifestyle behaviors, prevention and control over disease are main addressed targets [56]. Motivational interviewing can be a useful strategy to help patients decreasing their attitudinal barriers toward better management of their disease [57]. Coached patients showed a healthier lifestyle, i.e. increased physical activity [56], [58], healthier nutrition [56], better vitality [57]; less problems for pain related interference with function [57], higher mental health [57], and increased independence [58].

13.1.8 Requirements and design implications of self-care technology

13.1.8.1 Effective applications

A key challenge for self-care technologies is to provide proper clinical effectiveness for the user [106], [114]. Nevertheless many health applications lack evaluation, fail to incorporate and attribute evidence-based information, and so the information provided may not be accurate and accountable [106], [109]. To enhance system credibility for clinical outcomes, validity and reliability need to be established, and applications must be based on an evidence-based approach to provide scientifically proven content that can be verified, e.g. using ACR or EULAR guidelines for OA management [105], [114], [137], [115]. Furthermore, users with all levels of health literacy must be considered, when designing applications providing health-related information, as medical information can become easily complex and hard to understandable [106].

Another challenge is, that health apps can nowadays be easily accessed, downloaded and used from a growing pool of tools without guidance from a health professional [106]. So users can be easily become frustrated by using apps that don’t meet their needs, or worse, the applications may be misused leading to negative experience or clinical outcomes [106]. To tackle this issue, awareness must be raised and adequate information for potential users provided [123].

For the future effectiveness can be guaranteed through the support of standards, that allow application integration into public health or hospital information systems [105].

13.1.8.2 Motivational user experience

Usability problems can lead to the fail of an health technology and promised beneficial clinical outcomes can only be achieved, if the self-care app provides a proper user experience that attract people, motivates them, and increase their engagement [106], [114], [117], [124]. Applications should be easy and comfortable to use, provide a simple interface that shows the needed minimum of information in a simple format, employ behavioral science principles, and fulfill patient convenience factors, as time efficiency and flexibility [104], [107], [113], [114], [121], [133]. Also usability constraints regarding the used hardware, e.g. small screens that make reading and typing difficult, or slow Internet connection, must be considered [106]. To increase user acceptance, technology appearance, e.g. for wearable devices, matters, and it should be small, light, not ‘appear medical’ and don’t challenge the identity of its users [113].

To motivate users various features have shown beneficial outcomes. For example in educational apps personalized and interactive elements encouraged users [107], whereas when guiding physical activity, apps utilized gamification elements for bringing in fun into boring activities or provided space for exploration of users capabilities to address specific needs [118], [124]. Furthermore social features, as employment of dialogue support techniques, that provide communication and interaction with other patients or health professionals for giving feedback and support, encouraged users and increased adherence [115], [119], [123], [131]. Technologies should be customizable and adaptable to fit the changing needs of various users [123]. As individuals gain more and more expertise on their conditions, they want to adjust their application to better match their needs, or else they will abandon it and try out other ones [111], [114]. For example, in data collection, users should be allowed to flexible add or remove pieces of data that is meaningful to them [111].

Last, but not least the perceived trustworthiness of an application influence motivation to use it, and therefore privacy and security concerns, e.g. of users data, must be taken serous and be implemented [105], [106], [107], [114]. For industry-driven applications all conflicts of interest should be explained, as there can be bias in provided information, e.g. preference for specific types of treatments or interventions [105].

13.2 ETHIC COMMISSION APPLICATION

13.2.1 Study protocol

Prototyping Self-Care Technology for Osteoarthritis Patients: A mixed, qualitative Study: MQ-OA

Kohlmayr Patrick, Stamm Tanja, Fitzpatrick Geraldine

Introduction

Osteoarthritis (OA) is the most common joint disease worldwide that mainly affects the knees, hips, hands or feet [1, 4]. Nowadays millions of people in the western world are suffering under this disease, according to Lawrence [2] about 27 Million citizen of the United States had to deal with some kind of OA in 2005, tendency increasing. The most important risk factors leading to OA is foremost obesity followed by metabolic disease, age and sex [1, 3 and 4]. But also injuries in the specific joint regions, e.g. a traumatic knee injury, or a high, constant stress level of the joints, e.g. through professional sport or occupation, increases the incidence of OA [1, 3 and 4]. The elderly population is more likely to show the prevalence of OA, especially over the age of 60, and women have higher incidence rates than men [1, 3]. The progression of OA is usually slow and over many years, shows increasing symptoms of joint pain, stiffness and limitations of movement, which finally can lead to a failure of the joint and disability [1, 3]. Besides the physical burden of OA, there are also psychological and socioeconomic consequences. The psychological burden includes distress, devalued self-worth, loneliness and manifests in the disability to perform normal daily activities of the regular life, e.g. incapacity to work, reduced mobility or to be part of the regular societal life, whereas the socioeconomic burden manifests in the need of healthcare utilisation [1]. Furthermore given the high frequency of OA in the population, its economic burden, i.e. loss of productivity during the inability to work, is large [1].

Regarding the growing of the elderly population in western countries getting the health care systems closer to their limits, a shift to a new care paradigm becomes more important [5]. People’s awareness of their very own wellness and health has to rise, and opportunities and capabilities for conducting self-care in the case of illness have to be established [5]. These factors will lead away from the traditional, paternalistic patient-doctor relationship, to a more responsible patient with self-efficacy and health literacy, who knows how to deal with daily health-related issues [5]. Especially patients that have to cope with chronic diseases, as osteoarthritis, in their daily lives are affected by self-care [5]. Every day they have to make important decisions regarding their circumstances about what they will eat, if they will do exercises and how to achieve daily activities under the burden of the disease [5]. Hence, the patients have to be seen as the experts of their own lives, and the question, how to support them in achieving their own goals, is raised [5]. As nowadays technologies offer a huge amount of possibilities and opportunities and have been successfully involved in self-care by improving day-to-day life of people with chronic conditions [6], these technologies can also help our target group here suffering OA.

In this setting, including the target audience of patients with osteoarthritis and the success of self-care technologies, this work is grounded and motivated by the opportunity to make life for those people easier.

As research hypothesis in the present study we suppose that the patients can provide us sufficient information about their daily life managing their chronic illness. They know which everyday challenges they have to cope with and have the fundamental ideas for possible self-care technologies.

Aim

In this thesis we are following an open exploratory design process that puts the potential users, here patients with osteoarthritis, in the middle. Less sophisticated design processes, e.g. not recognizing the users and their needs, have been always a reason for exceeding costs or failures of new technology projects [7]. To gain a better understanding of the potential users, their contexts, underlying reasons, opinions and motivations, qualitative methods are used to conduct exploratory research within this work. The process includes applying 3 different user research methods on the given target group which outcomes will be analysed, reported and manifested in design concepts. Interesting design concepts will be prepared as detailed prototypes.

The central research question of this thesis is:

- How people with osteoarthritis manage their life, what are their everyday challenges and what kind of and how self-care technologies could support them?

To answer this question, 2 research goals are important:

- Understanding the patients, their contexts and issues
- Identifying use cases and their corresponding design requirements for self-care technologies, and framing these findings as design concepts and prototypes

At first, we want to have a look on the users, the OA patients, themselves and getting familiar with them and their contexts. This will be achieved through in-situ interviews with the participants conducted at their homes. Following sub-questions are of interest:

- Who are the patients, where and how are they living?
- How are they managing their daily lives routines and activities regarding OA?
- How do they manage their disease?
- Are there any kinds of technologies already in use?

As next step a focus group takes place. The intention is to gain knowledge about relevant issues, problem-solving practices or approaches and the perception of technology. Outcomes of the in-situ interviews, personal objects regarding their daily life with OA and existing self-care technologies will support this phase. Following sub-questions are of interest:

- Which personal objects did they bring to the group and why?
- What issues are relevant to the patients?
- What are possible solutions for these issues, e.g. workarounds or technologies?
- What are the opinions, notions and thoughts regarding existing technology and self-care technology?

As last step a design workshop will be conducted. The workshop format will be a future workshop comprising a critique phase, a fantasy phase and an implementation phase. 2 types of cards will support this phase. First domain cards, representing e.g. daily challenges or scenarios from the earlier 2 steps, are used to benefit envision of current practices or settings, which are criticized in the critique phase. In the fantasy phase, the participants create visions and come up with ideas about how to deal with the problems. At the implementation phase technology cards are added to create possible design concepts, identifying obstacles and activities, and to make estimates about what resources are needed and what they should be capable of to realize the visions. The expected outcomes of the workshop are design concepts that show the progress from an identified problem to a feasible solution.

All data collected will be anonymized and a thematic analysis will be performed on it. The overall expected outcome of this thesis is a description of challenges and issues of OA patients, a set of associated design concepts for self-care technologies, and detailed prototypes for interesting design concepts.

Methodological Approach

Design

A qualitative, mixed-method study will be performed, including an in-situ interview, a focus group and a design workshop. This thesis is part of a research project in cooperation between the Vienna University of Technology and the Medical University Vienna.

Participants

People with OA will be recruited from the database of the rheumatology outpatient clinics of the General Hospital of Vienna. The patients have to be diagnosed with osteoarthritis, and their age may vary between 18 and 85. Potential candidates will be personally asked in the ambulatory station of the rheumatology department at the General Hospital of Vienna. The recruitment will be done by a responsible person of the study and eligible patients will receive an informed consent form to approve. Patients will be informed that all data will be stored and analyzed in an anonymised way, i.e. separated from all personal data, such as name and birth date, only birth year and gender will be recorded. Data will not appear in the records of the patient at the clinic, so the treatment of patients will not be affected by anything that patients might say during the qualitative study. If patients agree to participate in the study an appointment will be arranged. Patients who are willing to participate will have to give oral and written informed consent according to the Declaration of Helsinki [34]. The study will be submitted to the institutional review board and ethics committee of the General Hospital of Vienna.

Sample Size

Qualitative research typically uses small sample sizes with a diverse range of participants. The sample size here is 4-6 for the in-situ interview, 6-8 for the focus group and 8-10 for the design workshop. Supposing that not everyone will take part of every step, and a dropout rate about 10%, the overall number of participants can vary between minimum 8 and maximum 24. At best there will be a core group of patients taking part in every phase around 5 people, filled up by new persons in every step to reach the required number.

In-situ interview

As one of the fundamental axioms in social sciences, it is stated, that what people say they do and what the actually do are not always the same [26]. This counts for health habits too [26]. In-situ interviews are special types of participant observation and contextual inquiry. Participant observation is a method in which the observer participates in the daily life of the people under study, here openly in the role as researcher, observing things that happen and listening to what is said [27]. Contextual inquiry consists of observing and talking with your audience in their contexts as they do their real daily activities, revealing participant's practices and needs [35]. Before setting out decisions need to be made. It is essential to know what the central concern is, who, what, where and when to observe, and what to ask [26, 35].

Here the focus is on observing and asking the individuals at their homes for their daily routines regarding OA. Therefore an interview guide will be developed. 4-6 patients will be visited in their homes for about 2 hours. Given the complexity of human behaviour, it is impossible to notice and record in real time everything of interest to the researcher [26]. Thus, an audio record of the interview and video records of interesting activities will be taken, which give the possibility to watch an event multiple times with different observational focus or viewing point [26].

Focus Group

Focus groups are a form of group interview that take advantage of communication between research participants and other group interaction in order to generate data for a specific topic or research question [28]. The discussions can provide information about a range of ideas and feelings that individuals have about the given issues, as well as illuminating the differences in perspective between groups of individuals [29]. The method is commonly used in the scope of health care and disease issues for exploring people's knowledge, their experiences, what they believe, what they think, how they think and why they think that way [28].

The concept of the focus group will be adapted here to accomplish an explorative discussion group for sharing experiences, ideas and thoughts. To have an easier start the patients are asked to bring a personal object that is meaningful and important in their daily lives regarding OA [31]. Explaining their choice should help to break the ice, enable us to access the patients' world and start a discussion on it [31]. The session is split into 2 parts. First open-ended question regarding the daily life with the disease, e.g. outcomes from the in-situ interviews, are asked to encourage a discussion within the participants. In the second part, available technologies will be shown and question will be asked about to enable a debate. A guide will be developed as reference for the session, supported by multi-media material and technical devices. The group size will be between 6 and 8 people. The session may last about 2 hours with a break, and take place in an adequate conference room [28, 29]. The discussions will be audio recorded and transcribed [28]. Photographs will be taken of the personal objects. For conducting the groups a moderator and, if possible, a note taker will be needed [29].

Design Workshop

A design workshop is not a specific method itself, more it is about a set of creative and collaborative activities, e.g. discussions, games or role playing, utilizing materials, e.g. Post-Its, cards or posters, and involving concerned stakeholders to create a participatory design process [32, 33]. The design workshop conducted during this thesis has the format of a Future Workshop [33] supported by the use of cards from the Inspiration Card Workshop [32]. 2 types of cards will be developed by us before the workshop session starts: domain and technology cards. Domain cards represent information on the domain for which we design, e.g. situations, people, settings or daily activities, too influenced by the outcome of earlier in-situ interview and focus group [32]. Technology cards represent either a specific technology or an application of a technology [32].

The fundamental shape of a Future Workshop comprises a critique phase, a fantasy phase and an implementation phase [33]. In the critique phase, participants criticise current situations and practices and cluster the outcomes into a number of problem areas [33]. Domain cards, showing problems and issues from previous stages, will be added to support critique outcomes. In the fantasy phase, the participants create visions and come up with ideas about how to deal with the problems identified in the previous phase [33]. The Implementation phase is about applying feasible solutions, identify obstacles and activities, and to make estimates about what resources are needed and what they should be capable of to realize the visions [33]. Technology cards are used as support and can be combined with domain cards to create design concepts [32]. In all phases small and large pieces of papers, e.g. Post-Its and Posters, are used to document and describe each phase in the progress [33]. 8-10 people are considered fruitful for the workshop, lasting about 2-3 hours, with breaks between the phases. The whole session will take place in an adequate conference room and will be documented by taking photographs.

Data collection

The data collection techniques in these 3 methods include videotapes, audio recordings, photographs and field notes. The video and audio records will be transcribed for further analysis. Only birth years and gender will be recorded, but no other personal information leading to identification of patients. For the interviews personal information will be replaced by codes. The association list will be stored in the General Hospital of Vienna. In the patient record, no information about the study will be stored.

Thematic Analysis

Thematic analysis is a method for identifying, analysing, and reporting patterns within data [30]. It minimally organises and describes your data set in detail [30]. A number of choices have to be considered and discussed, e.g. what counts as a theme, semantic or latent themes, inductive vs. theoretical approach [30]. The phases of the analysis are: familiarising with the data, transcription of the verbal data, generating initial codes which identify interesting features of the data, searching for themes, reviewing themes, defining and naming themes and producing the report [30].

The outcomes of the user research methods will undergo this analysis. The main results will be a description of the users, their issues, needs and a set of design concepts for self-care technologies.

Prototyping

For making the gathered data matter, it is important to communicate and apply the insights to a conceptual model [26]. Prototypes can be used to effectively inspire and guide the design of valuable and compelling human-computer interactive systems [26]. Representational artefacts as paper prototypes, mock-ups or working prototypes play an important mediating role in connecting the use requirements and design possibilities [26]. The prototypes go beyond simple demonstrations of functionality to incorporate materials from the participants' site, embody envisioned new technological possibilities, convey design ideas in relation to existing practices, and reveal requirements for new practices [26].

Interesting design concepts from the analysis phase will be elaborated as detailed prototypes, e.g. as paper sketches with rich description.

Related Work

Research has already been done about the concerns and problems of the people living with osteoarthritis. Hall et al. [12] explored the consequences of living with OA as living with unremitting pain and the limitations of mobility, leisure and social activities, whereas Pouli et al. [17] identified the themes of illness representation, experiences of limited pain relief and the use of drugs and surgery. In [18] the main concern, i.e. worsening of the illness, the factors of the concerns, which are psychological, coping, medication, social and financial, and the learning interests about illness specific topics of the patients are revealed. Power et al. [10] shows the perception of fatigue as exhaustion in daily life that makes it harder to participate in social activities and to do household chores. Study [20] had a closer look on the pain experience of patients and found unpredictable intermittent intense pain had the greatest impact on quality of life. Xie et al. [22] determined 5 important health-related quality of life domains as pain, physical disability, other symptoms of OA, mental health and social health. Other studies, [13] and [16], investigated the economic burden of the patients with OA, and highlight that financial problems increase with advanced disease and are mainly reasoned by the inability to and finally the loose of work. Regards solutions and self-management [15] explored strategies for supporting and managing the daily life of OA patients, e.g. through the use of assistive devices or activity adaptation.

Several research papers had a closer look on the outcome of patient education. The meta-analysis in [8] showed the positive influence on physical health and the overall impact of OA through patient education and exercise regimens. Penninx et al. [14] highlights the prevention of disability in activities of daily living through exercise. Mazzuca et al. [9] and Coudeyre et al. [11] agree with the positive effect of education, e.g. preservation of function and control, physical activity or weight reduction, but also recommended a prolonged follow-up adjunct to primary care by health professionals and dedicated continuing medical education programs. Campbell et al. [23] and Hendry et al. [24] manifested the problems of going on with exercise regimens as willingness and ability to accommodate exercises with everyday life, the perceived severity of symptoms, the physical capacity to exercise, exercise beliefs and other factors such as enjoyment and social support.

Some papers addressed self-care technologies. Umapathy et al. [19] examined the usage of a web-based resource containing tailored, evidence-based information and tools to improve self-management of OA, and showed improvements for lifestyle, physical activity and weight reduction. Brooks et al. [21] explored the use of a web-based therapeutic exercise resource centre, as a tool to prescribe strength, flexibility and aerobic exercise for OA treatment, and found an improved clinical outcome for the patients. In [25] design requirements, as small, light, discrete, not appear medical or challenge the identity of the user, and mode of use, as for exercise guidance and assessment only or for unobtrusive everyday monitoring, of a wearable technology for OA rehabilitation were found.

13.2.2 Informed Consent

PatientInneninformation und Einwilligungserklärung zur Teilnahme an einer mehrstufigen, qualitativen Studie

Konzeption technischer Hilfsmittel für Arthrose-Patienten: eine mehrstufige, qualitative Studie: MQ-OA

Sehr geehrte Teilnehmerin, sehr geehrter Teilnehmer!

Wir laden Sie ein an der oben genannten mehrstufigen, qualitativen Studie teilzunehmen. Die Aufklärung darüber erfolgt in einem ausführlichen Gespräch.

Ihre Teilnahme an dieser Studie erfolgt freiwillig. Sie können jederzeit ohne Angabe von Gründen aus der Studie ausscheiden. Die Ablehnung der Teilnahme oder ein vorzeitiges Ausscheiden aus dieser Studie hat keine nachteiligen Folgen für Ihre medizinische Betreuung.

Studien sind notwendig, um verlässliche neue medizinische und technologische Forschungsergebnisse zu gewinnen. Unverzichtbare Voraussetzung für die Durchführung einer Studie ist jedoch, dass Sie Ihr Einverständnis zur Teilnahme an dieser Studie schriftlich erklären. Bitte lesen Sie den folgenden Text als Ergänzung zum Informationsgespräch sorgfältig durch und zögern Sie nicht Fragen zu stellen.

Bitte unterschreiben Sie die Einwilligungserklärung nur

- wenn Sie Art und Ablauf der Studie vollständig verstanden haben,
- wenn Sie bereit sind, der Teilnahme zuzustimmen und
- wenn Sie sich über Ihre Rechte als Teilnehmer an dieser Studie im Klaren sind.

Zu dieser Studie, sowie zur PatientInneninformation und Einwilligungserklärung wurde von der zuständigen Ethikkommission eine befürwortende Stellungnahme abgegeben.

1. Was ist der Zweck der Studie?

Gelenksbeschwerden sind heute eine häufig auftretende, chronische Erkrankung, welche vor allem Hände, Knie oder Hüfte betrifft und mit zunehmendem Alter wahrscheinlicher wird. Das Auftreten der Erkrankung erfordert von den PatientInnen eine Anpassung ihres Lebens an die neuen Umstände und stellt sie vor neue Herausforderungen.

Wir möchten in dieser Studie herausfinden welche Herausforderungen und Probleme sich für PatientInnen mit Gelenksbeschwerden im Alltag ergeben und Ideen für mögliche technische Hilfsmittel finden und diskutieren. Ihre Gedanken als Patient oder Patientin sind dafür besonders wichtig.

2. Wie läuft die Studie ab?

Die Studie wird in Kooperation zwischen der Medizinischen Universität Wien und der Technischen Universität Wien durchgeführt. Es werden insgesamt ungefähr 24 Personen daran teilnehmen.

Der Ablauf der Studie gliedert sich in 3 Abschnitte, aus denen Sie einen, zwei oder alle drei auswählen können:

- Individuelles Interview Zuhause
  Hierbei besuchen wir die TeilnehmerInnen in Ihrem eigenen Zuhause um das alltägliche Leben mit Gelenksbeschwerden kennenzulernen und die damit einhergehenden Herausforderungen festzustellen. (Technische) Hilfsmittel, die Sie bereits in Ihrem Alltag verwenden, würden uns besonders interessieren. Dauer ca. 2 Stunden.
- Gesprächsrunde
  Gemeinsam mit den TeilnehmerInnen werden die unterschiedlichen Herausforderungen im Alltag besprochen und mögliche Lösungen diskutiert. Die PatientInnen nehmen dazu einen persönlichen Gegenstand mit, welchen Sie mit Ihrem Alltag, Ihren Herausforderungen oder Beschwerden in Verbindung bringen. Zudem werden technische Hilfsmittel vorgestellt und besprochen. Dauer ca. 2 Stunden.
- Arbeitsgruppe
  Gemeinsam mit den TeilnehmerInnen werden Lösungen für gegebene Probleme erarbeitet. Mit Hilfe Ihrer Ideen wollen wir neue Ideen und Konzepte für Hilfsmittel finden, die Ihnen den Alltag erleichtern. Dauer ca. 2 bis 3 Stunden.

<u>Folgende Maßnahmen werden ausschließlich aus Studiengründen durchgeführt:</u>

Wenn Sie Ihre Teilnahme zusagen, können Sie einen, zwei oder alle 3 Abschnitte wählen. Hierfür werden dann die jeweiligen Termine vereinbart. Das Gespräch beim individuellen Interview zuhause wird mittels Diktiergerät aufgezeichnet und durch eine Videokamera bildlich dokumentiert. Die Gesprächsrunde wird mittels Diktiergerät aufgenommen, die mitgebrachten Gegenstände per Fotographie festgehalten. Die Arbeitsgruppe wird mittels Fotos bildlich festgehalten. Die Aufnahmen werden transkribiert, d.h. wortwörtlich abgeschrieben und anschließend ausgewertet. Dabei werden alle persönlichen Daten gelöscht und die einzelnen Abschnitte, insbesondere die individuellen Interviews, mit einem Code versehen. Die Liste mit den Codes und der Zuordnung zu den Namen wird am AKH verwahrt. In der Krankengeschichte wird keine Information aus den Studienabschnitten vermerkt. Das individuelle Interview findet in Ihrem eigenen Zuhause statt und die Gesprächsrunde, sowie Arbeitsgruppe finden in Räumlichkeiten der teilnehmenden Universitäten statt.

3. Worin liegt der Nutzen einer Teilnahme an dieser Studie?

Durch Ihre aktive Teilnahme an dieser Studie können Sie Ihre Herausforderungen im Alltag mitteilen, gemeinsam mit anderen darüber diskutieren und Lösungen erarbeiten, die Ihnen das tägliche Leben erleichtern. Sonst haben Sie keinen darüber hinausgehenden Nutzen durch die Teilnahme an dieser Studie.

4. Gibt es Risiken, Beschwerden und Begleiterscheinungen?

Da es sich hierbei lediglich um individuelle Interviews Zuhause, Gesprächsrunden und Arbeitsgruppen handelt und Sie weder Medikamente noch andere Interventionen verabreicht bekommen, sind Sie keinem Risiko für Beschwerden und/oder Begleiterscheinungen aus dieser Studie ausgesetzt. Ihre Daten werden anonymisiert gespeichert und analysiert. Die Daten werden nicht in der Krankenakte der Ambulanz vermerkt, sodass Ihre Behandlung nicht durch Ihre Äußerungen beeinflusst werden kann.

5. Zusätzliche Einnahme von Arzneimitteln?

Für die Teilnahme an dieser Studie bekommen Sie keine zusätzlichen Arzneimittel oder andere Interventionen verschrieben.

6. In welcher Weise werden die im Rahmen dieser Studie gesammelten Daten verwendet?

Auf die gesammelten Daten haben ausschließlich die durchführenden Personen der Medizinischen Universität Wien und der Technischen Universität Wien zum Zwecke der Anonymisierung und Auswertung Zugriff. Die Weitergabe der Daten erfolgt ausschließlich zu statistischen Zwecken und Sie werden nie namentlich genannt. Auch in etwaigen Veröffentlichungen der Daten dieser Studie werden Sie nicht namentlich genannt.

7. Entstehen für die Teilnehmer Kosten? Gibt es einen Kostenersatz oder eine Vergütung?

Durch Ihre Teilnahme an dieser Studie entstehen für Sie keine zusätzlichen Kosten. Eventuelle Anfahrtskosten zu den Räumlichkeiten der teilnehmenden Universitäten können auf Nachfrage ersetzt werden.

8. Möglichkeit zur Diskussion weiterer Fragen

Für weitere Fragen im Zusammenhang mit dieser Studie stehen wir Ihnen gern zur Verfügung. Auch Fragen, die Ihre Rechte als PatientIn und TeilnehmerIn an dieser Studie betreffen, werden Ihnen gerne beantwortet.

Name der Kontaktperson:	**Patrick Kohlmayr, BSc**
Ständig erreichbar unter:	0650 24 82 353 oder e0926866@student.tuwien.ac.at
Name der Kontaktperson:	**Univ. Prof. Tanja Stamm, PhD**
Ständig erreichbar unter:	0676 534 60 17 oder tanja.stamm@meduniwien.ac.at

9. Einwilligungserklärung

Name des/der PatientIn in Druckbuchstaben: ....

Geb. Datum: .... Code: ....

Ich erkläre mich bereit, an der Studie MQ-OA in folgenden Abschnitten teilzunehmen:

- ○ Individuelles Interview Zuhause und/oder
- ○ Gesprächsrunde und/oder
- ○ Arbeitsgruppe

Ich bin von Herrn/Frau …………………………….............. ausführlich und verständlich über mögliche Belastungen und Risiken, sowie über Wesen, Bedeutung und Tragweite der Studie und sich für mich daraus ergebenden Anforderungen aufgeklärt worden. Ich habe darüber hinaus den Text dieser PatientInnenaufklärung und Einwilligungserklärung, die insgesamt 4 Seiten umfasst gelesen. Aufgetretene Fragen wurden mir verständlich und genügend beantwortet. Ich hatte ausreichend Zeit, mich zu entscheiden. Ich habe zurzeit keine weiteren Fragen mehr.

Ich werde den Anordnungen, die für die Durchführung der Interview-Studie erforderlich sind, Folge leisten, behalte mir jedoch das Recht vor, meine freiwillige Mitwirkung jederzeit zu beenden, ohne dass mir daraus Nachteile für meine weitere medizinische Betreuung entstehen.

Ich bin zugleich damit einverstanden, dass meine im Rahmen dieser Studie ermittelten Daten aufgezeichnet werden. Um die Richtigkeit der Datenaufzeichnung zu überprüfen, dürfen Beauftragte des Auftraggebers und der zuständigen Behörden Einblick in meine personenbezogenen Krankheitsdaten nehmen.

Die Bestimmungen des Datenschutzgesetzes in der geltenden Fassung werden eingehalten.

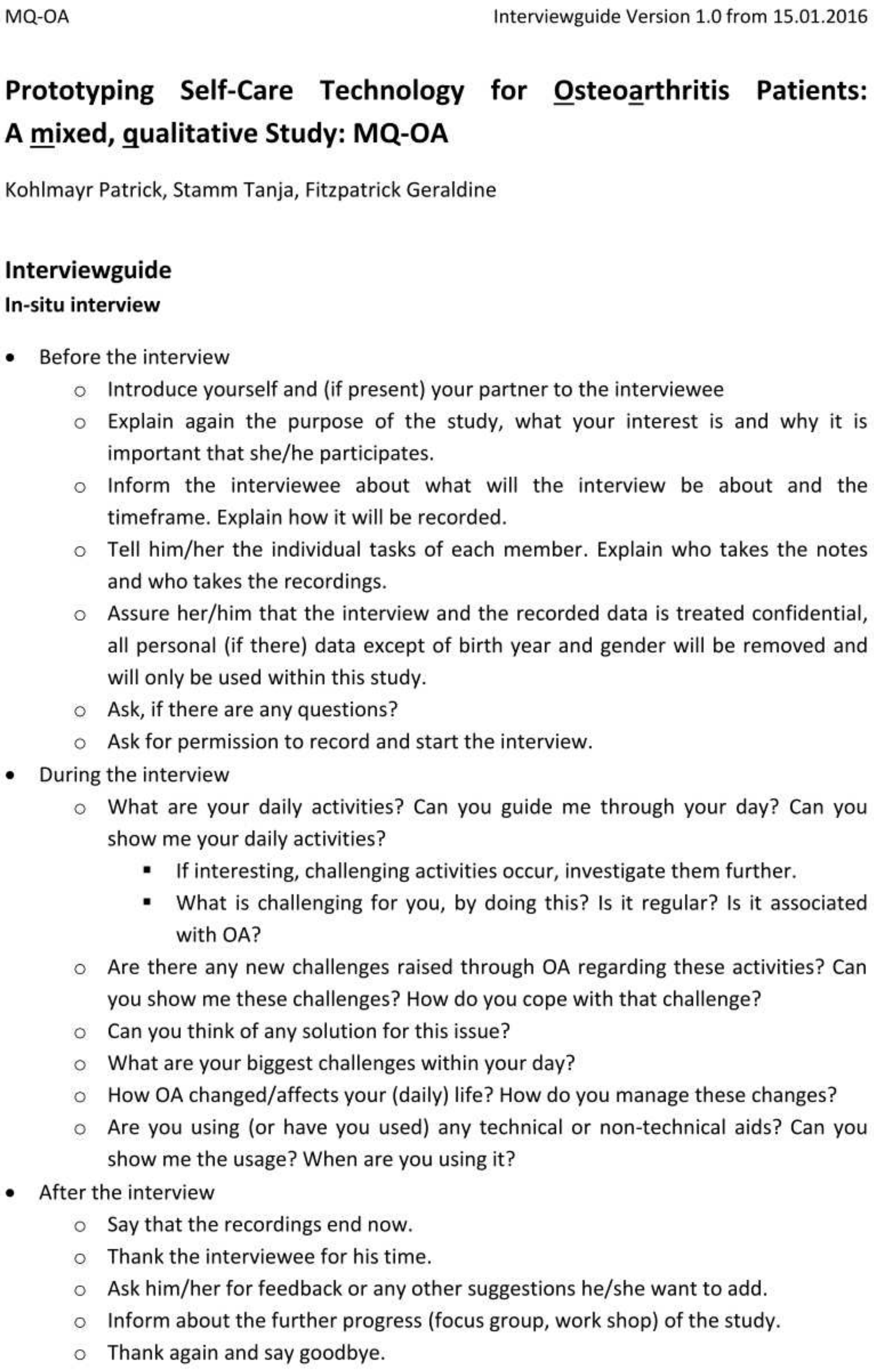
Eine Kopie dieser Patienteninformation und Einwilligungserklärung habe ich erhalten. Das Original verbleibt bei der aufklärenden Person.

....
(Datum und Unterschrift des Patienten)

....
(Datum, Name und Unterschrift der aufklärenden Person)

(Der Patient erhält eine unterschriebene Kopie der Patienteninformation und Einwilligungserklärung, das Original verbleibt im Studienordner.)

13.2.3 Interview Guide



MQ-OA Interviewguide Version 1.0 from 15.01.2016

Prototyping Self-Care Technology for Osteoarthritis Patients: A mixed, qualitative Study: MQ-OA

Kohlmayr Patrick, Stamm Tanja, Fitzpatrick Geraldine

Interviewguide

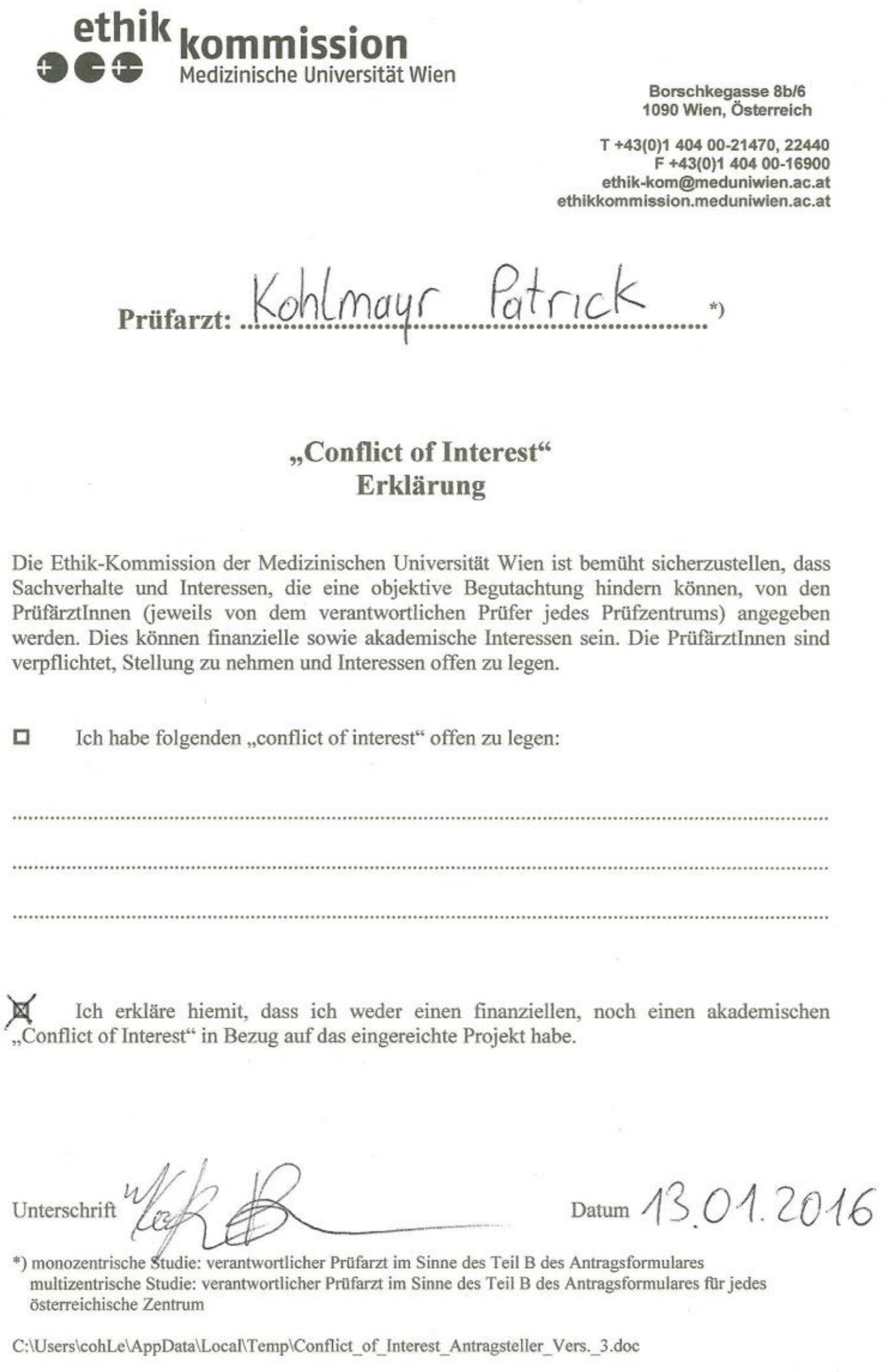
In-situ interview

- Before the interview
  - Introduce yourself and (if present) your partner to the interviewee
  - Explain again the purpose of the study, what your interest is and why it is important that she/he participates.
  - Inform the interviewee about what will the interview be about and the timeframe. Explain how it will be recorded.
  - Tell him/her the individual tasks of each member. Explain who takes the notes and who takes the recordings.
  - Assure her/him that the interview and the recorded data is treated confidential, all personal (if there) data except of birth year and gender will be removed and will only be used within this study.
  - Ask, if there are any questions?
  - Ask for permission to record and start the interview.
- During the interview
  - What are your daily activities? Can you guide me through your day? Can you show me your daily activities?
    - If interesting, challenging activities occur, investigate them further.
    - What is challenging for you, by doing this? Is it regular? Is it associated with OA?
  - Are there any new challenges raised through OA regarding these activities? Can you show me these challenges? How do you cope with that challenge?
  - Can you think of any solution for this issue?
  - What are your biggest challenges within your day?
  - How OA changed/affects your (daily) life? How do you manage these changes?
  - Are you using (or have you used) any technical or non-technical aids? Can you show me the usage? When are you using it?
- After the interview
  - Say that the recordings end now.
  - Thank the interviewee for his time.
  - Ask him/her for feedback or any other suggestions he/she want to add.
  - Inform about the further progress (focus group, work shop) of the study.
  - Thank again and say goodbye.

Focus Group

- Before group starts
    - Introduce yourself and (if present) your partner to the participants.
    - Explain again the purpose of the study, what your interest is and why it is important that they take part.
    - Inform them about what will happen during the group and about the timeframe.
    - Tell them the individual tasks of each member. Explain who takes the notes and who takes the recordings. Explain how it will be recorded.
    - Assure them that the recorded data is treated confidential, all personal (if there) except of birth year and gender data will be removed and will only be used within this study.
    - Ask if there are any questions?
    - Ask for permission to record and start the group.
- Within the group
    - Do a short introduction, where everyone makes a short statement, why he/she is here and what personal object he/she brought for us.
    - Which personal object regarding OA did you choose? Why?
    - What are the challenges of your daily life?
        - Outcomes from the in-situ interview may be used as reference, e.g. an issue you observed in some of the previous interviews.
    - How do you deal with those challenges? Do you have any solutions, e.g. a workaround?
    - Do you use or know any technical or non-technical aids?
    - Do you know any of these presented self-care technology? What do think about it? Would you use it? Why/Why not?
- After the group
    - Say that the recordings end now.
    - Thank the interviewees for their time.
    - Ask them for feedback, any suggestions and how they liked it.
    - Inform about the further progress (workshop) of the study.
    - Thank again and say goodbye.

13.2.4 Conflict of interest



ethik kommission
Medizinische Universität Wien

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1090 Wien, Österreich

T +43(0)1 404 00-21470, 22440
F +43(0)1 404 00-16900
ethik-kom@meduniwien.ac.at
ethikkommission.meduniwien.ac.at

Prüfarzt: Kohlmayr Patrick *)

„Conflict of Interest“
Erklärung

Die Ethik-Kommission der Medizinischen Universität Wien ist bemüht sicherzustellen, dass Sachverhalte und Interessen, die eine objektive Begutachtung hindern können, von den PrüfärztInnen (jeweils von dem verantwortlichen Prüfer jedes Prüfzentrums) angegeben werden. Dies können finanzielle sowie akademische Interessen sein. Die PrüfärztInnen sind verpflichtet, Stellung zu nehmen und Interessen offen zu legen.

☐ Ich habe folgenden „conflict of interest“ offen zu legen:

....

....

....

☒ Ich erkläre hiemit, dass ich weder einen finanziellen, noch einen akademischen „Conflict of Interest“ in Bezug auf das eingereichte Projekt habe.

Unterschrift

Datum 13.01.2016

*) monozentrische Studie: verantwortlicher Prüfarzt im Sinne des Teil B des Antragsformulares
multizentrische Studie: verantwortlicher Prüfarzt im Sinne des Teil B des Antragsformulares für jedes österreichische Zentrum

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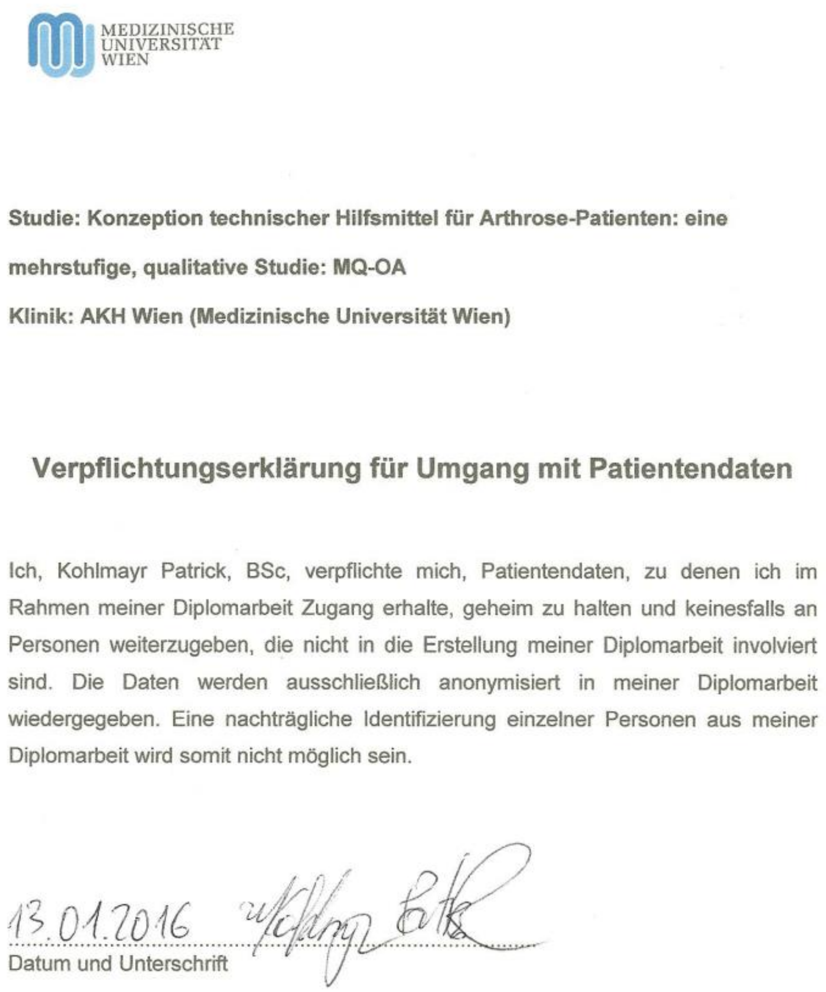
13.2.5 Handling of patient data



MEDIZINISCHE
UNIVERSITÄT
WIEN

Studie: Konzeption technischer Hilfsmittel für Arthrose-Patienten: eine mehrstufige, qualitative Studie: MQ-OA

Klinik: AKH Wien (Medizinische Universität Wien)

Verpflichtungserklärung für Umgang mit Patientendaten

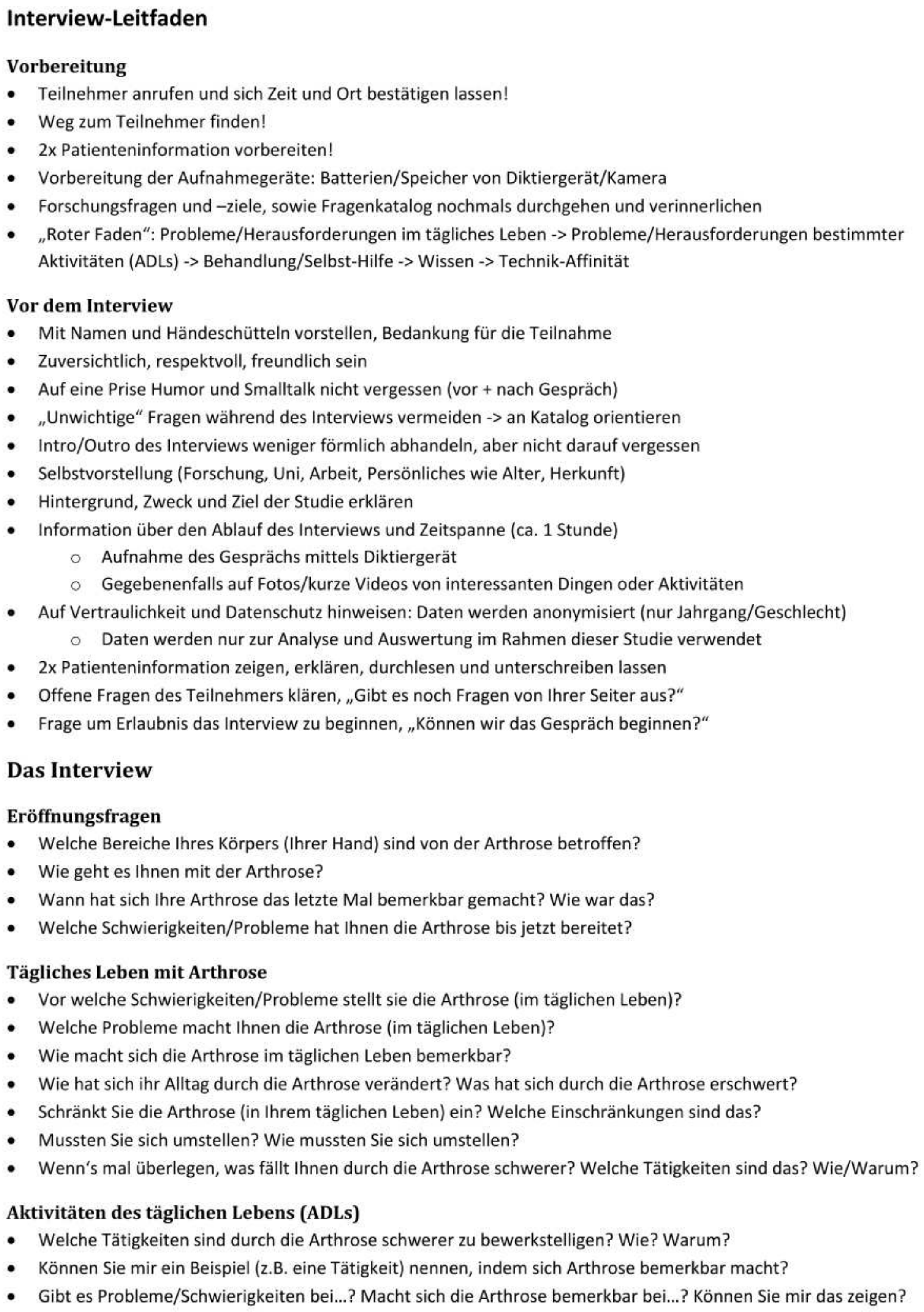
Ich, Kohlmayr Patrick, BSc, verpflichte mich, Patientendaten, zu denen ich im Rahmen meiner Diplomarbeit Zugang erhalte, geheim zu halten und keinesfalls an Personen weiterzugeben, die nicht in die Erstellung meiner Diplomarbeit involviert sind. Die Daten werden ausschließlich anonymisiert in meiner Diplomarbeit wiedergegeben. Eine nachträgliche Identifizierung einzelner Personen aus meiner Diplomarbeit wird somit nicht möglich sein.

13.01.2016

Datum und Unterschrift

13.3 INTERVIEW

13.3.1 Interview guide



Interview-Leitfaden

Vorbereitung

- Teilnehmer anrufen und sich Zeit und Ort bestätigen lassen!
- Weg zum Teilnehmer finden!
- 2x Patienteninformation vorbereiten!
- Vorbereitung der Aufnahmegeräte: Batterien/Speicher von Diktiergerät/Kamera
- Forschungsfragen und –ziele, sowie Fragenkatalog nochmals durchgehen und verinnerlichen
- „Roter Faden“: Probleme/Herausforderungen im tägliches Leben -> Probleme/Herausforderungen bestimmter Aktivitäten (ADLs) -> Behandlung/Selbst-Hilfe -> Wissen -> Technik-Affinität

Vor dem Interview

- Mit Namen und Händeschütteln vorstellen, Bedankung für die Teilnahme
- Zuversichtlich, respektvoll, freundlich sein
- Auf eine Prise Humor und Smalltalk nicht vergessen (vor + nach Gespräch)
- „Unwichtige“ Fragen während des Interviews vermeiden -> an Katalog orientieren
- Intro/Outro des Interviews weniger förmlich abhandeln, aber nicht darauf vergessen
- Selbstvorstellung (Forschung, Uni, Arbeit, Persönliches wie Alter, Herkunft)
- Hintergrund, Zweck und Ziel der Studie erklären
- Information über den Ablauf des Interviews und Zeitspanne (ca. 1 Stunde)
    - Aufnahme des Gesprächs mittels Diktiergerät
    - Gegebenenfalls auf Fotos/kurze Videos von interessanten Dingen oder Aktivitäten
- Auf Vertraulichkeit und Datenschutz hinweisen: Daten werden anonymisiert (nur Jahrgang/Geschlecht)
    - Daten werden nur zur Analyse und Auswertung im Rahmen dieser Studie verwendet
- 2x Patienteninformation zeigen, erklären, durchlesen und unterschreiben lassen
- Offene Fragen des Teilnehmers klären, „Gibt es noch Fragen von Ihrer Seiter aus?“
- Frage um Erlaubnis das Interview zu beginnen, „Können wir das Gespräch beginnen?“

Das Interview

Eröffnungsfragen

- Welche Bereiche Ihres Körpers (Ihrer Hand) sind von der Arthrose betroffen?
- Wie geht es Ihnen mit der Arthrose?
- Wann hat sich Ihre Arthrose das letzte Mal bemerkbar gemacht? Wie war das?
- Welche Schwierigkeiten/Probleme hat Ihnen die Arthrose bis jetzt bereitet?

Tägliches Leben mit Arthrose

- Vor welche Schwierigkeiten/Probleme stellt sie die Arthrose (im täglichen Leben)?
- Welche Probleme macht Ihnen die Arthrose (im täglichen Leben)?
- Wie macht sich die Arthrose im täglichen Leben bemerkbar?
- Wie hat sich ihr Alltag durch die Arthrose verändert? Was hat sich durch die Arthrose erschwert?
- Schränkt Sie die Arthrose (in Ihrem täglichen Leben) ein? Welche Einschränkungen sind das?
- Mussten Sie sich umstellen? Wie mussten Sie sich umstellen?
- Wenn‘s mal überlegen, was fällt Ihnen durch die Arthrose schwerer? Welche Tätigkeiten sind das? Wie/Warum?

Aktivitäten des täglichen Lebens (ADLs)

- Welche Tätigkeiten sind durch die Arthrose schwerer zu bewerkstelligen? Wie? Warum?
- Können Sie mir ein Beispiel (z.B. eine Tätigkeit) nennen, indem sich Arthrose bemerkbar macht?
- Gibt es Probleme/Schwierigkeiten bei…? Macht sich die Arthrose bemerkbar bei…? Können Sie mir das zeigen?

- Wie gehen Sie mit diesem Problem um? Was tun Sie dagegen?
- Haben Sie dafür einen bestimmten Kniff oder eine Lösung um sich dies zu vereinfachen?
- Wie helfen Sie sich dabei? Haben Sie eine Idee was helfen könnte?
- Verwenden Sie Dinge (wie Werkzeuge, Besteck, usw…) anders als zuvor? Verwenden Sie Geräte (eine Fernbedingung, Hand<, Computer) heutzutage anders (als davor)?

ADLs

- Hand in Ruhe-Position: Liegen, Schlafen, Sitzen, Gehen, Aufstehen
- Heben/tragen leichter/schwerer Sachen, Greifen kleiner/großer Sachen, (Fest)Halten von Dingen
- Nehmen, Greifen, Drücken, Halten, Öffnen, Schließen, Drehen-Öffnen von Flaschen, Benutzen eines Schlüssels
- Zähne putzen, Haare, Anziehen, Kochen, Tisch decken, Essen, Besteck verwenden, Trinken (Flasche/Dose)
- Bei der Arbeit, Bei der Hausarbeit/Gartenarbeit machen, Geschirr waschen, Putzen, Kehren
- Schreiben, Verwendung der Fernbedienung, eines Telefons, Computers, Tastatur/Maus
- In der Öffentlichkeit sein, Öffis fahren, Auto fahren
- Einkaufen gehen, Verwendung der Brieftasche, des Geldes, von Karten
- Spiele, Karten spielen, andere Freizeitaktivitäten
- Beim Handgeben/Händeschütteln

Selbst-Hilfe

- Was machen Sie selbst gegen die Arthrose? Tun sie selbst für sich etwas gegen die Arthrose?
- Machen Sie vorbeugende Maßnahmen? Irgendwelche Übungen?
- Welche Tätigkeiten machen sie zur Selbstbehandlung von Arthrose?
- Verwenden Sie irgendwelche Hilfsmittel, um sich das Leben zu erleichtern?
- Haben Sie Wege gefunden sich den Alltag mit der Arthrose zu erleichtern? Wie/Was?
- Haben Sie eine Idee, wie man Ihnen den Alltag mit der Arthrose erleichtern könnte?
- Wie haben sie die alltäglichen Probleme mit Arthrose in den Griff bekommen? Konkrete Lösungen? Oder haben sie bestimmte Ideen?
- Haben sie Tipps oder Tricks aus Ihren Erfahrungen für jemanden anderen der von Arthrose betroffen ist?

Wissen + Technik

- Wie haben Sie sich über die Arthrose informiert? Woher haben Sie Ihr Wissen über Arthrose?
- Benutzen sie einen Computer, das Internet oder ein Smartphone?

Beenden des Interviews

- Was würde Ihnen das Leben mit der Arthrose erleichtern? Was würden Sie sich wünschen?
- Teilnehmer Fragen ob noch irgendwelche Themen aus seiner Sicht offen sind? Ob irgendetwas noch nicht gesagt oder angesprochen wurde? Ob noch etwas hinzuzufügen ist?
- Zusammenfassung, wichtige Punkte nochmals wiederholen

Nach dem Interview

- Sagen, dass die Aufnahme nun endet
- Wenn Kamera noch nicht verwendet, fragen ob bestimmte interessante Sachen fotographiert oder als kurzes Video aufgenommen werden können.
- Bedanken für das Interview, die Teilnahme und Zeit
- Frage nach Feedback, Empfehlen was ich anders machen sollte
- Nach Email fragen für weitere Kommunikation
- Sagen, wie die gewonnene Information zum Forschungsprojekt beiträgt
- Über den weiteren Prozess informieren (Fokusgruppen, Arbeitsgruppe)
- Nicht vergessen: 1x Patienteninformation beim Teilnehmer lassen
- Smalltalk, bedanken und gehen

13.3.2 Transcript examples

Interview-Transkript

MQOA-IV01
Kohlmayr Patrick

Beschreibung

Code (.mp3-Datei)	MQOA-IV01	Datum des Interviews	22.09.2016
Interviewer	Kohlmayr Patrick	Dauer	37:59
Interviewte(r)	M/1948	Sprache	Deutsch
Transkribiert von	Kohlmayr Patrick	Datum der Transkription	02.11.2016

Verwendete Kürzel

Kürzel	Erklärung
T	Teilnehmer bzw. Interviewte(r)
I	Interviewer
[…]	Kommentar, Erläuterung, Beschreibung
(…)	Zeitstempel

Transkript

(00:00)

T: Und es ist so, es ist dann wirklich besser geworden. Ich hab dann auch beim Neubau, bei dem Haus, ausgerechnet zirka 1400m² gespachtelt, Beton, und jede Fläche dreimal. Und da war es dann so, dass die Hände schon, die eine Hand, ziemlich deformiert war. Jetzt ist sie wieder normal. Aber normalerweise ist dieser Knorpel und das [Zeit auf die Fingerwurzelknorpel seiner Hand], ist eine Ebene immer gewesen. Und der ist bisschen breiter schon [Zeigt auf einen Knorpel]. Und heute mach ich weniger [arbeiten], weil ich nicht mehr so fit bin und wenn ich etwas längere Zeit mache, dann krieg ich Probleme, dass mir ein Finger einklappt und den muss ich mir dann wieder rausholen. Also den [Finger] zieht es mir ein.

I: Und den kann man selber dann gar nicht mehr bewegen?

T: Nein, denn kann ich nicht mehr, den muss ich irgendwie rausholen. Das ist dann aber Überanstrengung.

I: Wie macht sich das, wenn Sie zurückdenken an den Anfang bemerkbar? Oder kommt es schleichend?

T: Wann ich ein Werkzeug in der Hand habe, das kann ich dann gar nicht mehr auslassen. Das verkrampft dann.

I: Also man bekommt die Hand zu?

T: Aber ich kriege sie nicht mehr auf. Das ist dann ein Zeichen das ich schon wieder bisschen überlastet habe, schon wieder.

I: Ist das bei beiden Händen?

T: Nein, ich bin Rechtshänder, das ist eigentlich normal. Aber das ist schon ziemlich deformiert gewesen. Meine Mutter hat, wie sagt man da? Gicht?

I: Gicht. Ja, umgangssprachlich.

Seite 1 von 13

Knetmasse. Kneten, rollen, drücken, und dann da herum und so aufmachen [Zeigt eine Wurscht aus Knete um die Finger gewickelt, und versucht die Finger auseinander zu spreizen].

(16:03)

I: Und das dauert so 20 Minuten? Viertel Stunde?

T: Das dauert eine halbe Stunde. Und da kann ich mich noch so beeilen, also mit einer halben Stunde muss ich rechnen. Jetzt habe ich aber eh schon umgestellt, jetzt tu ich nicht mehr eine Hand nach der anderen, jetzt mache ich diese Übungen gleichzeitig. Dass so wenigstens auch ein wenig Zeit gespart wird. Und das andere geht halt nur mit einer Hand immer, das mit der Knetmasse, nur da muss ich mir jetzt eine Neue kaufen, weil diesen Sommer, die hat so gepickt, das ich sie fast nicht von den Händen weggebracht habe. Na, ungut.

I: Weils so gummig war?

T: Ja. Und ich mein, ich habe sie [Knetmasse] auch schon seit dem ich dort war, also mindestens schon 2 Jahre oder länger, dass ich die Knetmasse hab. Die hab ich dort bekommen, in so einer Plastikschachtel. Das hab ich auch noch da [Holt die Knetmasse]. Alles da. [Räumt die Knetmasse aus einem Regal hervor]. Und im Sommer wenn es heiß ist, ist es so klebrig geworden. So jetzt geht es ja, das funktioniert eh, jetzt ist sie richtig, aber wenn es heiß ist rennt einem das davon. Das pickt alles, dann muss man es zwischen den Fingern rausnehmen, das ist voll grauslich.

I: Okay, also alle 2 Tage die Übungen und die Knetmasse.

T: Ja, 20ig mal. Da hat sie gesagt [die Doktorin], es genügt wenn ich sie jeden 2. Tag 20ig Mal mache jede Übung, und an das halte ich mich jetzt. Das mach ich jetzt halt so lang ich kann, man weiß eh nicht ob es so weitergeht, es ist halt ein Jammer. Wenn man älter wird, wird alles schwieriger.

I: Ja, muss sich da wohl immer ein bisschen umstellen?

T: Ja, nur man muss einfach zur Kenntnis nehmen, dass das einfach nicht mehr so geht. Und das ist ein schwieriger Prozess. Weil man glaubt es geht immer und ewig so weiter, und so lange man sich wohlfühlt und alles funktioniert denkt man ja gar nicht das man das einmal nicht mehr machen könnte. Das ist das Problem.

I: Benutzen sie denn auch Computer und Internet?

T: Ja, habe ich. Aber ich häng nicht ständig dran, ich schau nur kurz hinein und meine Bilder tu ich mir einspeichern, und ab und zu ein E-Mail schreiben. Und wenn ich irgendetwas suche, oder Englisch wenn ich was brauche, aber sonst, also ich sitz sicher manche Tage überhaupt nicht, und wenn ich lange sitz eine Stunde dann reicht es mir schon.

I: Aber da ist die Verwendung auch kein Problem? Zum Beispiel, wenn sie ein Gerät haben wie eine Tastatur, oder Fernbedienung?

T: Nein, das macht mir nichts. Das ist kein Problem. Fernbedienung, die Maus, Tastatur, das ist alles kein Problem.

I: Handy? Auch kein Problem?

überhaupt nicht hilft, ist so Käse- und Topfenwickel, mit dem komm ich überhaupt nicht auf die Reihe.

(09:36)

I: Haben Sie in ihren Lebensbereichen oder im Alltag irgendwo stark umstellen müssen? Weil gewisse Sachen gar nicht mehr möglich waren, oder einfach sehr schwer?

T: Nein, eigentlich nicht. Ich brauche halt für manches länger, aber das ist teilweise altersbedingt. Man braucht ja für manche Dinge aufgrund des Alters auch schon länger. Also wirklich umstellen hab ich mich nicht müssen.

I: Verwenden Sie heute irgendwelche Gegenstände, oder Besteck, oder…

T: Nein. Gegenstände, ja, wie gesagt, das eine zum Flaschen öffnen aber sonst das normale Werkzeug wie sonst auch.

I: Wie ist es beim Tragen oder Halten von Sachen?

T: Da habe ich eigentlich kaum ein Problem. Die Kraft ist schon da in den Händen.

I: Und auch Sachen länger halten? Oder wenn sie schwerer werden, haben Sie da mal Probleme gehabt?

T: Nein, ist mir noch nicht aufgefallen.

I: Also es war jetzt auch noch nie so, dass Ihnen etwas unabsichtlich aus der Hand gefallen ist?

T: Nein, also so nicht, ich meine wenn man patschert ist, dann fällt einem schon etwas aus der Hand, aber so aufgrund, dass mich die Kraft verlässt, das ist noch nicht passiert. So ich glaub das war meine Frage jetzt, dass die Kraft mich verlässt [das ist noch nicht passiert].

I: Oder das die Arthrose dabei hindert ist?

T: Nein, das hab ich noch nicht gehabt.

I: Und beim Greifen nach kleinen Sachen, wenn so darüber nachdenken?

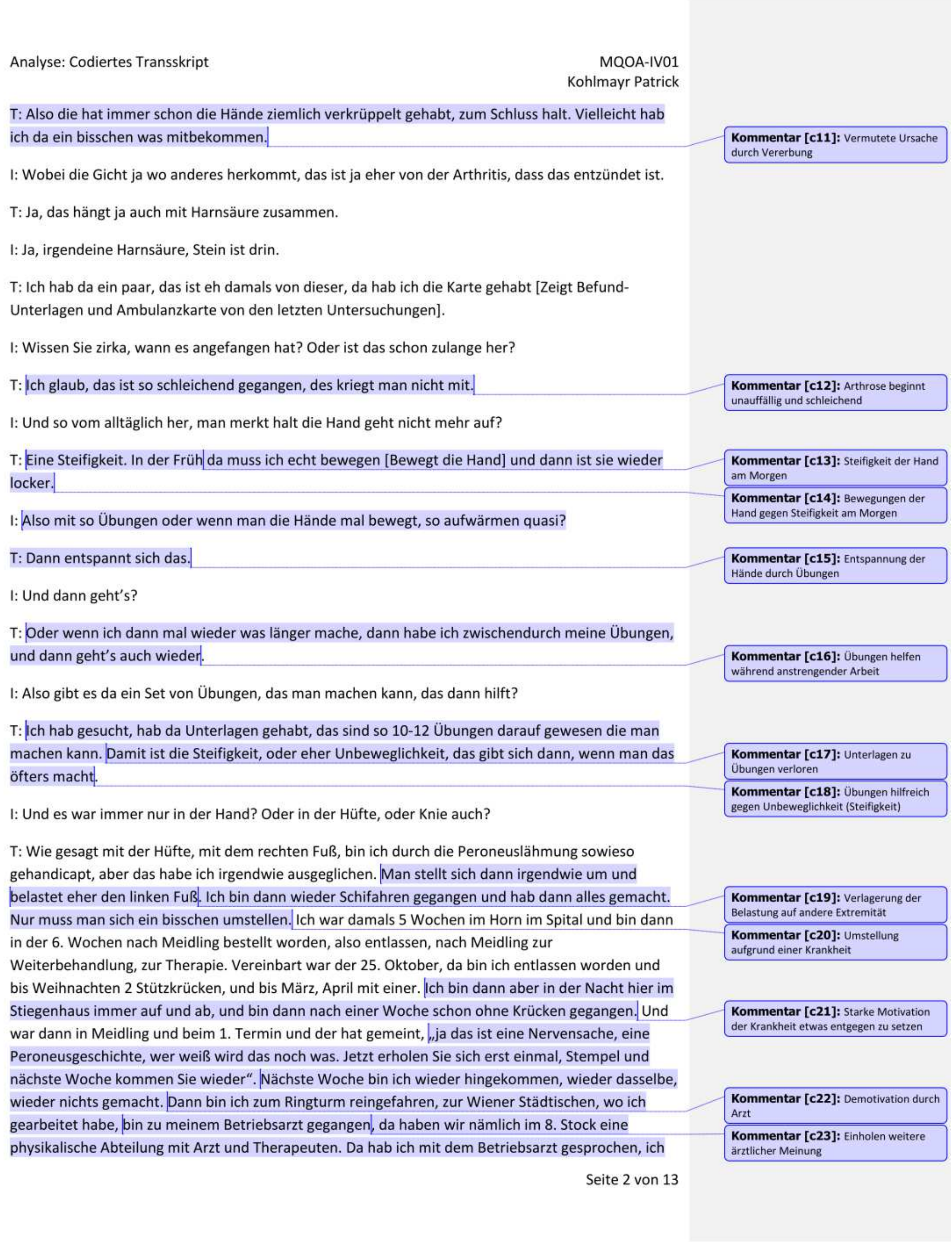
T: Naja, bei ganz kleinen Sachen spüre ich schon die Gelenke. Aber ich meine, ich hab kein Problem mit diesem Greifen. Also ich kann noch nach ganz kleinen Sachen greifen, aber manchmal, wenn es so ist wie das Wetter jetzt, dann spür ich es auch. Also wenn hier zum Beispiel eine Nähnadel liegt, dann spür ich es schon, wenn ich da jetzt herum tue. Und beim Einfädeln habe ich ein anderes Problem, weil ich nicht mehr so gut sehe, aber das hat ja damit nichts zu tun. Das ist eine andere Alterseinschränkung.

I: Nähen Sie noch?

T: Naja sicher tu ich nähen, das ist bei uns so eingeteilt. Das ich diese Sachen mach und meine Frau macht andere Sachen. Also das ist bei uns „gegendert“ sozusagen.

I: Sehr gut. Wenn Sie an Freizeitaktivitäten denken, macht sich da die Arthrose in irgendwelchen Bereichen bemerkbar?

13.3.3 Coding examples



Analyse: Codiertes Transskript

MQOA-IV01
Kohlmayr Patrick

T: Also die hat immer schon die Hände ziemlich verkrüppelt gehabt, zum Schluss halt. Vielleicht hab ich da ein bisschen was mitbekommen.

Kommentar [c11]: Vermutete Ursache durch Vererbung

I: Wobei die Gicht ja wo anderes herkommt, das ist ja eher von der Arthritis, dass das entzündet ist.

T: Ja, das hängt ja auch mit Harnsäure zusammen.

I: Ja, irgendeine Harnsäure, Stein ist drin.

T: Ich hab da ein paar, das ist eh damals von dieser, da hab ich die Karte gehabt [Zeigt Befund-Unterlagen und Ambulanzkarte von den letzten Untersuchungen].

I: Wissen Sie zirka, wann es angefangen hat? Oder ist das schon zulange her?

T: Ich glaub, das ist so schleichend gegangen, des kriegt man nicht mit.

Kommentar [c12]: Arthrose beginnt unauffällig und schleichend

I: Und so vom alltäglich her, man merkt halt die Hand geht nicht mehr auf?

T: Eine Steifigkeit. In der Früh da muss ich echt bewegen [Bewegt die Hand] und dann ist sie wieder locker.

Kommentar [c13]: Steifigkeit der Hand am Morgen

Kommentar [c14]: Bewegungen der Hand gegen Steifigkeit am Morgen

I: Also mit so Übungen oder wenn man die Hände mal bewegt, so aufwärmen quasi?

T: Dann entspannt sich das.

Kommentar [c15]: Entspannung der Hände durch Übungen

I: Und dann geht's?

T: Oder wenn ich dann mal wieder was länger mache, dann habe ich zwischendurch meine Übungen, und dann geht's auch wieder.

Kommentar [c16]: Übungen helfen während anstrengender Arbeit

I: Also gibt es da ein Set von Übungen, das man machen kann, das dann hilft?

T: Ich hab gesucht, hab da Unterlagen gehabt, das sind so 10-12 Übungen darauf gewesen die man machen kann. Damit ist die Steifigkeit, oder eher Unbeweglichkeit, das gibt sich dann, wenn man das öfters macht.

Kommentar [c17]: Unterlagen zu Übungen verloren

Kommentar [c18]: Übungen hilfreich gegen Unbeweglichkeit (Steifigkeit)

I: Und es war immer nur in der Hand? Oder in der Hüfte, oder Knie auch?

T: Wie gesagt mit der Hüfte, mit dem rechten Fuß, bin ich durch die Peroneuslähmung sowieso gehandicapt, aber das habe ich irgendwie ausgeglichen. Man stellt sich dann irgendwie um und belastet eher den linken Fuß. Ich bin dann wieder Schifahren gegangen und hab dann alles gemacht. Nur muss man sich ein bisschen umstellen. Ich war damals 5 Wochen im Horn im Spital und bin dann in der 6. Wochen nach Meidling bestellt worden, also entlassen, nach Meidling zur Weiterbehandlung, zur Therapie. Vereinbart war der 25. Oktober, da bin ich entlassen worden und bis Weihnachten 2 Stützkrücken, und bis März, April mit einer. Ich bin dann aber in der Nacht hier im Stiegenhaus immer auf und ab, und bin dann nach einer Woche schon ohne Krücken gegangen. Und war dann in Meidling und beim 1. Termin und der hat gemeint, „ja das ist eine Nervensache, eine Peroneusgeschichte, wer weiß wird das noch was. Jetzt erholen Sie sich erst einmal, Stempel und nächste Woche kommen Sie wieder". Nächste Woche bin ich wieder hingekommen, wieder dasselbe, wieder nichts gemacht. Dann bin ich zum Ringturm reingefahren, zur Wiener Städtischen, wo ich gearbeitet habe, bin zu meinem Betriebsarzt gegangen, da haben wir nämlich im 8. Stock eine physikalische Abteilung mit Arzt und Therapeuten. Da hab ich mit dem Betriebsarzt gesprochen, ich

Kommentar [c19]: Verlagerung der Belastung auf andere Extremität

Kommentar [c20]: Umstellung aufgrund einer Krankheit

Kommentar [c21]: Starke Motivation der Krankheit etwas entgegen zu setzen

Kommentar [c22]: Demotivation durch Arzt

Kommentar [c23]: Einholen weitere ärztlicher Meinung

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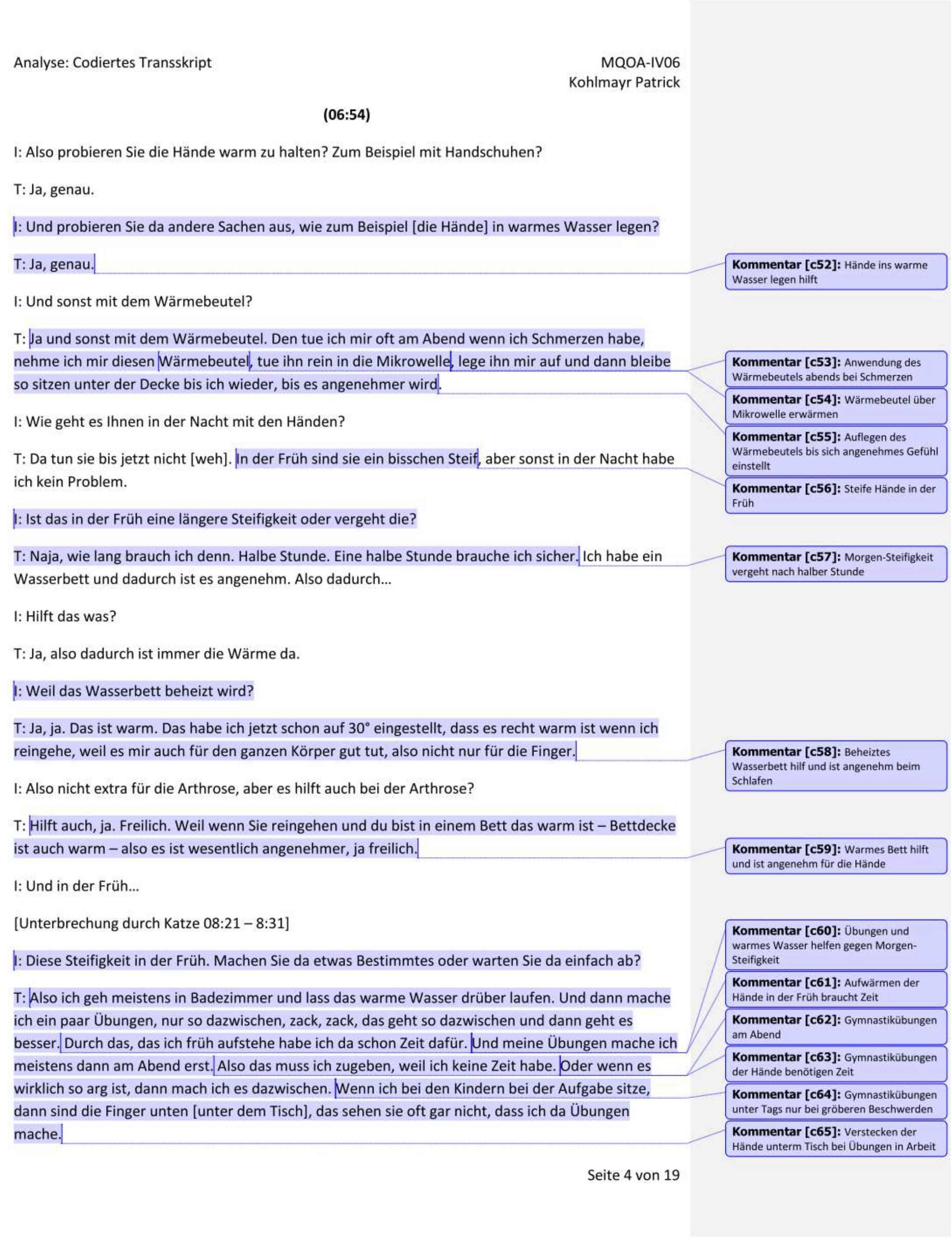


(06:54)

I: Also probieren Sie die Hände warm zu halten? Zum Beispiel mit Handschuhen?

T: Ja, genau.

I: Und probieren Sie da andere Sachen aus, wie zum Beispiel [die Hände] in warmes Wasser legen?

T: Ja, genau.

Kommentar [c52]: Hände ins warme Wasser legen hilft

I: Und sonst mit dem Wärmebeutel?

T: Ja und sonst mit dem Wärmebeutel. Den tue ich mir oft am Abend wenn ich Schmerzen habe, nehme ich mir diesen Wärmebeutel, tue ihn rein in die Mikrowelle, lege ihn mir auf und dann bleibe so sitzen unter der Decke bis ich wieder, bis es angenehmer wird.

Kommentar [c53]: Anwendung des Wärmebeutels abends bei Schmerzen

Kommentar [c54]: Wärmebeutel über Mikrowelle erwärmen

Kommentar [c55]: Auflegen des Wärmebeutels bis sich angenehmes Gefühl einstellt

I: Wie geht es Ihnen in der Nacht mit den Händen?

T: Da tun sie bis jetzt nicht [weh]. In der Früh sind sie ein bisschen Steif, aber sonst in der Nacht habe ich kein Problem.

Kommentar [c56]: Steife Hände in der Früh

I: Ist das in der Früh eine längere Steifigkeit oder vergeht die?

T: Naja, wie lang brauch ich denn. Halbe Stunde. Eine halbe Stunde brauche ich sicher. Ich habe ein Wasserbett und dadurch ist es angenehm. Also dadurch...

Kommentar [c57]: Morgen-Steifigkeit vergeht nach halber Stunde

I: Hilft das was?

T: Ja, also dadurch ist immer die Wärme da.

I: Weil das Wasserbett beheizt wird?

T: Ja, ja. Das ist warm. Das habe ich jetzt schon auf 30° eingestellt, dass es recht warm ist wenn ich reingehe, weil es mir auch für den ganzen Körper gut tut, also nicht nur für die Finger.

Kommentar [c58]: Beheiztes Wasserbett hilf und ist angenehm beim Schlafen

I: Also nicht extra für die Arthrose, aber es hilft auch bei der Arthrose?

T: Hilft auch, ja. Freilich. Weil wenn Sie reingehen und du bist in einem Bett das warm ist – Bettdecke ist auch warm – also es ist wesentlich angenehmer, ja freilich.

Kommentar [c59]: Warmes Bett hilft und ist angenehm für die Hände

I: Und in der Früh...

[Unterbrechung durch Katze 08:21 – 8:31]

I: Diese Steifigkeit in der Früh. Machen Sie da etwas Bestimmtes oder warten Sie da einfach ab?

T: Also ich geh meistens in Badezimmer und lass das warme Wasser drüber laufen. Und dann mache ich ein paar Übungen, nur so dazwischen, zack, zack, das geht so dazwischen und dann geht es besser. Durch das, das ich früh aufstehe habe ich da schon Zeit dafür. Und meine Übungen mache ich meistens dann am Abend erst. Also das muss ich zugeben, weil ich keine Zeit habe. Oder wenn es wirklich so arg ist, dann mach ich es dazwischen. Wenn ich bei den Kindern bei der Aufgabe sitze, dann sind die Finger unten [unter dem Tisch], das sehen sie oft gar nicht, dass ich da Übungen mache.

Kommentar [c60]: Übungen und warmes Wasser helfen gegen Morgen-Steifigkeit

Kommentar [c61]: Aufwärmen der Hände in der Früh braucht Zeit

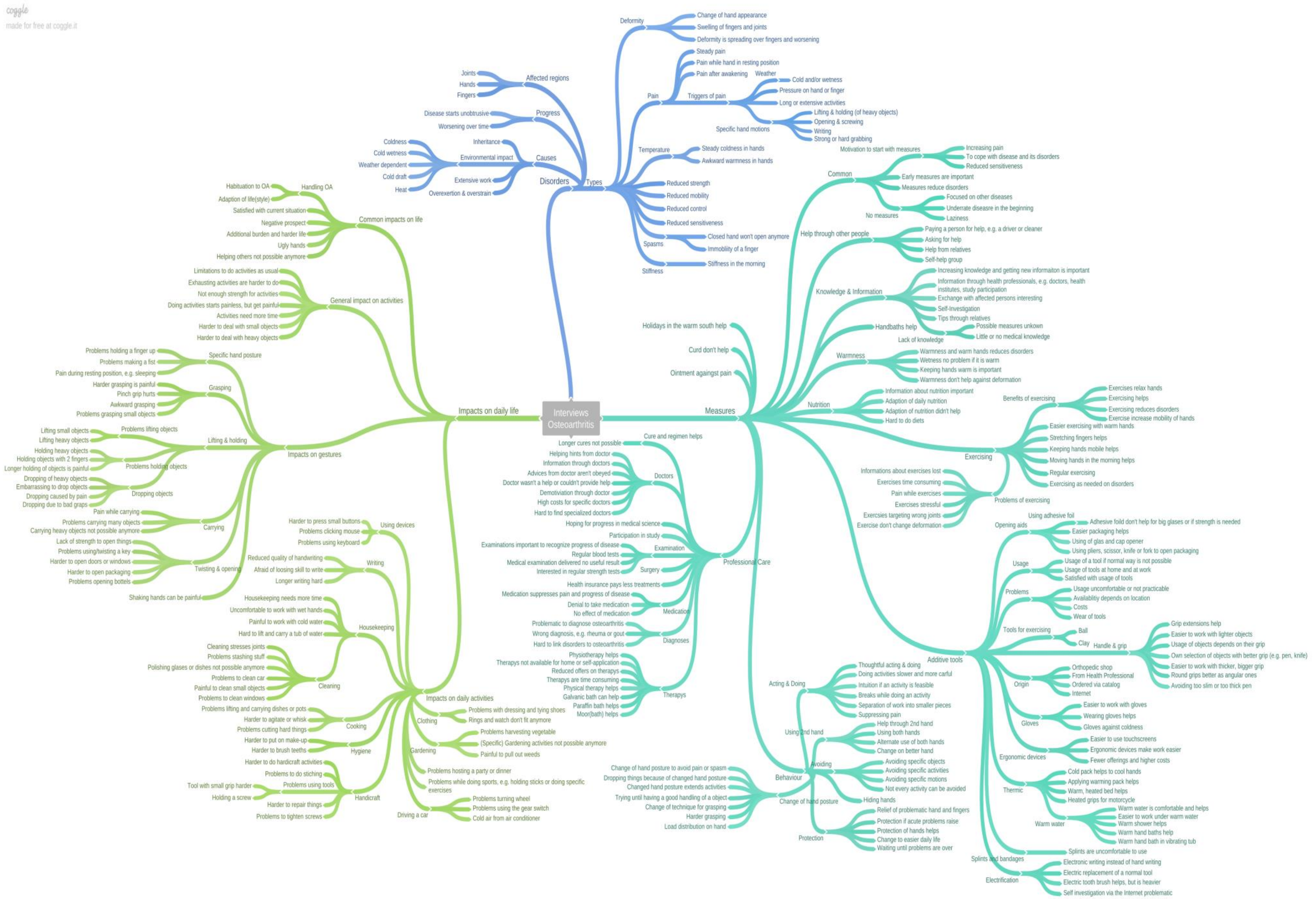
Kommentar [c62]: Gymnastikübungen am Abend

Kommentar [c63]: Gymnastikübungen der Hände benötigen Zeit

Kommentar [c64]: Gymnastikübungen unter Tags nur bei gröberen Beschwerden

Kommentar [c65]: Verstecken der Hände unterm Tisch bei Übungen in Arbeit

13.3.4 Mind map of emerged themes

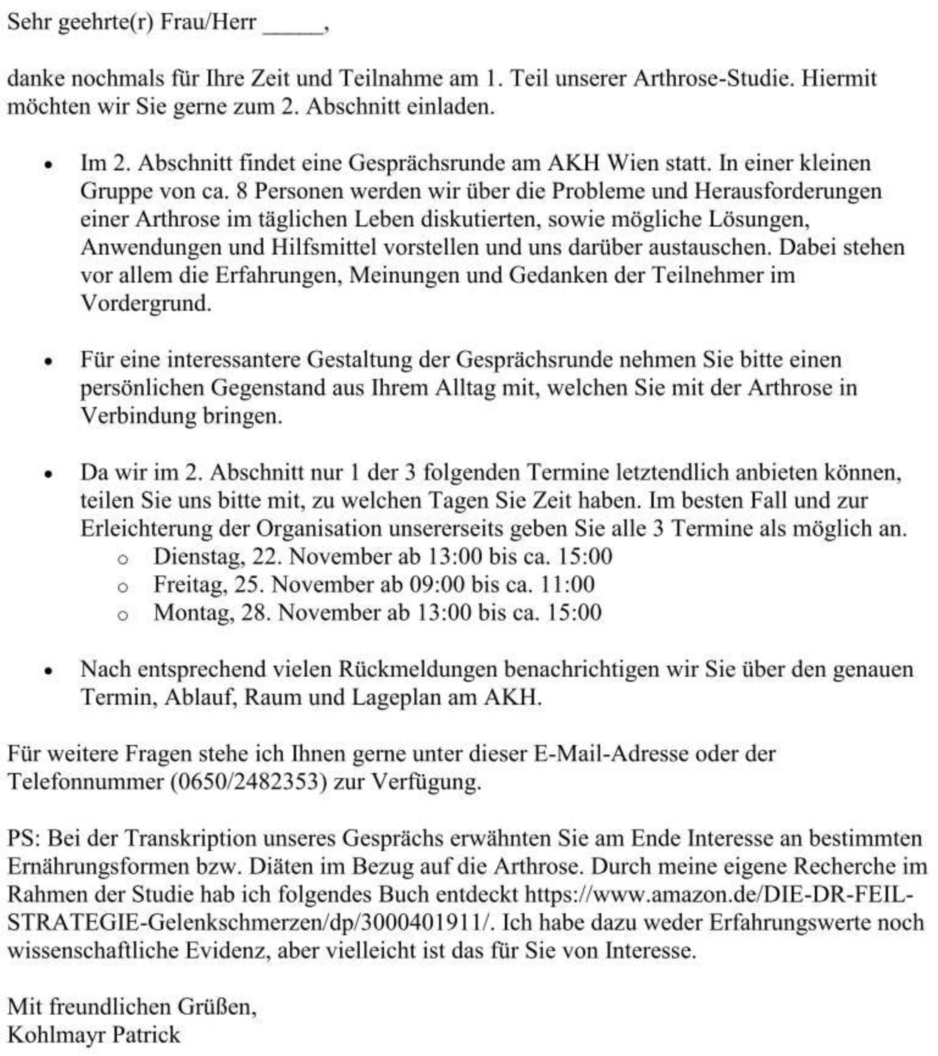


13.3.5 Reflection notes

Lessons learned were how to get the interview started from the previous small talk with good opening questions, keep focus on the central topics, avoid too much topic switching, avoid asking suggestive question that contain already an answer, dig deeper on interesting statements or stories and keep out own knowledge or opinions.

13.4 FOCUS GROUP

13.4.1 Focus group invitation



Sehr geehrte(r) Frau/Herr _____,

danke nochmals für Ihre Zeit und Teilnahme am 1. Teil unserer Arthrose-Studie. Hiermit möchten wir Sie gerne zum 2. Abschnitt einladen.

- Im 2. Abschnitt findet eine Gesprächsrunde am AKH Wien statt. In einer kleinen Gruppe von ca. 8 Personen werden wir über die Probleme und Herausforderungen einer Arthrose im täglichen Leben diskutierten, sowie mögliche Lösungen, Anwendungen und Hilfsmittel vorstellen und uns darüber austauschen. Dabei stehen vor allem die Erfahrungen, Meinungen und Gedanken der Teilnehmer im Vordergrund.

- Für eine interessantere Gestaltung der Gesprächsrunde nehmen Sie bitte einen persönlichen Gegenstand aus Ihrem Alltag mit, welchen Sie mit der Arthrose in Verbindung bringen.

- Da wir im 2. Abschnitt nur 1 der 3 folgenden Termine letztendlich anbieten können, teilen Sie uns bitte mit, zu welchen Tagen Sie Zeit haben. Im besten Fall und zur Erleichterung der Organisation unsererseits geben Sie alle 3 Termine als möglich an.
    - Dienstag, 22. November ab 13:00 bis ca. 15:00
    - Freitag, 25. November ab 09:00 bis ca. 11:00
    - Montag, 28. November ab 13:00 bis ca. 15:00

- Nach entsprechend vielen Rückmeldungen benachrichtigen wir Sie über den genauen Termin, Ablauf, Raum und Lageplan am AKH.

Für weitere Fragen stehe ich Ihnen gerne unter dieser E-Mail-Adresse oder der Telefonnummer (0650/2482353) zur Verfügung.

PS: Bei der Transkription unseres Gesprächs erwähnten Sie am Ende Interesse an bestimmten Ernährungsformen bzw. Diäten im Bezug auf die Arthrose. Durch meine eigene Recherche im Rahmen der Studie hab ich folgendes Buch entdeckt https://www.amazon.de/DIE-DR-FEIL-STRATEGIE-Gelenkschmerzen/dp/3000401911/. Ich habe dazu weder Erfahrungswerte noch wissenschaftliche Evidenz, aber vielleicht ist das für Sie von Interesse.

Mit freundlichen Grüßen,
Kohlmayr Patrick

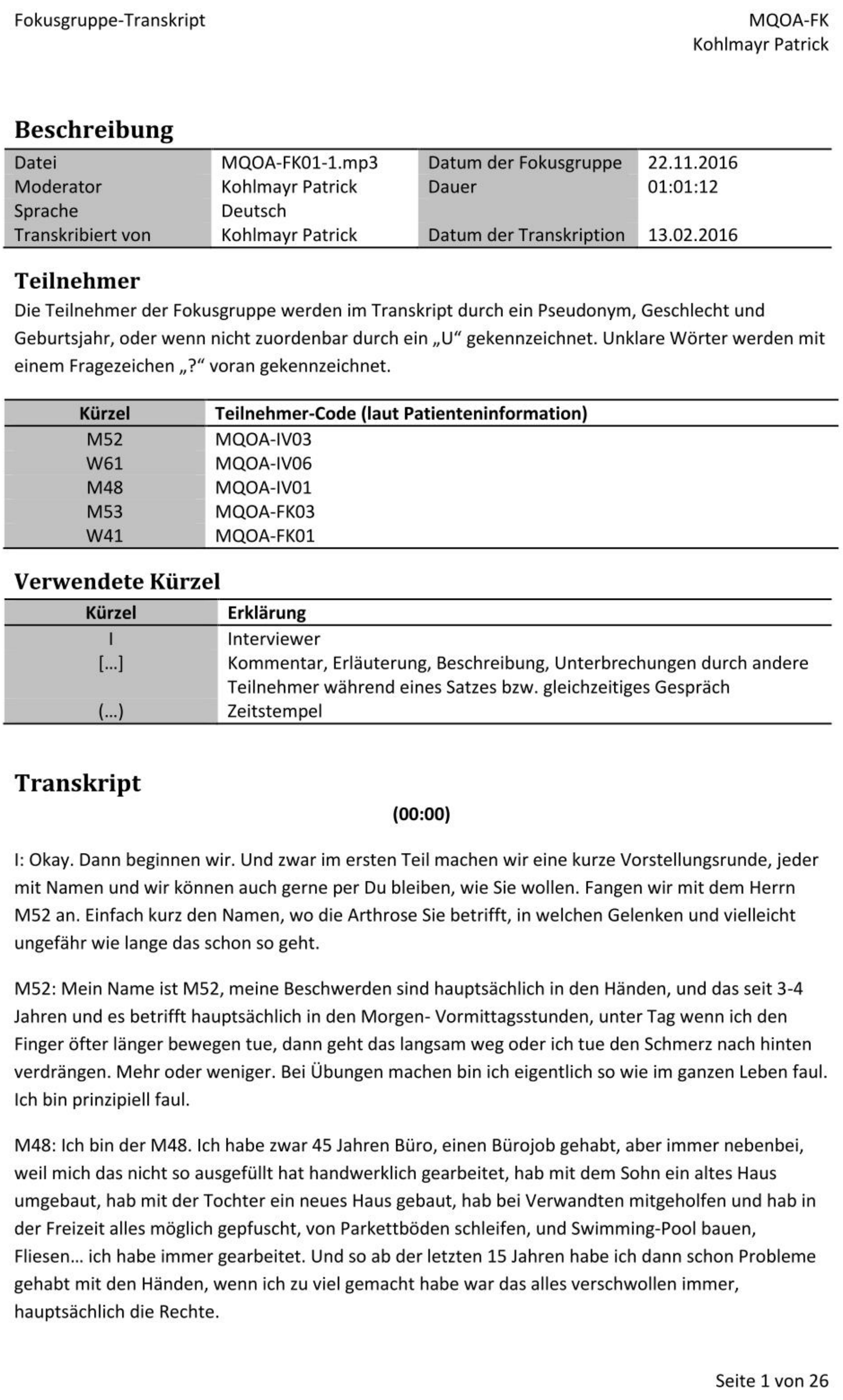
13.4.2 Focus group guide

- **Vor der Fokusgruppe**
  - Vorbereitung des Raumes (12:00 – 13:00)
    - Lage von WCs und Kaffeeautomaten feststellen, Raum lüften
    - Tische und Stühle vorbereiten: im Quadrat oder Kreis für 8 Personen, jeder soll den anderen sehen
    - Vorbereitung & Platzierung des Equipments: Audio-Recorder (Zentral), Kamera, Kulis, Schreibunterlagen, Guide
    - Notebook/Beamer starten und benötigtes Material öffnen, Bildschirmtest
    - Essen/Trinken vorbereiten: Auf einem separaten Tisch zur freien Entnahme
    - Patientenerklärungen vorbereiten (evtl. am Vortag bereits ausfüllen)
    - Guide/Checkliste/Fragen noch einmal durchgehen
  - **Begrüßung der Teilnehmer (12:50 – 13:10)**
    - An der Türe des Raumes, Vorstellung mit Namen und Händeschütteln
    - Auf Erfrischungen, Sitzplätze und Garderobe hinweisen
    - Aushändigung der vorausgefüllten Patienteninformation (Seeliger, Burg, Bernhard)
  - **Einleitung (13:10 – 13:20)**
    - „Herzlich Willkommen bei der Gesprächsrunde und Danke für Ihr Kommen. Mein Name ist Kohlmayr Patrick und ich werde heute durch die Gesprächsrunde führen. Im Rahmen der Arthrose-Forschung beschäftige ich mich damit, welche Probleme und Veränderungen eine Arthrose ins Leben und in den Alltag mitbringt, wie man damit umgeht, und welche Lösungen und Möglichkeiten es gibt das Leben zu erleichtern. Jeder von Ihnen hat seine persönlichen Erfahrungen im Laufe der Jahre mit der eigenen Arthrose gemacht, und diese Erfahrungen, Erlebnisse, Meinungen und Gedanken interessieren uns. Ihr Wissen bildet für uns die Grundlage zu sehen welche Probleme existieren, was dagegen getan wird, ob etwas gut oder schlecht funktioniert, und wo es noch offene Probleme gibt."
    - „Für die Gesprächsrunde ist folgendes zu beachten:"
      - „Handys bitte lautlos schalten, bei wichtigen Anrufen bitte vor die Tür gehen"
      - „Den anderen immer ausreden lassen, nicht durcheinander Reden, u.a. erleichtert und das die Auswertung der Aufnahme"
      - „Wenn Sie zu bestimmtes Themen und Dingen etwas anmerken oder Ihre Ansicht oder Erfahrung mitteilen wollen, erzählen Sie uns davon und bringen Sie sich ein"
      - „Ziel ist es, dass Sie sich untereinander über ihre Erfahrungen, Erlebnisse und Meinungen austauchen"
      - „Wichtig ist immer beim Thema bleiben"
      - „Es gibt keine falschen Antworten, jeder hat seine eigenen persönlichen Erfahrungen gesammelt und sich eigene Gedanken über die Jahre gemacht."
      - „Ich bin heute nur der Moderator, ich führe durch die Themen, schaue das wir uns nicht zu weit davon weg bewegen und stelle auch nachfragen."
    - Ablauf der Gesprächsrunde
      - 2 Abschnitte für ca. 45min und dazwischen 5-10min Pause
      - „Im ersten Teil haben wir eine kurze Vorstellungsrunde und besprechen die Probleme und Herausforderungen, die Sie durch die Arthrose in Ihrem Alltag und Tätigkeiten erfahren haben."

        - „Im zweiten Teil geht es um die Möglichkeiten mit den auftretenden Problemen umzugehen, dazu gehören Aufklärung & Information, Vorbeugung, Hilfsmittel und Umstellungen im Leben und andere Strategien."
    - Die Gesprächsrunde wird per Diktiergerät für eine spätere Auswertung aufgenommen
    - „Gibt es von Ihrer Seite aus noch Fragen?"
    - „Okay dann starte ich die Aufnahme und beginne mit dem ersten Thema."
- **Während der Fokusgruppe**
  - Fragen und Themen
    - 1. Teil
    - Vorstellungsrunde: „Zu Beginn machen wir eine kurze Vorstellungsrunde. Stellen Sie sich mit Namen vor und zeigen Sie uns welche Hand- und Finger-Gelenke die Arthrose betrifft."
    - Generelle Probleme der Arthrose (20-25min)
      - „Kommen wir zum ersten Thema. Wir beginnen allgemein mit der Frage, welche Auswirkungen hat die Arthrose auf Ihr Leben. Schreiben Sie dazu bitte 2-3 Punkte, Auswirkungen als Stichworte auf Ihren Zettel, ich gebe Ihnen Zeit."
      - „Fangen wir bei Ihnen an, was haben Sie als 1. Aufgeschrieben? Erzählen Sie uns warum Sie das hingeschrieben haben." „Wer kennt das noch?" „Erzählen Sie davon"
      - Zusammenfassung, Übersicht wie viele ein bestimmtes Problem haben „Lassen Sie mich zusammenfassen, wir hatten folgendes:" „Wie viele aus der Runde haben das Problem, bitte ein kurzes Handzeichen" „Fehlt Ihnen noch etwas?"
    - Probleme in verschiedenen Tätigkeitsbereichen (ADLs) (20-25min)
      - „Kommen wir zum zweiten Thema. Nun geht es um bestimmte Tätigkeiten. Welche Ihrer Tätigkeiten auf Ihrem täglichen Leben fallen Ihnen durch die Arthrose schwerer?" „Schreiben Sie 3 Tätigkeiten auf, die Ihnen durch die Arthrose schwerer fallen."
      - (Verschiedene Szenarien ansprechen: Beim Schlafen/Liegen, im Badezimmer, Küche, Hausarbeit, Gartenarbeit, Schreiben, Verwendung von Gegenständen und Geräten, Öffnen, Halten, Heben von Dingen)
      - Zusammenfassung, Übersicht wie viele ein bestimmtes Problem haben „Lassen Sie mich zusammenfassen, wir hatten folgendes:" „Wie viele aus der Runde haben das Problem, bitte ein kurzes Handzeichen" „Fehlt Ihnen noch etwas?"
    - - Pause -
    - 2. Teil
    - Besprechung der mitgebrachten Gegenstände (10 min)
      - „So gehen wir durch die Runde, und erzählen Sie uns welchen Gegenstand Sie mitgebracht haben, warum, und wie Sie diesen verwenden." (Wenn kein Gegenstand: „Überlegen Sie sich welcher Gegenstand für Sie zu Hause in Bezug auf die Arthrose eine Rolle spielt.")
      - „Wer kennt diesen Gegenstand noch?" „Verwenden Sie auch (in dieser Art)?" „Was halten Sie davon?"
    - „Wie machen Sie sich das Leben mit der Arthrose einfacher, was tun Sie um sich zu helfen?" „Was halten Sie davon?" (25min)
      - Aufklärung & Information über die Arthrose und Möglichkeiten etwas dagegen zu tun
      - Vorbeugung und Anwendung von Übungen und Gymnastik
      - Verwendung von Hilfsmitteln

            - Hilfe durch Angehörige
            - Vermeidung bestimmter Tätigkeiten
            - Erholung (der Hände) herbeiführen, Therapien, Kur
        - Zusammenfassung der Hilfen
        - Präsentation verschiedener Hilfsmittel (10min)
            - Was denken Sie darüber? Was halten Sie davon?
        - Zusammenfassung
            - „Was war das wichtigste Thema für Sie, dass heute gesagt oder besprochen wurde?“
        - Ende
            - Gibt es von Ihrer Seite noch ein Thema, dass Sie gerne Ansprechen wollen?
    - **WICHTIG**
        - ENJOY and HAVE FUN!
        - Pausieren nach gestellten Fragen (5 Sekunden)
        - Zeit beachten, Diskussion unterstützen, Neue Teilnehmer einbauen
        - Bei Möglichkeit weiter/tiefer nachfragen, Spontane/interessante (Nach-)Fragen stellen
        - Bei bestimmten Problematiken nachfragen, wie viele betroffen sind (Handzeichen)
        - Nicht nach dem „Warum“ fragen, sondern „Wie“
        - Nachfragen „Wann hatten Sie zuletzt dieses Problem, können Sie die Situation beschreiben?“
        - Nach Erklärungen bzw. Beschreibungen fragen, „Können Sie mir darüber mehr erzählen?“
        - Kontrolle über das Gespräch behalten, Richtung korrigieren wenn nötig
        - Stille Teilnehmer ins Gespräch holen z.B. Blickkontakt, „Was sind Ihre Erfahrung damit?“, „Was denken Sie dazu?“
        - Körpersprache der Teilnehmer beobachten, Mehr Zuhören, Gespräche fördern
        - Bei verschiedenen Meinungen -> „Warum sehen Sie das anders“?
        - Unterbrechungen wenn jemand zu lange am Reden bleibt, Blickkontakt abwenden -> zu anderen schauen -> Unterbrechen „Ja, danke, kurze Wiederholung“, Zuwendung zu anderen -> „Hat jemand eine ähnliche Erfahrung damit?“
        - Gespräche zulassen
        - Richtung der Diskussion kontrollieren -> Einschreiten wenn zu Off-Topic
        - Verwendung von Zettel + Stift um eine Liste von 3 Dingen zu einem bestimmten Thema niederzuschreiben, evtl. größere Liste auf Flipchart erstellen, Diskussion starten
        - Handzeichen bei Umfragen wie viele ein bestimmtes Problem haben
- **Nach der Fokusgruppe**
    - Bedankung für die Teilnahme, Hinweise auf weitere Schritte: Auswertung, Arbeitsgruppe Ende Jänner
    - Jegliche Beobachtung während der Fokusgruppe aufschreiben

13.4.3 Transcript examples



Beschreibung

Datei	MQOA-FK01-1.mp3	Datum der Fokusgruppe	22.11.2016
Moderator	Kohlmayr Patrick	Dauer	01:01:12
Sprache	Deutsch		
Transkribiert von	Kohlmayr Patrick	Datum der Transkription	13.02.2016

Teilnehmer

Die Teilnehmer der Fokusgruppe werden im Transkript durch ein Pseudonym, Geschlecht und Geburtsjahr, oder wenn nicht zuordenbar durch ein „U“ gekennzeichnet. Unklare Wörter werden mit einem Fragezeichen „?“ voran gekennzeichnet.

Kürzel	Teilnehmer-Code (laut Patienteninformation)
M52	MQOA-IV03
W61	MQOA-IV06
M48	MQOA-IV01
M53	MQOA-FK03
W41	MQOA-FK01

Verwendete Kürzel

Kürzel	Erklärung
I	Interviewer
[…]	Kommentar, Erläuterung, Beschreibung, Unterbrechungen durch andere Teilnehmer während eines Satzes bzw. gleichzeitiges Gespräch
(…)	Zeitstempel

Transkript

(00:00)

I: Okay. Dann beginnen wir. Und zwar im ersten Teil machen wir eine kurze Vorstellungsrunde, jeder mit Namen und wir können auch gerne per Du bleiben, wie Sie wollen. Fangen wir mit dem Herrn M52 an. Einfach kurz den Namen, wo die Arthrose Sie betrifft, in welchen Gelenken und vielleicht ungefähr wie lange das schon so geht.

M52: Mein Name ist M52, meine Beschwerden sind hauptsächlich in den Händen, und das seit 3-4 Jahren und es betrifft hauptsächlich in den Morgen- Vormittagsstunden, unter Tag wenn ich den Finger öfter länger bewegen tue, dann geht das langsam weg oder ich tue den Schmerz nach hinten verdrängen. Mehr oder weniger. Bei Übungen machen bin ich eigentlich so wie im ganzen Leben faul. Ich bin prinzipiell faul.

M48: Ich bin der M48. Ich habe zwar 45 Jahren Büro, einen Bürojob gehabt, aber immer nebenbei, weil mich das nicht so ausgefüllt hat handwerklich gearbeitet, hab mit dem Sohn ein altes Haus umgebaut, hab mit der Tochter ein neues Haus gebaut, hab bei Verwandten mitgeholfen und hab in der Freizeit alles möglich gepfuscht, von Parkettböden schleifen, und Swimming-Pool bauen, Fliesen… ich habe immer gearbeitet. Und so ab der letzten 15 Jahren habe ich dann schon Probleme gehabt mit den Händen, wenn ich zu viel gemacht habe war das alles verschwollen immer, hauptsächlich die Rechte.

M53: Immer wieder kommen entweder so kleine Schübe, dann habe ich immer Angst – wird es jetzt noch schlechter bei so einem Schub. Oder wenn nicht, dann schmerzt es einfach und man massiert – was man eigentlich nicht machen sollte, aber man tut es dann doch weil… [es angenehmer wird]

(20:56)

M52: Also ich mache dann beim Fernsehen, mache ich nur so, nur so mit den Händen, so [zeigt Wischen der Finger mit der anderen Hand]. Es ist vielleicht die Wärme.

W61: Ja, das sollte man nicht tun.

W41: Mir ist auch gesagt worden, die Wärme kommt durch das Massieren der Finger ist schon sehr gut. Das kann man auch so zwischendurch machen.

M52: Oder ich nehme mir das [holt einen Knetball hervor] und mache dann so.

M53: Mir hat man gesagt genau diese Klumpfe und Dinge sollte man eigentlich nicht massieren. Sondern…

W61: Überhaupt, man sollte es überhaupt nicht stärker angreifen. Man soll wenn nur… man soll es nicht drücken, man soll es nicht quetschen.

M53: Ja so habe ich es auch gehört.

W61: Es ist auch bei mir so, ich spüre es irrsinnig stark, wenn mir ein Mann die Hand gibt, der einen festeren Griff hat…

W41: Das ist, da kann man aufsteigen.

W61: …das habe ich früher nicht gespürt. Und das spüre ich jetzt in den letzten, sicher 2 Jahren, extrem.

M53: Ja, da bin ich an der Decke. Ja sicher, ich schrei dann sogar manchmal.

W61: Und ich arbeite in einem Beruf, wo ich täglich mit – zu tun habe mit Vätern – ich arbeite im Kindergarten, also da gibst du öfters die Hand einen Mann, und da habe ich oft kräftige Männer dabei, also wo ich oft sage bitte nicht so stark, weil naja dann…

M52: Ist es schon zu spät.

W61: Ja, weil sonst ist es zu spät. Aber es ist wirklich extrem [M53: Bejaht].

M52: Also ein Wort noch, diese von Smolen oder anderen empfohlenen, er hat immer gesagt: ja manchen hat es geholfen, bis zu allen möglichen Aufbautabletten…

W41: Condrosulf?

W61: Das hat er mir auch gesagt.

M53: Ja, was es da alles gibt. Und das kann man über 2-3 Monate nehmen, was für mich schon wieder die Hölle ist, aber ich habe das dann vielleicht ein Monat durchgehalten, aber keinerlei Veränderung.

(18:02)

M53: Das sagt diese ganze asiatische Philosophie. Und die Wissenschaft übrigens auch, die asiatische Wissenschaft. Und das Dinge miteinander verbunden gehören, das wir sehr oft diese Dinge trennen. Und diese Übungen, zum Beispiel auch im Tai Chi, gehen alle über die Diagonale, gehen also alle in den Versuch diese verschiedenen Chis, also Yang und… [W41: Zu beleben] zu verbinden vor allen Dingen auch. Zu beleben und zu verbinden, ja, und das ist die ganze Theorie. Und ich glaube da ja auch ein bisschen daran, aber ich bin nur zu faul, aber… mir fehlt nicht der Glaube.

W41: Ja das stimmt schon, es gibt schon erstaunliche Sachen.

M52: Ja, das ist es ja [das Problem des faul seins].

W61: Aber wenn ich daran glaube, dann dürfte ich nicht zu faul sein. Weil ich glaube jetzt daran an den Topfen. Und ich werde das machen heute, und dann bin ich nicht zu faul [M53: Ja, ja, dann ist es ja gut], weil ich möchte das versuchen, ich will mir helfen. Und das ist, wissen Sie was das auch ist – Ehrgeiz, man braucht Ehrgeiz bei unserer Krankheit. Und wenn ich den Ehrgeiz nicht habe, dass ich meine Übungen mache, dann war diese Studie, die Erste, schon einmal umsonst für mich, dann hätte ich mich an der Zweiten gar nicht mehr anschließen brauchen.

W41: Also für mich war das ein Trumpf, diese vielen [neuen Informationen aus der ersten Studie]. Mir hat jeder Arzt gesagt, nein das kriegen sie nicht mehr [in Ordnung]. Und bei mir war der [Finger] so, dass also jeder Handschuh, ich konnte den schon nicht mehr richtig [anziehen].

W61: Und bei mir ist jetzt Ehrgeiz da, dass ich meinen [krummen Finger] auch hinbringe. Und das was ich mir heute erhofft habe, eben bei diesem Gespräch, war eben das Austauschen, was macht der Patient…

M48: Wie geht jeder um damit.

W61: Ja, genau. Und das war die Hoffnung, dass ich erfahre, was macht der, was macht – das hat mir eben der Patrick, mit dem ersten Gespräch diese Hoffnung gegeben, und da war ich jetzt erfreut, und ich bin jetzt bestätigt worden.

W41: Also wenn man einen guten Physiotherapeuten hätte, also wir fahren ein bis maximal zwei Mal nach Monte Grotto, und das ist ein Hotel wo auch immer die Skimannschaft war zur Rehab und so. Da gibt es eine Physiotherapeutin, die so irre gut ist, die eine Massage der Wirbelsäule, das heißt nach Preuss ist das Eine und das Andere… Also das ist fantastisch, also da werden sie 50 Minuten bearbeitet, sie sind nachher ein Stückchen größer, sie sind komplett schmerzfrei, also ich hab schon solche… ich hab mit 35 eine Wirbelsäule gehabt, wo nach dem Röntgenbild… also bitte, jedes halbe Jahr Physiotherapie und sie werden überhaupt keinen Sport betreiben und was weiß ich. Ich habe alles weitergemacht, Tennis gespielt wie eine verrückte, Skigefahren wie eine verrückte, und das ist alles gegangen… (*)

I: Dazu eine Frage. Bei so Kuren, Therapien einen richtigen Ergotherapeuten zu finden, der speziell für die Hände das macht, wie finden Sie so etwas?

W46: Gibt es so etwas wirklich?

M53: Ich weiß nicht, dass es so etwas gibt.

13.4.4 Coding examples (export from MAXQDA)

14

Auswirkungen auf den Alltag

Einschränkungen

Zeitaufwendig morgens die Hände in Gang zu bringe

1.

Und ich damit mehr Zeit aufbringen muss, alleine schon morgens, ich muss schon mal mindestens eine viertel Stunde früher aufstehen, ich stehe wenn ich Frühdienst habe auf zwischen dreiviertel 5 und 5, steh um halb 5 auf, damit ich meine Finger in Gang bringe, meine Hände, dass sie in die Gänge kommen, muss ich noch früher aufstehen, und das ist das was mich sehr, sehr beschäftigt und sehr…

[Transskript_MQOA-FK01-1; Position: 314-314]

2.

W61: Nein ich muss sagen, ich bin zufrieden mit meine Übungen, [M53: Das ist auch die Hauptsache], wenn ich es täglich mache, dann bin ich… [M53: Und aktiv sein ist überhaupt das Beste, was man selber tut], es ist einfach, ja, ich muss halt zeitiger aufstehen in der Früh

[Transskript_MQOA-FK01-2; Position: 461-461]

Höhere Zeitaufwand für Hände nervt

1.

ich muss schon mal mindestens eine viertel Stunde früher aufstehen, ich stehe wenn ich Frühdienst habe auf zwischen dreiviertel 5 und 5, steh um halb 5 auf, damit ich meine Finger in Gang bringe, meine Hände, dass sie in die Gänge kommen, muss ich noch früher aufstehen, und das ist das was mich sehr, sehr beschäftigt und sehr…

(44:42)

M41: Nervt?

W61: Nervt.

[Transskript_MQOA-FK01-1; Position: 314-317]

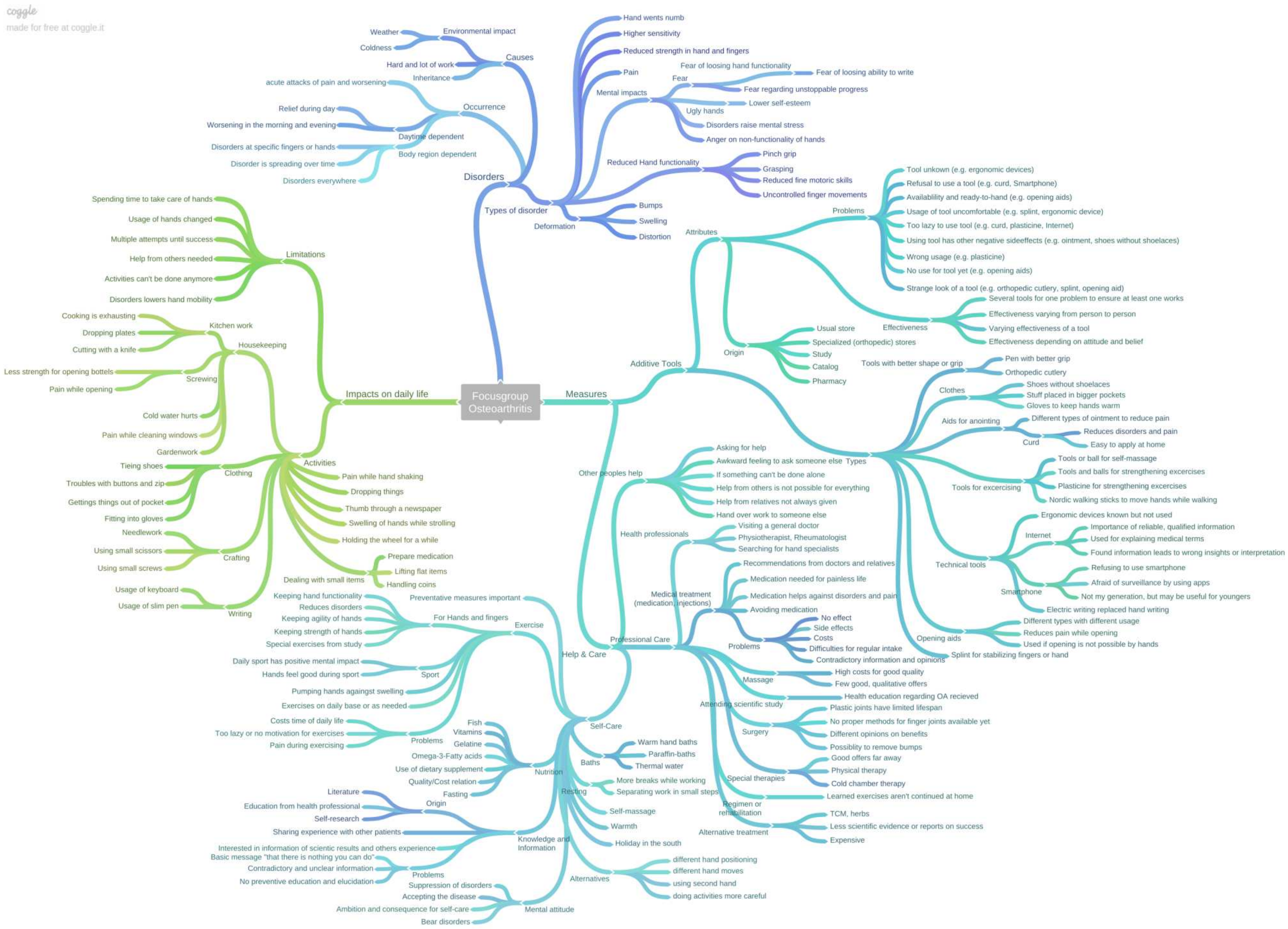
Schmerzen mindern Bewegungsfreiheit

1.

Aber man hat natürlich die Schmerzen nicht gern und bewegt sich auch gern

[Transskript_MQOA-FK01-1; Position: 258-258]

13.4.5 Mind map of emerged themes



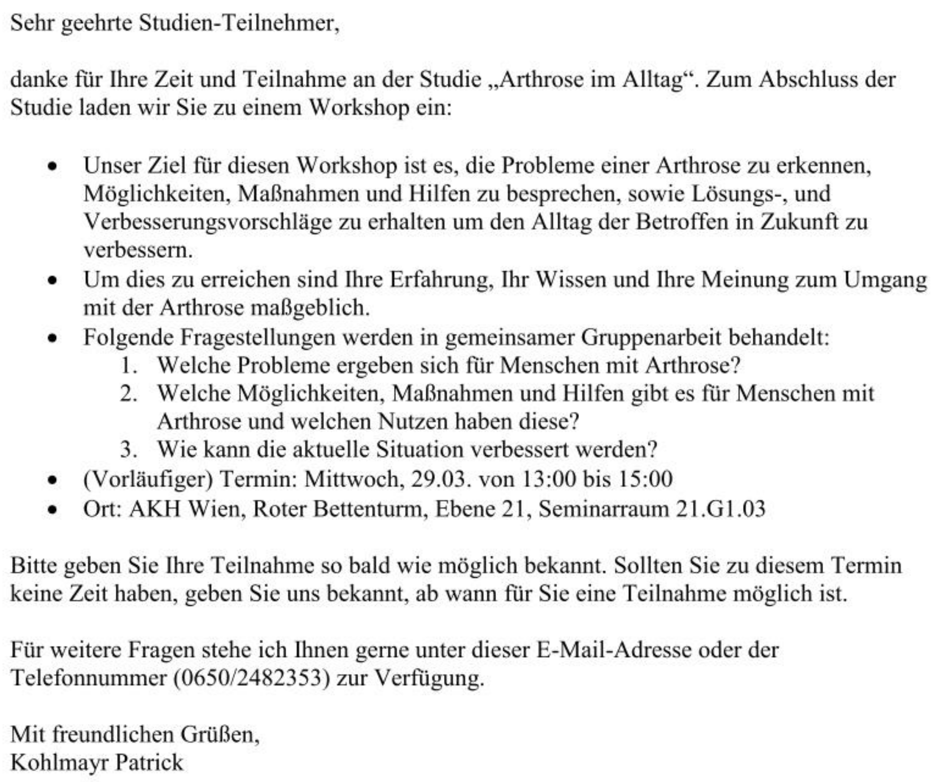
13.4.6 Reflection notes

Lessons learned were write-down action can help to start discussion – but shouldn’t be used a second time on a close related topic, let discussion grow but keep in control where the discussion goes – the later the intervention the harder it is to get people back to the original question, how to softly interrupt discussion and direct them back to the main question, directing questions to specific persons – e.g. when opening a new theme – is better than asking all at once, not all topics covered in appropriate time – planned first half of the session exceeded to second half – therefore topics of the second half were shortened, avoid own opinions e.g. if participants ask specific questions and direct them into the round, proper time check to keep in schedule – session extended regular plan about 20 minutes, brought-in objects were not discussed as planned in the schedule – a participant just started a discussion out of it, not every topic was covered in the same detail – but maybe there was not more to get, and forgot to take photographs of the brought-in objects. To good points I take out of this sessions were a well-prepared room (aligning tables and chairs, provide drinks and cookies), good introduction so that everyone was focused on the topic, letting discussion grow and have patience during it, setting new topics to discuss and using write-down actions.

A further issue appeared was related to discussion culture, manifesting as simultaneously speaking participants, parallel discussions, mutual interruption of participants, and participants that tried to drive the group conversation per repetitive interrupting or taking a lead opinion and don’t want to hear others.

13.5 WORKSHOP

13.5.1 Workshop invitation



Sehr geehrte Studien-Teilnehmer,

danke für Ihre Zeit und Teilnahme an der Studie „Arthrose im Alltag“. Zum Abschluss der Studie laden wir Sie zu einem Workshop ein:

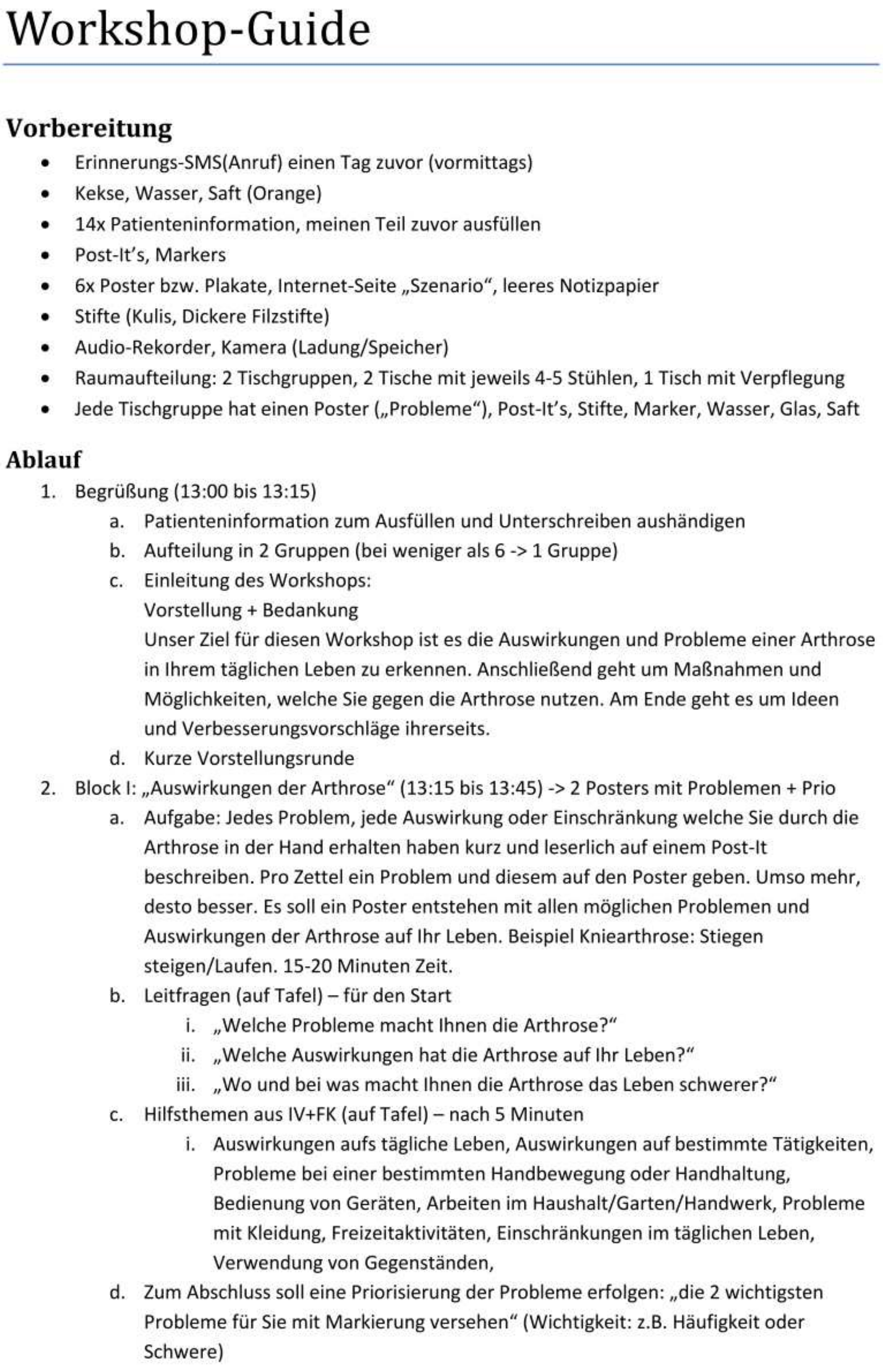
- Unser Ziel für diesen Workshop ist es, die Probleme einer Arthrose zu erkennen, Möglichkeiten, Maßnahmen und Hilfen zu besprechen, sowie Lösungs-, und Verbesserungsvorschläge zu erhalten um den Alltag der Betroffen in Zukunft zu verbessern.
- Um dies zu erreichen sind Ihre Erfahrung, Ihr Wissen und Ihre Meinung zum Umgang mit der Arthrose maßgeblich.
- Folgende Fragestellungen werden in gemeinsamer Gruppenarbeit behandelt:
  1. Welche Probleme ergeben sich für Menschen mit Arthrose?
  2. Welche Möglichkeiten, Maßnahmen und Hilfen gibt es für Menschen mit Arthrose und welchen Nutzen haben diese?
  3. Wie kann die aktuelle Situation verbessert werden?
- (Vorläufiger) Termin: Mittwoch, 29.03. von 13:00 bis 15:00
- Ort: AKH Wien, Roter Bettenturm, Ebene 21, Seminarraum 21.G1.03

Bitte geben Sie Ihre Teilnahme so bald wie möglich bekannt. Sollten Sie zu diesem Termin keine Zeit haben, geben Sie uns bekannt, ab wann für Sie eine Teilnahme möglich ist.

Für weitere Fragen stehe ich Ihnen gerne unter dieser E-Mail-Adresse oder der Telefonnummer (0650/2482353) zur Verfügung.

Mit freundlichen Grüßen,
Kohlmayr Patrick

13.5.2 Workshop guide



Workshop-Guide

Vorbereitung

- Erinnerungs-SMS(Anruf) einen Tag zuvor (vormittags)
- Kekse, Wasser, Saft (Orange)
- 14x Patienteninformation, meinen Teil zuvor ausfüllen
- Post-It's, Markers
- 6x Poster bzw. Plakate, Internet-Seite „Szenario", leeres Notizpapier
- Stifte (Kulis, Dickere Filzstifte)
- Audio-Rekorder, Kamera (Ladung/Speicher)
- Raumaufteilung: 2 Tischgruppen, 2 Tische mit jeweils 4-5 Stühlen, 1 Tisch mit Verpflegung
- Jede Tischgruppe hat einen Poster („Probleme"), Post-It's, Stifte, Marker, Wasser, Glas, Saft

Ablauf

1. Begrüßung (13:00 bis 13:15)
    a. Patienteninformation zum Ausfüllen und Unterschreiben aushändigen
    b. Aufteilung in 2 Gruppen (bei weniger als 6 -> 1 Gruppe)
    c. Einleitung des Workshops:
    Vorstellung + Bedankung
    Unser Ziel für diesen Workshop ist es die Auswirkungen und Probleme einer Arthrose in Ihrem täglichen Leben zu erkennen. Anschließend geht um Maßnahmen und Möglichkeiten, welche Sie gegen die Arthrose nutzen. Am Ende geht es um Ideen und Verbesserungsvorschläge ihrerseits.
    d. Kurze Vorstellungsrunde
2. Block I: „Auswirkungen der Arthrose" (13:15 bis 13:45) -> 2 Posters mit Problemen + Prio
    a. Aufgabe: Jedes Problem, jede Auswirkung oder Einschränkung welche Sie durch die Arthrose in der Hand erhalten haben kurz und leserlich auf einem Post-It beschreiben. Pro Zettel ein Problem und diesem auf den Poster geben. Umso mehr, desto besser. Es soll ein Poster entstehen mit allen möglichen Problemen und Auswirkungen der Arthrose auf Ihr Leben. Beispiel Kniearthrose: Stiegen steigen/Laufen. 15-20 Minuten Zeit.
    b. Leitfragen (auf Tafel) – für den Start
        i. „Welche Probleme macht Ihnen die Arthrose?"
        ii. „Welche Auswirkungen hat die Arthrose auf Ihr Leben?"
        iii. „Wo und bei was macht Ihnen die Arthrose das Leben schwerer?"
    c. Hilfsthemen aus IV+FK (auf Tafel) – nach 5 Minuten
        i. Auswirkungen aufs tägliche Leben, Auswirkungen auf bestimmte Tätigkeiten, Probleme bei einer bestimmten Handbewegung oder Handhaltung, Bedienung von Geräten, Arbeiten im Haushalt/Garten/Handwerk, Probleme mit Kleidung, Freizeitaktivitäten, Einschränkungen im täglichen Leben, Verwendung von Gegenständen,
    d. Zum Abschluss soll eine Priorisierung der Probleme erfolgen: „die 2 wichtigsten Probleme für Sie mit Markierung versehen" (Wichtigkeit: z.B. Häufigkeit oder Schwere)

3. Pause 5 (13:45 bis 13:50): Evtl. längere Pausen
4. Block II „Maßnahmen gegen die Arthrose“ (13:50 bis 14:20)
    a. Aufgabe (15-20 Minuten): Jede Maßnahme, Möglichkeit oder Hilfe die Sie wegen der Arthrose verwendet oder probiert haben, schreiben Sie nun leserlich, kurz auf einen Zettel, und kommt auf das Poster wie zuvor. Dabei spielt es noch keine Rolle ob es hilfreich oder nicht hilfreich war. Umso mehr, umso besser. Beispiel Kniearthrose: „Gehstock oder Krücke“
    b. Leitfragen (auf Tafel)
        i. „Was haben Sie gegen die Probleme der Arthrose versucht, verwendet oder probiert“
        ii. „Wie und mit was haben Sie sich das Leben mit der Arthrose erleichtert“
    c. Hilfsthemen aus IV+FK (auf Tafel) – nach 5 Minuten
        i. Selbst-Hilfe, Hilfsmittel, Hausmittel, Umstellungen, Tätigkeiten/Dinge die Sie vermeiden, Änderung der Handhaltung, Ernährung, Wie und wo haben Sie sich über die Krankheit informiert, Hilfe von anderen, Bewegung/Sport, andere Gegenstände/Geräte mit denen Sie sich leichter tun, Änderung Ihres Verhaltens (wie Sie Dinge tun)
    d. Zum Abschluss gehen Sie nochmals alle Zettel durch, und markieren Sie hilfreiche Maßnahmen mit Blau/Gelb, und nicht hilfreiche Maßnahmen mit rot.
    e. Diskussion rot-markierter, problematischer Maßnahmen (Notieren auf Tafel/Audio)
        i. „Warum waren diese Hilfsmittel nicht hilfreich?“
        ii. „Was sind die Probleme dieser Maßnahmen?“
5. Pause 5 (14:20 bis 14:25): Evtl. längere Pausen
6. Block III „Verbesserungsvorschläge + Szenarios“ (14:30 bis Ende)
    a. Diskussion: Notieren auf Tafel + Audio-Rekorder
    b. Szenario 1: Wie kann man die Welt für Menschen mit Arthrose einfacher gestalten?
        i. Ideen und Verbesserungsvorschläge
    c. Szenario 2: Internet-Seite
        i. Internet-Seite: „Welche Information wollen Sie auf einer Arthrose-Seite finden?“
        ii. Stellen Sie sich vor, Sie suchen im Internet nach Arthrose, Klicken auf die erste Seite, www.arthrose.at, welche Informationen wollen Sie dort sehen? Alle Ideen für eine solche Seite bitte hier niederschreiben. Bitte leserlich schreiben.
    d. Allgemeine Diskussion zu Ideen und Verbesserungsvorschlägen
        i. „Welche Ideen oder Verbesserungsvorschläge haben Sie“?
7. Verabschiedung + Bedankung
    a. Patienteninformationen einsammeln
    b. Bedanken

13.5.3 Session room

13.5.4 Created posters

13.5.5 Reflection notes

Lessons learned of this session were: don’t make a workshop format too complicated so that is easy to understand what they have to do and what the goal is, give simple explanation why we are doing this, preparation of a slide-show to guide through the sessions and to support leading topics with focus areas, e.g. with pictures, is better than only reading those helping areas aloud, good to have a big heading for describing the main focus of the session e.g. “Hand osteoarthritis” to avoid wrong and misleading expectations, during participants are working on their behalf visit, help and guide them towards the aim of their task, don’t give bad metaphors – e.g. with knee osteoarthritis – that mislead participants to other topics, better/special preparation on how to facilitate, encourage creativity with the elderly, keep control of discussion directions. Compared with the focus group the whole session was in time and uncontrolled discussions were detected and avoided early.

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