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Data-driven Patient Profiles

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Tessa Dekkers

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Definition, validation, and implementation for tailored orthopaedic healthcare services

Dissertation

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by

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CONTENTS

PREFACE

In 2012 Delft University of Technology struck a partnership with the local hospital Reinier de Graaf hospital and medical device company Zimmer Biomet to optimize the experience journey of patients undergoing total hip replacement surgery. They would do so primarily through individualization, hence the name of the new consortium: Highly individualized Patient Projects (HiPP). As the double entendre acronym suggests, the efforts of the HiPP consortium were concentrated around the cure of and care for patients with hip joint disorders.

The present thesis is a direct result of the HiPP consortium, which was extended in 2015 to include Dutch design agencies Panton and VanBerlo. As such, it shares a similar focus on orthopaedic patients who undergo joint replacement surgery and orthopaedic health consumers who have untreated joint complaints. As a case study, joint replacement surgery holds interesting characteristics that differentiate it from other illnesses and treatments: it is very common and has a highly standardized, relatively predictable patient journey. It is neither acutely life threatening, nor a chronic condition that requires major lifestyle change. It is also an elective procedure, meaning that the surgery and healthcare services around the surgery can be planned (some would say designed) in advance. As you will see in the introduction of this thesis, these characteristics allow for optimization of the process through personalization and enabled me to frame joint replacement surgery in the larger ongoing shift in medicine to healthcare consumerism. Still, readers outside the orthopaedic discipline should keep this particular focus in mind while interpreting the research.

Besides the focus on orthopaedic surgery, which may make the studies presented of interest to orthopaedic surgeons, nurses, physiotherapists, and other allied health professionals, the audience of this thesis is thought of to include creative professionals with interest in designing tailored medical products, services, or product-service systems. In may also be of interest for researchers who, like myself, identify with the label 'interdisciplinary' and wonder what happens when you combine medicine, psychology, design science and computer science in one big pot. Thank you for reading.

Tessa Dekkers, Delft, August 2019

INTRODUCTION

Fuelled by societal and technological change, the healthcare system has shifted considerably over the past decades. To illustrate, take a moment to imagine that you have a persistent pain in your hip. In the 1960s, you would have presented your complaints to a physician, who may have prescribed *low friction arthroplasty,* a surgery to replace your painful arthritic hip joint (Knight, Aujla, & Biswas, 2011). Likely, you would not have been informed about this treatment plan, since the healthcare system was authoritative and held the implicit expectation that patients would naturally comply to the physician's treatment decisions (Hoving, Visser, Mullen, & van den Borne, 2010). After several weeks of hospitalization the success of your surgery would be evaluated by mortality rates and the incidence of mechanical and technical failures (Burton & Imrie, 1973; Eftekhar, Kiernan, & Stinchfield, 1976).

The role of the surgeon as decision maker, the lack of patient education, and the technical evaluation of surgery all demonstrate a healthcare system centred primarily on the norms and values of the medical profession. In reaction to this medico-centric perspective the patient rights movement emerged in the decades that followed, which advocated greater patient autonomy, choice, and involvement in healthcare (Hoving et al., 2010). Now, firmly in the twenty-first century, patient-centeredness, patient activation, and patient empowerment have become key priorities for healthcare services (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016; Fumagalli, Radaelli, Lettieri, Bertele', & Masella, 2015; Gruman et al., 2010; Hoving et al., 2010).

The modern day equivalent of low friction arthroplasty, *total hip replacement* (THR) surgery, has evolved into one of the most common and clinically successful surgical procedures today (Knight et al., 2011; Learmonth, Young, & Rorabeck, 2007). Should you consider THR surgery nowadays, you likely look for online information about your complaints (Baker et al., 2010; Fraval, Chong, Holcdorf, Plunkett, & Tran, 2012) before you meet an orthopaedic surgeon. For example, you may watch a YouTube video about a personal experience with joint surgery (2nd Try LLC, 2019), contact your health insurer for advice (Victoor, Potappel, & de Jong, 2019), or compare the quality of nearby hospitals on websites such as kiesbeter.nl[1] or zorgkaartnederland.nl (van de Berg et al., 2016). Ideally, the treatment decision will be taken jointly by the healthcare professional and the patient and is supported by the use of one of the many decision aid tools available (Slover, Shue, & Koenig, 2012). After the surgery, chances are that you are discharged on the same day, as THR is now increasingly offered as a fast-track out-patient treatment[2] (M. S. Ibrahim,

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[1] Kiesbeter.nl (*Choose Better*) and zorgkaartnederland.nl (*Care Map Netherlands)* are public websites managed by the Dutch government and the Patient Federation NPCF respectively to help consumers choose healthcare providers.

[2] This is a significant reduction compared to the several weeks of hospitalization following low friction arthroplasty which was already considered an extremely short rehabilitation period at the time (Burton & Imrie, 1973)

Twaij, Giebaly, Nizam, & Haddad, 2013; Mathijssen, Verburg, van Leeuwen, Molenaar, & Hannink, 2016; Specht, Kjaersgaard-Andersen, Kehlet, Wedderkopp, & Pedersen, 2015). To build strength and monitor your own process as you recover, you may make use of a telemonitored rehabilitation system (Nelson, Bourke, Crossley, & Russell, 2017; Nelson, Crossley, Bourke, & Russell, 2017).

Of course, the innovations described above are not yet available at all clinics, for all patients, at all times[3]. Still, the immense changes in how patients, healthcare providers, and technology interact have led to new ideas regarding the qualities a healthcare system should deliver. Hospital care is no longer solely evaluated on medical and technical performance alone, but also on the way that technical care is implemented through interpersonal processes (Donabedian, 1988). Part of this is that the patient is recognized not just as a passive recipient of care, but as an active consumer who makes use of the healthcare system to treat conditions, prevent disease, promote health and manage chronic illness[4]. This is further reflected in the growing importance of the *patient experience*, defined as 'the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care' (The Beryl Institute, 2016).

An excellent patient experience means that healthcare services are integrated (e.g. aligned and coordinated across healthcare services), recognize patients foremost as human beings, and seek collaborative partnerships with patients and family (Wolf, Niederhauser, Marshburn, & LaVela, 2014). In the United States, the quality of the experience that hospitals offer impacts hospitals' profitability directly, due to purchasing incentives and penalties as well as indirectly through hospital reputation and customer choice (Betts, Balan-Cohen, Shukla, & Kumar, 2016; Hibbard, Stockard, & Tusler, 2005; Richter & Muhlestein, 2017; Victoor, Delnoij, Friele, & Rademakers, 2012). Yet, there is also an important clinical interest to improve patient experience, as better experiences are associated with higher overall quality of care, including improved safety, person-centeredness, and clinical effectiveness (Anhang Price et al., 2014; Black, Varaganum, & Hutchings, 2014; Browne, Roseman, Shaller, & Edgman-Levitan, 2010; Doyle, Lennox, & Bell, 2013).

Examining the patient experience in THR, total knee replacement (TKR), and total joint replacement (TJR) surgery paints a sobering picture. Despite excellent mechanical, technological, and surgical performance, 1 in 5 patients is not satisfied after TJR surgery

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[3] Many studies, particularly those from the United States setting, note racial and economic disparities in the healthcare services and outcomes after TJR surgery. See for example (Freburger et al., 2011; S. A. Ibrahim, 2007; Ottenbacher et al., 2003).

[4] This definition is an adaption of the American Medical Informatics Association, Consumer Health Informatics Working Groups, the International Medical Informatics Association, and the Nursing Informatics Interest Group who defined health consumers in the context of health information as "a person who seeks information about health promotion, disease prevention, treatment of specific conditions, and management of various health conditions and chronic illnesses." as mentioned in Lewis, Chang, and Friedman (2005, p. 1)

(Bourne, Chesworth, Davis, Mahomed, & Charron, 2010; Hamilton et al., 2013; Harris et al., 2013; Palazzo et al., 2014; Van Onsem et al., 2016). The reasons for dissatisfaction are diverse. It may be due to poor outcomes after surgery, such as functional limitations and persistent pain (Ali et al., 2014; Bourne et al., 2010; Gunaratne et al., 2017; Halawi et al., 2019). Dissatisfaction may also be due to patients' beliefs, their expectations of the outcome and whether these expectations have been fulfilled (Bourne et al., 2010; Culliton, Bryant, Overend, MacDonald, & Chesworth, 2012; Gunaratne et al., 2017; Halawi et al., 2019; Hamilton et al., 2013; Shirley & Sanders, 2013; Swarup, Henn, Gulotta, & Henn, 2018). Finally, there is mixed evidence (Gunaratne et al., 2017; Hamilton et al., 2013) that some non-modifiable patient factors are associated with dissatisfaction, such as female sex (Peres-da-Silva et al., 2017), higher socioeconomic status (Peres-da-Silva et al., 2017; Shirley & Sanders, 2013), younger age (Specht et al., 2015), and worse mental health (Ali et al., 2014; Anakwe, Jenkins, & Moran, 2011).

In all these reasons, the single consistent source of dissatisfaction is poor patient-provider communication (Bjertnaes, Sjetne, & Iversen, 2012; Halawi et al., 2019; Hamilton et al., 2013; Rademakers, Delnoij, & de Boer, 2011; Shirley & Sanders, 2013). When patients are asked for areas of improvement, communication and information provision are most frequently mentioned (Fielden, Scott, & Horne, 2003; Lane, Hamilton, MacDonald, Ellis, & Howie, 2016; Moore, Hamilton, Krusel, Moore, & Pierre-Louis, 2016). Particularly, patients want communication to better address their specific individual needs and preferences (Hamilton et al., 2013; van Kasteren, Freyne, & Hussain, 2018). For example, patients want to be able to choose through which channels and devices they receive information (van Kasteren et al., 2018) and have a say in the amount of information they receive (Groeneveld, Melles, Vehmeijer, Mathijssen, Dekkers, et al., 2019). These demands resonate with the larger shift towards patient-centeredness. However, are healthcare services ready to provide such *tailored healthcare*?

1.1 Standardized versus tailored healthcare

Before I debate tailored healthcare, I will discuss the current (and opposite) way through which care is provided: *standardized healthcare*. Standardization is formally defined as "the process of developing, agreeing upon and implementing uniform technical specifications, criteria, methods, processes, designs or practices that can increase compatibility, interoperability, safety, repeatability and quality" (Leotsakos et al., 2014, p. 111). Standardized healthcare, in turn, is an approach to care in which the methods, processes, and practices are uniform across patients, physicians, and care facilities. Standardized healthcare is the norm in Western medicine (Timmermans & Berg, 2003), including TJR surgery. Clinical practice guidelines are in place to formalize all TJR-related services from preoperative patient education to pain management, to outpatient follow-up and physiotherapy (Nederlandse Orthopaedische Vereniging, 2014, 2019). The production of standardized guidelines has not been in vain: standardization of care has resulted in better predictable and controllable outcomes, reductions of medical errors, and clearer responsibilities for clinical team members (Lehmann & Miller, 2004).

However, standardization is not without its downsides. In particular, physicians have expressed their concern that standardized care fails to incorporate individual patients' circumstances, needs, and preferences in care provision (McCartney, Treadwell, Maskrey, & Lehman, 2016). From these concerns, tailored healthcare emerged as a competing practice (Mannion & Exworthy, 2017). Tailored healthcare, which is also referred to as personalised, customized, or individualised healthcare, is an approach to care provision in which methods, processes, and practices vary across patients[5]. Central to tailored healthcare is the process of *tailoring*. Throughout this dissertation I adhere to a slightly modified version[6] of Kreuter, Strecher, and Glassman's (1999) definition of tailoring as "*a combination of services, intended for one specific person, based on characteristics that are unique to that person, related to the outcome of interest, and derived from individual assessment*". In contrast to standardization, tailored approaches to care do not aim to reduce variability, but explicitly acknowledge that variability between patients exists and try to adapt to this variability.

Before the advent of standardized care typical of the 20th century tailored healthcare was common practice. For example, care was adjusted to patients' *prakriti* in Ayurvedic medicine or to patients' *humour* in ancient Greece (Dance, 2016). Yet, tailored care was also largely ineffective due to a lack of understanding of the underlying disease biology. From a tailoring perspective, healthcare professionals lacked the instruments and insights needed to accurately *individually assess* differences between patients that were actually related to the *outcome of interest* (health). This deficiency remained until the first reference sequence of the human genome was produced in 2003 ("2003: Human Genome Project Completed", 2014). Because this resulted in tremendous advancements in genetic assessment as well as understanding of how genetic characteristics relate to outcomes, it became progressively more possible to provide healthcare services tailored to one's DNA (Burke et al., 2010; Ginsburg & Willard, 2009). Rapid developments in the fields of pharmacogenomics and personalised medicine followed.

Against the backdrop of the Human Genome Project, personalised medicine was defined as a clinical process where preventive, diagnostic, and treatment decisions are based on patients' biological and genetic makeup (Fierz, 2004). Recent work advocates

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[5] In this sense, tailored healthcare is closely related to person-centred care which is defined as "services which respect them [patients] as individuals and which are arranged around their needs" (Department of Health, 2001). However, I use the term tailored healthcare here to refer to care that is not only arranged around patient needs, but also takes into account patients' preferences and competences.

[6] The original definition reads "any combination of strategies and information intended to reach one specific person, based on characteristics that are unique to that person, related to the outcome of interest, and derived from an individual assessment." (Kreuter et al., 1999, p. 277). Because this definition was developed in the context of tailored print health communication, it more narrowly focusses on strategies and information and on reach. To reflect the broader intention of tailoring healthcare services for (existing) patients, I modified the definition.

to extent the principles of personalised medicine beyond ensuring therapeutic clinical appropriateness only (Dekkers & Hertroijs, 2018; Minvielle, Waelli, Sicotte, & Kimberly, 2014). Specifically, it is argued that in order to provide a truly tailored healthcare service, health care organizations should also take into account patients' psychological and social preferences, needs, and competences. In this way, care can be delivered that is not just clinically sound, but also organizationally, socially, and psychologically appropriate (Dekkers & Hertroijs, 2018; Minvielle et al., 2014).

To some extent, healthcare professionals already do so in medical practice. For example, medical specialists' often adjust the way they counsel and inform different patients. However, these intuitive approaches to tailoring are based on the specialists' perception, rather than on an explicit assessment of patients' preferences or needs (Dekkers, Melles, Mathijssen, Vehmeijer, & de Ridder, 2018; Douma, Koning, de Haes, et al., 2012; Elit et al., 2015). As such, these tailored approaches are highly dependent on the abilities of individual health professionals to pick up idiosyncratic preferences during short consultations. Overall, accurate insight in patients' preferences, needs, and competences is missing to systematically provide tailored care.

This thesis draws from the concepts of *mass customization* and *customer profiling* to provide insight in patients' preferences, needs, and competences. These concepts have originally been used to design tailored consumer products and services. In this thesis it is proposed that these concepts can be extended to the healthcare system through what I will refer to as *data-driven patient profiling*[7].

1.2 From mass customization to data-driven patient profiling

Mass customization (MC) emerged in manufacturing and service industries as a response to increasingly flexible production processes, increasing customer demands for customization, and expanding competition in segmented markets (Da Silveira, Borenstein, & Fogliatto, 2001) – drivers that are not unlike the ones the healthcare industry faces today. MC provides customized products and services, specifically through modularized product and service design and flexible manufacturing processes (Da Silveira et al., 2001; Fogliatto, Da Silveira, & Borenstein, 2012). A key feature of MC are product varieties or variants: adaptations of the standard product (or service, or product-service system) derived from the individual customer's needs (Tseng & Hu, 2014). These adaptations may range from simple to complex. For example, a simple adaptation of a running shoe could offer models with different levels of cushioning, dependent on the customer's need for comfort. An example of a complex adaption would be the NIKE BY YOU range offered

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[7] Upfront, I want to address the negative connotation of patient profiling in (especially) the North American context as a practice where patients are assumed to exhibit certain behaviours or illnesses (e.g. drug abuse) based on appearance, race, gender, or socioeconomic status (Wimble, 2014). This particular use of the term patient profiling originates as a harmful extension of *racial profiling*. Our use of profiling instead follows from the term *user profiling* (i.e. customer profiling, user modelling) as it is used in marketing, human computer interaction, and design science.

by Nike. Through their website, Nike invites customers to fully customize a running shoe by selecting their preferred colour for the tongue, laces, sole, etc. This offers customers countless possibilities to design a shoe that fits their preferences. Both of these examples describe product variants. In the case of the first running shoe, only one element is tailored (the sole) which may result in 3 or 4 different variants. In the case of the Nike shoe, several elements are tailored which may result in thousands possible variants. Yet, both also still include standardized design elements, for example the iconic Nike swoosh which customers cannot adjust in size or shape[8]. By delivering adapted products under one product family via a common platform, MC integrates tailoring to customer's needs with the efficiency of standardized mass production. This combination is also what makes MC affordable and manageable (Tseng & Hu, 2014) and thus interesting for health care services.

A prerequisite for mass customization is a thorough understanding of consumers' universal needs to develop the product family and of individual customer's unique preferences to design product variants (Tseng & Hu, 2014). A high degree of modularity more closely addresses customer's unique preferences at the expense of increased assembly and other costs. Therefore, commonality and modularity need to be balanced. A common way to achieve this balance is to segment consumers into several homogenous target groups with similar product or service interests. This process is known as customer profiling (Gunter & Furnham, 2015). After segmentation, individuals in each segment share a similar customer profile; e.g. similar demographic, psychological, behavioural, and/or geographical characteristics. The amount and nature of the profiles are used to design product variants. This allows designers to gradually introduce more variety in the product family without having to develop a completely new product for each individual customer.

I propose that industry's approach to mass customization can be extended to the healthcare through *data-driven patient profiling*. Data-driven patient profiles represent the common characteristics of a specific subgroup of patients that are unique compared to the overall patient population[9]. Profiles are data-driven because they are based on the analysis of data rather than intuition or personal experience (Provost & Fawcett, 2013). This also distinguishes patient profiles from personas, i.e. "hypothetical archetypes of actual users" (Cooper, 2004, p. 124). Personas are often used in the healthcare design sector as user representations, but have limited applicability due to poor generalizability, credibility, and the risk of imposing stereotypes (Chapman & Milham, 2006; Floyd, Cameron Jones, & Twidale, 2008; Massanari, 2010; Vincent & Blandford, 2014).

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[8] This was the case in August 2019. Customization options may have changed.

[9] We acknowledge that while certain characteristics may be common in a patient profile, a certain amount of heterogeneity within the subgroup will remain (Dekkers & Hertroijs, 2018). Simply put, just because individuals share a *similar* profile does not mean that they have exactly the *same* underlying characteristics.

In Dekkers & Hertroijs (2018, p. 1454) patient profiling is described as an approach which "uses the individual's preferences to tailor the content, context and delivery mode of care to improve care experience and health outcomes". Profiling is done in four steps: 1) identification of the target population (for example, people who undergo TJR surgery), (2) assessment of relevant characteristics of individuals in that population (for example, information and support preferences), (3) stratification of individuals into profiles based on the collected data, and (4) tailoring, by creating healthcare service variants appropriate for each profile. In theory, variants could be developed for services across the continuum of care. For example, there could be different variants of the preoperative patient education service (e.g. different health information packages written depending on health literacy), counselling services (e.g. referrals to additional psychological care depending on anxiety), and product-service systems (PSs) used during rehabilitation (e.g. level of human involvement during telemonitored rehabilitation depending on experience with technology).

Figure 1.1 shows an extended version of the patient profiling approach. The updated approach now describes two integrated processes: *profiling* and *designing*. Profiling has remained the same as described above and ends in a set of patient profiles. The set of patient profiles is then used in the *design* process. Designing consists of two steps, *identification* of standardized services suitable for tailoring, and *adjusting* these services on the basis of the patient profiles. This process ends in a set of variants of the service (or product, or product-service system) designed for each patient profile.

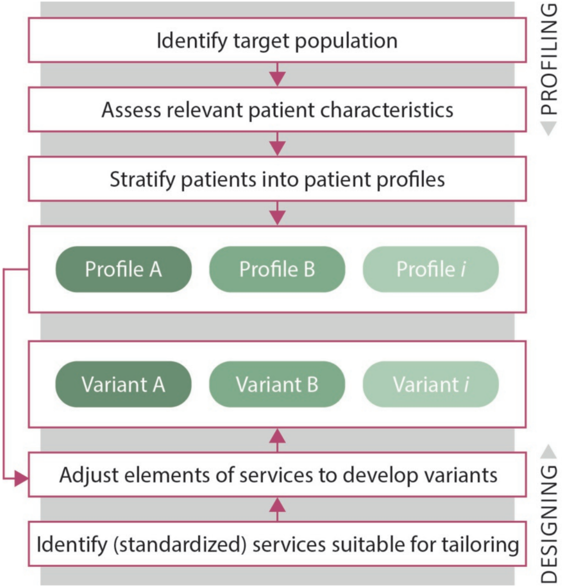

Figure 1.1 The patient profiling approach

Adapted from 'Tailored healthcare: Two perspectives on the development and use of patient profiles' by T. Dekkers and D.F.L. Hertroijs, 2018, *Advances in Therapy, 35*, p. 1455.

1.3 Aims and thesis outline

Patient experience is one of the pivotal indicators of healthcare quality. However, 20% of patients who undergo a total joint replacement surgery, the specific case under study in this thesis, are dissatisfied with their healthcare experience. Communication that addresses the preferences, needs, and abilities of individual patients could improve the experience of orthopaedic patients, but the current standardized healthcare system seems unable to deliver this level of tailored service. This may result in healthcare that is less organizationally, socially, and psychologically appropriate than desired. Data-driven patient profiles that represent the common characteristics of a specific subgroup of patients that are unique compared to the overall patient population could be used to design and gradually introduce more tailoring in the healthcare system. To our knowledge, such data-driven patient profiles are not yet available.

The primary aim of this thesis is to define and validate a set of data-driven patient profiles that represent common and distinctive characteristics of orthopaedic patients. The secondary aim is to examine the effect of a tailored healthcare service (designed using the patient profiling approach) on patient experience.

To address these aims, this thesis describes five studies, divided in two parts. The first part comprises chapters two, three, and four, and outlines the development and validation of the set of patient profiles. The second part consists of chapters five and six and applies patient profiles in the design of a web-based patient education platform and examines the effects on patient experience. The last chapter provides an overall discussion of the findings and its implications for the medical and creative industry. A visual outline of the thesis is presented in Figure 1.2.

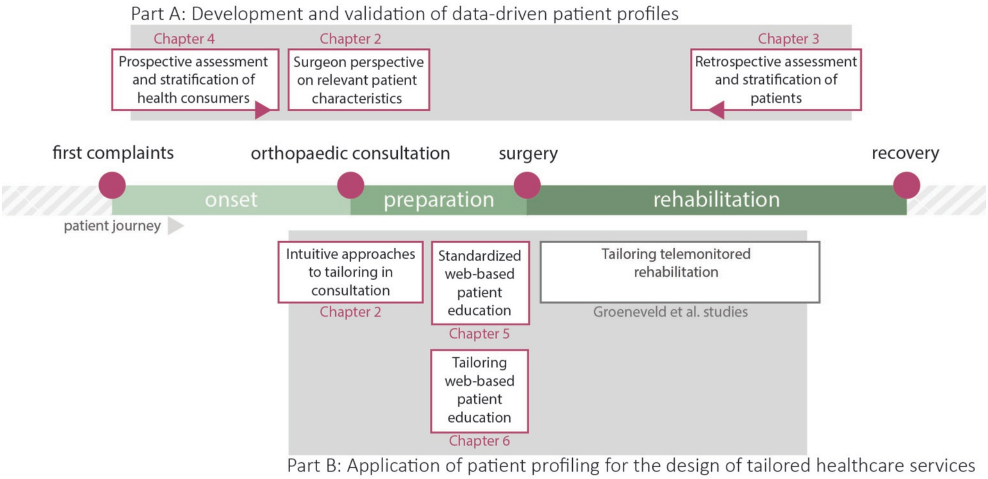

Figure 1.2 Visual thesis outline

Part A: Definition and validation of data-driven patient profiles

The patient profiling approach proposes that profiles can be defined by assessment of relevant patient characteristics and stratification of patients into profiles. In order to identify relevant characteristics from the surgeon's perspective, **Chapter 2** explores if and how surgeons intuitively tailor patient-provider consultations in the absence of formal tools (e.g. individual assessment). It discusses how surgeons construct perceptions of patients and how patient-provider communication changes as a result of these perceptions. In this way, orthopaedic consultations can be conceptualised as an intuitive approach to tailoring. The main finding of Chapter 2 is that surgeons consider patients' abilities, preferences, and behaviour in illness management and communication relevant for tailoring healthcare services.

Chapter 3 assesses these aspects from the patients' perspective. The clinical, psychological, and communicative characteristics of individual TJR patients were retrospectively assessed. This data was used to develop a set of three patient profiles: the managing profile, the optimistic profile, and the modest profile. Each describes a distinct way in which TJR patients may experience their health, cope with major surgery and wish to communicate with their healthcare provider.

The patients involved in Chapter 3 retrospectively reflected on their experience of TJR surgery. In contrast, **Chapter 4** prospectively assesses the preferences, needs, and competences of people who have untreated joint complaints (the general health consumer population). This chapter explores the similarities and differences between the patients from Chapter 3 and the general health consumer population. It also evaluates the fit of the three profiles in the new population. This chapter ends with a description of the final set of patient profiles and the patient stratification instrument.

Part B: Implementation of patient profiling for the design of tailored orthopaedic healthcare services

The first step in the design process with patient profiling is to identify a standardized service suitable for tailoring. **Chapter 5** systematically reviews one common service offered in orthopaedic care, web-based patient education. The review shows that web-based education can increase patients' knowledge and satisfaction, but does not reduce anxiety or improve health attitudes, behaviour or clinical outcomes. Because web-based patient education was identified as a currently standardized service that influences patient satisfaction, it was selected as a case to redesign following the patient profiling approach.

Chapter 6 describes the design process of three web-based variants of existing patient education material, developed in correspondence to each of the three patient profiles. Each variant offers a different structural design (e.g. information architecture) to address patients' different preferences, needs, and competences. Each variant was experimentally tested for its effectiveness, use, and user experience. Chapter 6 also includes a general model of how design choices in information architecture can improve the patient experience. The main findings indicate that information architecture affects the user experience, and that tailoring is beneficial for some, but not all patient profiles.

The final **Chapter 7** discusses the findings of this thesis and concludes that joint replacement surgery patients can be represented in three patient profiles that reflect the common and unique preferences, needs, and competences of patients. We provide suggestions for future research and implications of the findings for the medical and creative industry.

Part A

Definition and validation of data-driven patient profiles

Chapter 2

Tailoring the orthopaedic consultation: How perceived patient characteristics influence surgeons' communication

Summary

The patient profiling method proposes that care can be tailored by assessment of relevant biopsychosocial patient characteristics, stratification of patients into profiles and tailoring of care in concordance with the common care preferences of these profiles. Orthopaedic surgeons may already intuitively perform these steps of assessment, stratification, and tailoring during a specific moment of the care trajectory – the orthopaedic consultation. Systematic understanding about their practice informs which biopsychosocial patient characteristics are relevant to objectively assess from the physicians' point of view.

Therefore, the aim of the present chapter is to explore if and how medical specialists tailor patient-provider consultations in the absence of formal tools (e.g. patient profiles). The phenomenon of intuitive tailoring in orthopaedics is introduced in Section 2.1, Section 2.2 details the ecological momentary assessment-based interview and observation method, and Section 2.3 describes how surgeons construct perceptions of patients and how patient-provider communication changes as a result of these perceptions. The identified *informing*, *social*, and *counselling* approaches to tailored care are discussed in Section 2.4 and later used as the basis for patient profile assessment in Chapter 3.

This chapter is published as: Dekkers, T., Melles, M., Mathijssen, N. M. C., Vehmeijer, S. B. W., & de Ridder, H. (2018). Tailoring the orthopaedic consultation: How perceived patient characteristics influence surgeons' communication. *Patient Education and Counseling, 101,* 428-438. doi:10.1016/j.pec.2017.08.018

Parts of this chapter have been presented at Health Ergonomics and Patient Safety 2016 as: Dekkers, T., de Ridder, H., Mathijssen, N. M. C., & Melles, M. (2016). Do physicians tailor their communication during medical consultations?

ABSTRACT

Objective. To investigate whether and how orthopaedic surgeons tailor communication during medical consultations based on perceived patient characteristics.

Methods. Seven orthopaedic surgeons were repeatedly interviewed following an approach based on ecological momentary assessment. Qualitative content analysis was used to analyse the eighty short interviews. The association between patient characteristics and tailoring approaches was explored in a correspondence analysis of the counted codes.

Results. Surgeons estimate patients' competence (illness management and communication abilities), autonomy, and interpersonal behaviour. They report tailoring communication in two-thirds of the consultations. The surgeons' perception was associated with the employment of specific approaches to communication: (1) high patient competence with extensive information provision or no changes in communication, (2) less autonomy and less competence with reassurance and direction, (3) high autonomy with discussions about pace and expectations, and (4) high sociability with communication about personal circumstances and wishes.

Conclusions. The surgeon's perception of a patient influences communication during consultations. Future research should address whether these intuitively employed approaches are appropriate, effective, and generalizable to other medical specialists.

Practice implications. Tailoring physician-patient communication can improve its quality. The novel approaches identified in this study can be used to formulate and test formal guidelines for tailored communication.

2.1 INTRODUCTION

During perioperative care, patients meet with their physicians over the course of several medical consultations to discuss treatment options, evaluate surgical outcomes and monitor physical rehabilitation. Effective communication during these consultations contributes to the patient's health outcomes (Stewart, 1995). In general, effective physician-patient communication is characterized by the physician expressing empathy and asking questions about the patient's perspective while the patient expresses his opinion and fully participates in the discussion (Stewart, 1995). To improve communication, communication skills training is being introduced to practice for both patients and physicians (Cegala, McClure, Marinelli, & Post, 2000; Cegala, Post, & McClure, 2001; Haskard et al., 2008). Some of these training courses focus on increasing the physicians' ability to adjust their communication to each individual patient. In this process, known as tailoring, information about an individual is used to determine the appropriate content, context and channel of communication, which is expected to increase its impact (Hawkins, Kreuter, Resnicow, Fishbein, & Dijkstra, 2008). Physician-patient communication that is tailored, for example to patients' preferred level of participation in decision making or preferred amount of information, enhances coping, reduces anxiety, and increases satisfaction after surgery (Carrard, Schmid Mast, & Cousin, 2016; Kiesler & Auerbach, 2006; Lee & Lin, 2010).

To support physicians in tailoring communication to different patients, tools have been developed that assess patient characteristics prior to the consultation and suggest suitable communication strategies (Gorini et al., 2015; Kondylakis et al., 2014, 2013; Vercoulen, 2012). Such tools are developed under the assumption that physicians are able and willing to adapt their own communication approach when provided with objectively assessed patient characteristics. Contrarily, analysis of physicians' communication patterns suggests that while physicians demonstrate the ability to adjust communication to different situations, they are also quite consistent in their interaction style (Leighl, Gattellari, Butow, Brown, & Tattersall, 2001; Zandbelt, Smets, Oort, Godfried, & de Haes, 2006). Thus, a physician who uses objective tools to assess patient characteristics will likely integrate both their tried-and-tested approaches to communication and the tool's suggestions into one communication strategy. To formulate communication guidelines that integrate objective assessment with physicians' own intuitive approaches to tailoring, systematic understanding about the latter topic is needed.

The few studies available on intuitive tailored communication demonstrate that physicians' perceptions of patients influence information exchanges (Douma, Koning, de Haes, et al., 2012; Elit et al., 2015). However, the chances that the tailored information provided by the oncologists under study actually matched patients' information needs was "comparable to flipping a coin" (Douma, Koning, de Haes, et al., 2012). Apparently, patients' actual preferences do not cause physicians to provide information differently, but it remains unclear what did. In addition, little is known about the tailoring behaviour of other medical specialists.

Insight into the intuitive tailoring behaviour of orthopaedic surgeons may be especially important. Orthopaedic surgeons' serve a large diversity of patients who find high communication quality particularly important compared to other patient groups such as breast cancer and diabetic patients (De Boer, Delnoij, & Rademakers, 2010; van der Esch et al., 2015). Furthermore, the elective nature of most orthopaedic interventions means that a substantial part of the consultation is reserved for (shared) decision-making. While Dutch national guidelines recommend discussing expectations with patients and providing them with tailored information, no universal, clear protocol for these physician-patient interactions is in practice yet (Nederlandse Orthopaedische Vereniging, 2014, 2019)[10]. Due to the variety of patients, the emphasis on tailored communication, and the absence of strict protocols to guide said communication, intuitive tailoring likely occurs during orthopaedic consultations.

To further explore how specialists tailor communication during medical consultations, the current paper investigated how orthopaedic surgeons form a perception of a patient, and how they perceive they tailor communication consequently. We were specifically interested in investigating whether the surgeons' perception was associated with the employment of specific approaches to communication.

2.2 METHODS

2.2.1 Ethics

This study was approved by the Research Department of Orthopaedics and Traumatology, Reinier de Graaf Hospital, Delft, The Netherlands and the Human Research Ethics Committee of Delft University of Technology, Delft, The Netherlands. Patients were observed during the consultation, but as the focus of the study lay with understanding the surgeons' perspective on tailoring, they were not interviewed. Therefore, only surgeons provided written informed consent for their participation in the interviews, while their visiting patients verbally consented to observation of the consultations.

2.2.2 Participants and context

The full chirurgical team of the department Orthopaedics and Traumatology in a Dutch public hospital (Reinier de Graaf Hospital, Delft, The Netherlands) was contacted for participation in the study. All invited surgeons agreed to participate, resulting in a convenience sample of seven surgeons included in the study. The surgeons did not receive an incentive for participating in the study.

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[10] This reference has been updated to refer to the 2019 guidelines mentioned in the introduction of this thesis which were published after the original publication of this paper.

Surgeons in this centre perform surgeries as well as patient consultations. They typically saw 30-35 patients a day in a mix of first, repeat and telephonic consultations. Most consultations were dyadic exchanges and lasted between 5 and 25 minutes.

2.2.3 Data collection

We employed an explorative, qualitative approach to understand tailoring of communication from the surgeons' perspective. Our approach consisted of conducting semi-structured interviews in the normal working environment of the surgeons following an interview technique based on ecological momentary assessment (EMA) (Shiffman, Stone, & Hufford, 2008; Stone & Shiffman, 1994).

2.2.4 Procedure

To capture the tailoring process in context we based our interview technique on EMA. EMA is an approach to collecting data which aims to provide insight into how processes vary over time and persons, while tackling some of the issues known to self-reported data such as recall bias and poor ecological validity (Shiffman et al., 2008; Stone & Shiffman, 1994). In essence, it entails collecting data while subjects go about their daily routines by repeatedly prompting them to reflect on current feelings (for a complete overview of the methodology see Shiffman et al., 2008). For EMA, it is required that data collection is contextualized, random, repeated, and momentary (Shiffman et al., 2008; Stone & Shiffman, 1994).

The first author was present in the orthopaedic clinic on eight regular working days between January and March 2016. She shadowed one to two surgeons per day and was present during most consultations (total 171), with the exception of telephonic consultations and consultations with patients under 18 years. At the start of each day, up to ten consultations were randomly selected (using a random integer generator, Haahr, 1998) and marked on the researcher's copy of the clinic schedule for a follow-up interview. The surgeons were not informed of the consultation selection. To ensure that surgeons remained unaware of the selection, the researcher was also present during consultations that were not selected for follow up. During all consultations, field notes were taken of the surgeon's behaviour and surgeon-patient interaction to later compare these to the surgeon's account of the consultation. Finally, clinic schedules were used to identify demographics of the patients and the type of consultation. We refer to *first consultations* if patients had not visited the surgeon before.

To ensure that the data collection was momentary, the surgeon was interviewed directly after selected consultations, after the patient had left the consultation room. These short interviews were audio-recorded and lasted 2-4 minutes. Investigation into the surgeon's perception of the patient was initiated by asking "*What type of patient did you think this was?*" To examine how surgeons inferred patient characteristics we asked "*On what grounds did you base this?*" and to examine whether and how this was incorporated in the consultation we asked *“Did your approach to the consultation change according to your view of the patient?”* [11] The surgeons were not provided a specific definition of tailoring.

Data collection was stopped after 80 interviews when saturation of the data was reached (e.g. additional gathering of data did not result in new theoretical insights, Charmaz, 2006) and each surgeon had been interviewed at least 10 times (mean interviews per surgeon = 11.4). Overall, the EMA interview technique was endorsed by the surgeons as it invited them to directly reflect on practice and did not interfere with the outpatient clinic schedule.

2.2.5 Data analysis

The 80 interview transcripts were compared to the 80 corresponding field notes. No discrepancies between the reported and observed behaviour were found, and the interviews were thereafter used as the primary unit of analysis in conventional qualitative content analysis (Elo & Kyngäs, 2008; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). This approach to content analysis is appropriate when there is limited existing theory regarding a phenomenon, as is the case with physicians’ intuitive tailoring (Hsieh & Shannon, 2005). Inductive content analysis was used to analyse the first 35 interview transcripts. First, to facilitate immersion the transcribed interviews were read through multiple times (Hsieh & Shannon, 2005). Next, a line-by-line analysis was used to produce ‘in-vivo’ codes, meaning that the codes’ names were derived directly from the words of the participants (Corbin & Strauss, 2008). Similar codes were clustered to form an initial coding scheme with categories (Corbin & Strauss, 2008). The initial coding scheme was discussed extensively among the authors and supplemented with definitions to promote consistency in coding. To check the coding scheme’s categories for accuracy, deductive analysis was used in the remaining 45 interview transcripts. Further discussions among the authors after the deductive analysis generated minor changes in the coding scheme which were retroactively incorporated in the final coding of all 80 interview transcripts. QSR International’s NVivo 11 Software (QSR International Pty Ltd., 2015) was used to organize and manage the data.

To explore patterns in the qualitative data, we counted and tabulated the frequency of codes (Morgan, 1993; Sandelowski, 2000). As one objective of the study was to see how surgeons’ perceptions of patients influence tailoring of communication, we performed a multiple correspondence analysis (CA) specifically on codes related to patient characteristics (see 2.3.2) and tailored approaches (see 2.3.4). CA is an exploratory research tool to graphically depict the pattern of the associations between nominal or ordinal variables dispersed among rows and columns (Greenacre, 2017). In this respect, it is similar to the use of scatterplots for continuous variables. To visualize the association,

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[11] Original questions in Dutch: “Wat voor type patiënt denkt u dat dit is?”, “Waar baseert u deze typering op?”, “Heeft u op basis van deze typering uw aanpak aangepast?” “Zo ja, hoe?”

each row of data from a contingency table is transformed to a *profile*, which shows the relative contribution of that row to each category in the columns. Furthermore, profiles are created that represent fictitious rows that load on only one of the columns. This allows the representation of row categories as well as column categories in the plot. The profiles are then plotted in a dimensional space of which each axis is proportional to the total frequency of observations (e.g. column-axis with lower frequency are longer than those with higher frequency). Due to this transformation, data points placed close to the origin of the axes are more prevalent. While the resulting plot would show the association between rows and columns perfectly, it is impossible to visualize given that it has many axes (in this case, eleven, corresponding to the eleven tailored approaches). So, the last step of CA is reducing the dimensions projecting these to a two-dimensional plot (Greenacre, 2017). Much akin to factor or principal component analysis, each dimension is latent, and explains some of the variance in the data. For a detailed discussion on the theoretical background and application of CA, see Greenacre (2017).

In the current study, rows represented patient characteristics. Columns represented approaches and the visited surgeon. While a multiple CA was carried out (in which visited surgeon was included as a secondary column), the association between visited surgeon, characteristics, and approaches is not further reported nor visualized. The reasoning for including, but not presenting the relation of visited surgeons to characteristics and associations was two-fold. First, the visited surgeon was included as supplementary variable because we assumed that the association between characteristics and approaches may be affected by the patient as well as the surgeon. This means, for example, that surgeons may be more inclined to perceive most of their patients as *insecure* and consequently, *restrict information*, regardless of the patient seen. On the other hand, *insecure* patients may also always receive *restricted information*, regardless of the surgeon seen. Secondly, we considered the number of interviews per surgeon too limited (10-12) compared to the overall number of interviews to show in an exploratory visualization that does not test the statistical significance of the associations depicted (Greenacre, 2017). Thus, to account for the potential influence of surgeons without misrepresenting it, the analysis is presented as a conventional CA[12]. JMP 13 Software (SAS Institute Inc., n.d.) was used for CA.

2.3 RESULTS

2.3.1 Demographics of surgeons and patients

The seven interviewed surgeons were all male, Dutch, and aged between 40 and 62 years (mean age 51, SD 8.0). On average, they had 15.6 years of practice as an orthopaedic surgeon (not including years spent in training). The majority of the surgeons were trained

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[12] A copy of the full analysis can be obtained by contacting the first author.

in the Netherlands, but 43% had followed (research) training in the United States as well. The team had received the communication training 'Videotraining on the job' to improve their communication skills a year prior to the current research ("Videotraining voor artsen. Een krachtig middel [Videotraining for physicians. A powerful tool]," 2012).

The mean (±SD) age of patients (N = 80) was 60.3 ± 14.9 years (Table 2.1). Most patients were female (70%). There were no significant differences in the sociodemographic characteristics of visiting patients between surgeons (Table 2.1). Patients' sex and patients' age were not significantly associated with surgeons' mentioning of specific characteristics, cues, or approaches (not reported, all > *p* = .26).

Table 2.1 Sociodemographic characteristics of patients per surgeon

	Surgeon							%[a]	χ^2
	A	B	C	D	E	F	G		
Age (years)									**12.94**[b]
<50	3	1	1	2	4	3	2	20.3	
50-64	3	5	5	5	2	3	5	35.4	
65-80	6	4	4	2	4	4	5	36.7	
>80	0	0	1	1	2	2	0	7.6	
Sex									**9.92**[b]
Female	5	6	9	9	10	7	10	70.0	
Male	7	4	3	1	2	5	2	30.0	
Consultation									**5.99**[b]
First	7	4	3	4	4	8	4	43.0	
Repeat	5	6	8	6	8	4	8	57.0	

[a] Sample size is 79 for variables age and consultation type due to missing data of one patient.

[b] Patients were equally distributed across surgeons: patients' age (χ^2 (1,18) = 12.94, *p* = .80), patients' sex (χ^2 (1,6) = 9.92, *p* = .13) and consultation type (χ^2 (1,6) = 5.99, *p* = .42) were not significantly associated with surgeons.

2.3.2 Perceived patient characteristics

The surgeons stated 103 unique patient characteristics when asked to describe the type of patient they had seen. On average, patient descriptions contained 2.2 characteristics (1.6 when excluding duplicates). We identified seventeen main characteristics which are discussed in four global categories: the patient's ability to manage illness, autonomy, communication competence and interpersonal behaviour (Table 2.2). The interview excerpts illustrating these global categories can be found in Table 2.3.

Table 2.2 Patient characteristics perceived by orthopaedic surgeons

	Surgeon (N)							**Total[a]**	**%[b]**
	A	**B**	**C**	**D**	**E**	**F**	**G**		
The patient…	**12**	**10**	**12**	**10**	**12**	**10[c]**	**12**		
Illness management ability	**10**	**9**	**9**	**6**	**10**	**4**	**9**	**57**	**71.3**
High	8	4	6	2	5	3	4	32	40
…is realistic about illness and complaints									
…is willing to deal with the illness									
…accepts the illness and its discomforts									
Low	3	6	3	4	5	1	5	27	33.8
…is insecure about illness and future prospects									
…is preoccupied with (monitoring) the illness									
…is in denial about being ill									
Not mentioned	2	1	3	4	2	6	3	21	26.3
Autonomy	**5**	**5**	**1**	**8**	**4**	**3**	**4**	**30**	**37.5**
High	1	2	0	5	2	1	4	15	18.8
…knows what he wants and expects from the physician									
…makes demands about care and treatment									
…dominates communication during the consultation									
Low	4	3	1	5	2	3	0	18	22.5
…submissive and does not push opinion									
…quiet and listens to the physician									
Not mentioned	7	5	11	2	8	6	8	47	58.8
Communication competence	**3**	**3**	**2**	**1**	**4**	**3**	**2**	**18**	**22.5**
High	3	1	1	1	2	1	1	10	12.5
…is smart									
…is easy to talk to being similar to the surgeon									
Low	0	3	2	0	2	2	1	10	12.5
…is impaired (hearing or cognition)									
…is low literate									
Not mentioned	9	7	10	9	8	6	10	59	73.8
Interpersonal behaviour	**3**	**3**	**0**	**0**	**4**	**1**	**2**	**13**	**16.3**
Sociable	3	1	0	0	4	1	1	10	12.5
…is amicable and friendly									
Formal	1	2	0	0	0	0	1	4	5
…is formal									
Not mentioned	9	7	12	10	8	8	10	64	80

[a] Due to multiple characteristics being mentioned per interview (1.61 ± .75) totals and percentages do not add up to 100%.

[b] Percentage of interviews (N = 80) in which one or more characteristics under each category were (not) mentioned.

[c] Surgeon F was interviewed 12 times, but data regarding perceived patient characteristics was missing in two patients due to one missing audio recording and one audio recording starting late.

Surgeons most often stated characteristics corresponding to the patient's ability to manage his illness. By considering the patient's own efforts to attain a realistic treatment goal while managing insecurities and monitoring the illness, the surgeons estimated the patient's likelihood to meet treatment goals. For example, they stated that insecure patients were less able to manage their illness independently. They also considered patients' management abilities a continuum which ranges from better to worse. This was demonstrated through their description of some patients as both competent (e.g. *willing*) and incompetent (e.g. *in denial*) in different aspects simultaneously.

Surgeons also estimated the autonomy of patients during consultations. Most patients were perceived as submissive and quiet people who leave control to their physician. On the other hand, they also considered some patients as highly autonomous people who knew what they wanted and expected from physicians and were not afraid to make demands regarding their care and treatment.

To a lesser extent, surgeons estimated the competence of a patient to communicate effectively during the consultation. They mentioned that poor hearing and cognitive impairments formed barriers to good communication, while intelligence and similarities between the patient and the surgeon contributed to higher quality communication.

Finally, not all surgeons (Surgeon C & D, respectively) mentioned characteristics related to the patient's interpersonal behaviour. Surgeons who did note this stated that patients who are sociable during consultations preferred friendly interactions, especially in comparison to formal patients, who they described as preferring functional and direct communication.

Table 2.3 Interview excerpts illustrating patient characteristics perceived by orthopaedic surgeons

Illness management ability
This is, according to me, a no-nonsense person. It is someone who is very realistic and willing to do whatever it takes to regain function and make a good recovery. So I consider this is a very realistic patient. (Surgeon C)
To me, this is the best situation, or at least, the easiest. You see someone who takes their own responsibility, is willing to deal with it, and gets started. They make good progress, and that's what I like to see most. (Surgeon G)
She's very satisfied now that the tingling is gone, but not so much about the hand function but well, she accepts that. So I think she adequately realizes the limits of what is currently possible. (Surgeon D)
This is someone who is a little insecure, and does not know what to do about her complaints. You notice that this has an impact on her independence. (Surgeon G)
Certain aspects of her behaviour give me the impression that she somaticizes. She has something alright, but the way she manages it… (Surgeon E)
This lady, I don't think she accepts her condition. She just really wants to get rid of the pain and discomforts, but it's not possible. All the while she still wants to exercise and do all sorts of things. But she's not ready for a prosthesis. So it is a… well let's just say that I can imagine a resident saying 'she is not my type'. (Surgeon C)

Autonomy

This is kind of a pushing, self-conscious, knows all the ins and outs type of patient. Despite all that, she didn't know that rehabilitation takes a year, while we clearly told her so. (Surgeon D)

This is someone who just thinks 'go go go!' They know what they want. And they are active! I always kind of like that. (Surgeon G)

It is like he says himself, a handyman. He wants to be understood and he liked the concept of shared decision making and I think that is what he prefers to see. Not the doctor making the decisions, but for him to retain control over his own body. That is the type of man I thought this was. (Surgeon A)

This is a lady who doesn't really know what is going on anymore, she needs a lot of support, so you can nudge her in any direction you want. I could have put her on the waiting list. She just follows, she is a follower, and they follow the doctor. (Surgeon B)

What should I say? Compliant patient who has faith in the doctor. They will say 'tell me what to do and I will do that. Whatever you say is fine and I believe you. (Surgeon D)

She was a bit quiet. She first has to see which way the wind blows, I noticed that. She didn't talk a lot and was listening more. A type who listens. (Surgeon A)

Communication competence

She is smart. I saw that she is an engineer. You notice this right away in the communication, that she's a smart lady. (Surgeon E)

Each specialist attracts their own type of patients and this is my type of patient. With them, conversations just run smoothly. With some patients, I have to jump through hoops to be able to level with them. This [consultation] was not that hard. (Surgeon A)

She is a typical grateful older lady who is quite positive. However, I think that she's no longer able to figure everything out completely considering the fact that she forgot that she had been her for check-ups. So that limits the information she is able to provide. (Surgeon E)

It is very difficult to appreciate what she can do when there's a big language barrier. (Surgeon F)

Interpersonal behaviour

She is funny, very amicable. You notice that right away. (Surgeon E)

I couldn't seem to figure her out but I got the feeling that this was a madam who really valued the relationship with her physician and has immense trust in that [relationship]. (Surgeon B)

He is just frank, he requires little information. Before the surgery, he did require a lot of information, he wanted to know exactly what material I was using. He is a dentist, former dentist, an implant dentist, and he knows a lot about it. But what he wants is just very short, to the point information. He is really not in the mood for endless chitchat. I think that's quite pleasant, but well. Short and concise information. (Surgeon B)

2.3.3 Surgeons' estimation of patient characteristics through cues

As the surgeons had no tools at their disposal to assess patient characteristics, they inferred these from various cues. The surgeons stated 76 unique cues that they had used to make sense of the patient, which we grouped to eight main categories (Table 2.4). The interview excerpts illustrating these cues can be found in Table 2.5. In all but 5% of the consultations surgeons were able to provide a cue on which they had based the patient description.

Table 2.4 Orthopaedic surgeons' estimation of patient characteristics through cues

	FC[a]	RC[a]	Total (median)	%[b]
Communication that takes place during the consultation	**18**	**20**	**38 (5)**	**47.5**
Explicit statements of the patient			17 (2)	21.3
Communication between patient and physician			11 (1)	13.8
Question asking			11 (2)	13.8
Communication between patient and companion			3 (0)	3.8
Experience	**5**	**17**	**22 (3)**	**27.5**
Previous experience with the patient			14 (1)	17.5
Experiences with other patients			13 (2)	16.3
The patient's involvement with care	**7**	**9**	**16 (2)**	**20**
Passive involvement			9 (1)	11.3
Active involvement			8 (1)	10
Other				
Socio-demographical information stored in the EHR	5	7	13 (2)	16.3
The patient's description of his experience with pain	2	8	11 (1)	13.8
The patient's clothing, looks or general appearance	7	2	9 (1)	11.3
Patient disrupts 'planned' consultation	2	2	4 (0)	5
Unknown	0	3	3 (0)	3.8

[a] Number of times a cue was mentioned during a first consultation (FC) and repeat consultation (RC). Cue was significantly associated with consultation type (χ^2 (1,18) = 15.99, p = .043).

[b] Total percentage of interviews (n = 80) in which one or more cues under each category were mentioned.

Almost half of the patient characteristics were inferred from the communication that had taken place during the consultation. From these conversations, the surgeons mostly recalled explicit statements patients had made. In addition, they also described other aspects of communication between the patient, themselves, and patient companions who were present during some consultations. They specifically emphasised the importance of how patients asked questions, and noted the amount, repetition and omission of questions. For example, surgeons considered patients more insecure when they asked many questions.

These experiences with patients were put into perspective by comparing them to previous experiences surgeons had had with either the same patient or others. Surgeons were aware of the subjective nature of these comparisons, which they described as resulting in a 'feeling' about typical patient characteristics. Reflecting on previous experiences was done more often when meeting with repeat patients as opposed to first time patients (Table 2.4). This accumulation of experiences was seen as particularly valuable for tailoring communication, and surgeons expressed that repeat visits allow for more accurate tailoring.

One specific characteristic surgeons compared across patients was the patient's extent of involvement with care. They described cues of passive involvement as patients' waiting and ruminating about complaints without taking action, whereas active involvement meant, for example, searching the Internet for additional information. In general, active behaviour was considered a sign of adequate illness management, but sometimes passive behaviour was also reappraised as such. For example, after one patient had waited a considerable time before going to the specialist, she was seen as 'realistic about her minor complaints' as opposed to 'being in denial'.

Cues that were mentioned less often, and not by every surgeon, include the patient's experience with pain, their appearance, and whether they displayed disruptive behaviour, for example by discussing topics unrelated to the consultation. While the latter rarely occurred, it resulted in patients being perceived as less competent communicators.

The patient's pain experience was interpreted by the surgeons in relation to visual proof of pain. Surgeons explained that the difference between the pain that is apparent (e.g., through radiographic evidence, limping, or swelling) and the pain that is reported, informed them whether the patient's complaints were realistic or excessive. When the reported pain exceeded the apparent pain, the patient was perceived as being preoccupied with his illness. Vice versa (less reported than apparent pain), they perceived patients as having a realistic outlook. The larger the difference was, the more certain surgeons became of their perception.

Again, we noticed a difference between repeat and first consultations, such that patients' pain experiences were mostly monitored over repeat consultations, and were less likely to be mentioned after first consultations. In first consultations, on the other hand, patients' physical appearance played a larger role. However, no single aspect of a patient's appearance was consistently related to specific patient characteristics.

Table 2.5 Interview excerpts illustrating orthopaedic surgeons' estimation of patient characteristics through cues

Communication that takes place during the consultation
Well, it was mostly when she said. 'I'm very satisfied; it's going fine this way. And I don't need anything else, and that includes therapy'. She has complaints, of course, and she clearly states them, but if you ask how many of these result in a disruption of daily life activities… 'Yes, things get broken around the house, but it's not as if that didn't happen before'. So then I know that she is accepting things. It is fine the way it is. (Surgeon D)
My outpatient clinic kept taking half-hour longer than planned when she was there, because she had so many questions. And just now she had another catalogue of questions which left me thinking 'how do you manage to dream them all up'. It probably just comes from her own insecurity, but the more you explain things to her the more questions you get back, so at some point you start thinking 'I'd better cut out all this giving of information because she's clearly unable to cope with it. (Surgeon C)
She told me about Australia. She tells a little story during the visit. So that means she's quite relaxed sitting here, and that she's relaxed in communication. (Surgeon E)

Experience

Well okay, I did not have the idea that she plays things down or anything. But, no, that's just a feeling, I guess. (Surgeon G)

They are those… [patients] you just feel that… some people will just keep on complaining. To put it very bluntly. (Surgeon C)

You see, with a first-time patient you always have to figure out who you are talking to, and this is a lady, well, if I count the appointments, maybe she's been with me for as much as 15 consultations, so then you're no longer figuring it out. They know who they are seeing, and I know who they are. (Surgeon A)

The patient's involvement with care

The case history showed that she's been suffering from bad health for many years. In the meantime, she tried to find ways to experience less pain. She has been under the care of the general practitioner for that whole time and only now has she been referred. So she clearly doesn't complain easily, otherwise she'd have been here much sooner, and she wouldn't have taken no for an answer. That type of person. (Surgeon B)

It's because she behaves distinctly, the fact that she sets her own appointments, even though she doesn't need to see me if it were up to me, because essentially she's now being treated at [another hospital]. She always complains about the doctors over there. However, when she's here, I don't do anything about it [her complaint] either. But she does travel all the way from [village] to see me. (Surgeon E)

Other: socio-demographical information in EHR, description of pain, appearance, disruptions, unknown

This is a typical patient from this region. Surgeon checks EHR. [village], indeed. And then you know, and you hear, they have to work and they come in saying: 'Doctor, I have this complaint, it has been like this for a while, please fix it for me. (Surgeon D)

You know, it also has to do with being peers, and I see myself as… Surgeon checks patient's age in EHR. Well, so much for being peers. (Surgeon A)

So, what do I base that on? It's his manner. He's not a complainer. He walks in and he's limping, which I notice. It makes me think 'yes, there's something the matter here'. He also has a swollen knee, which doesn't lead us to conclude straight way that there is a problem, but I would definitely say that this man is entitled to complain. Let's just say that he's not overreacting. (Surgeon C)

Honestly, you see this from the way they present their complaints, it is so broad. You should let them talk first but eventually, you have to direct them because you will not get to a solution otherwise. (Surgeon E)

This man is somewhat softer, a little bit more out there, a very friendly guy. It's in the way he presents himself, like the colour of the clothes he is wearing. On top of that, he practices yoga. (Surgeon F)

I notice his clothes, the way he talks. I have known him for a while, he's an electrician, I knew that. (Surgeon A)

But also, I tried to explain her about the pain and its longer duration and she started talking about something completely different. And then I think 'I'm not getting through to her. Should I say it again?' I do find that quite difficult. (Surgeon C)

With her, I just don't know. I can't explain it very well. (Surgeon B)

2.3.4 Surgeons' approaches to tailoring

The surgeons stated that they had changed, or tailored, their communication after two-thirds of the consultations. We did not consider changes as tailored if these occurred as a result of time constraints and rescheduling (9%). After being asked whether they made changes according to their view of the patient for the first time, most shared that they regard themselves able to tailor communication intuitively and considered this a skill worth pursuing.

> *That [way of communicating] works best for that type of person. But it doesn't work for everyone so you always try to adjust a little bit to whoever's in front of you. (Surgeon E)*
>
> *Yes, sure, I really try to, some patients, you know, how should I put this. It's a sort of hospitality that you're trying to offer. And yes, certainly, the consultation is completely adapted to how the patient experiences it, and to how they might want it to be. So I do make use of this. (Surgeon D)*

In one-third of consultations surgeons reported no changes in their approach from what they considered 'the standard'. Surgeons did not report tailoring when clear guidelines were available for common diagnoses or physical problems, or when they perceived patients as competent communicators and managers of their illness.

The surgeons reported 43 unique tailored approaches to communication which we first sorted into nine main categories, each related to four aspects of physician-patient communication (Table 2.6): information provision, guidance through insecurity and decision making, communication about personal circumstances, and inhibition of unrealistic goals and expectations. Interview excerpts illustrating these approaches can be found in Table 2.7.

Table 2.6 Orthopaedic surgeons' approaches to tailoring

	Surgeon							Total	%[a]
The surgeon…	**A**	**B**	**C**	**D**	**E**	**F**	**G**		
Information provision								**24**	**30**
…elaborates the amount of information	1	2	0	1	3	2	3	12	15
…restricts the amount of information	0	3	1	0	0	3	2	9	11.3
…verifies the current understanding of the patient	0	1	1	0	0	1	0	3	3.8
Guidance through insecurity and decision making								**21**	**26.3**
…reassures the patient	2	2	2	3	1	1	2	13	16.3
…is more directive in decision-making	1	0	0	1	1	0	1	4	5
Communication about personal circumstances								**14**	**17.5**
…has a social chat	3	0	1	1	4	0	1	10	12.5
…explores the patient's wishes	0	1	0	1	2	0	0	4	5
Inhibition of unrealistic goals and expectations								**8**	**10**
…discusses pace of rehabilitation	0	1	1	1	0	0	1	4	5
…discusses high patient expectations	1	1	0	1	0	0	1	4	5
Did not change his approach	6	2	7	3	3	3	4	**28**	**35**

[a] Percentage of interviews (N = 80) in which one or more approaches of the corresponding category were mentioned. Due to multiple approaches being employed per consultation (1.19 ± .43) percentages do not add to 100%.

The tailored approach mentioned most often was adjustment of the amount of information provided to the patient. When tailoring information, surgeons determined the current knowledge and understanding of a patient and corrected misconceptions. Provision of elaborate information was associated with the surgeon's perception of good illness management in patients. They expressed that these patients appreciated the additional information and considered them able to cope with more information. In contrast, information was restricted for insecure patients as surgeons feared that providing extensive information would only increase the patient's anxiety. Rather, they provided simpler, abbreviated or less information than they would normally do.

The second most prevalent approach consisted of adjusting how patients were guided through insecurity and decision-making. The surgeons expressed that particularly insecure patients needed additional reassurance, which they offered by making the patient feel heard and taken seriously. The latter was pursued by discussing and offering additional care. Additional guidance was also provided to patients with less perceived autonomy. This was especially apparent in consultations during which treatment decisions needed to be made, after which surgeons reported being more directive than normal. Yet, despite this general tendency to direct passive patients, some surgeons responded differently: instead of limiting patients' input to the dialogue, they reflected on exploring patients' wishes and refrained from advising specific treatments. Findings from the multiple CA (see section 2.3.5) indicate that this behaviour mostly occurred during socials chats. As such, we considered exploration of wishes a change in personal communication rather than an expression of guidance, but it could be categorized as both.

All surgeons tailored their approach to information provision and guidance during at least one of the observed consultations. However, tailoring communication about personal circumstances was never mentioned by some surgeons (Surgeon F) while often by others (Surgeon E). Social chats were mostly held with patients perceived as friendly and competent. Apparently, surgeons felt that the patient's adequate illness management allowed more room for talk.

Finally, the least mentioned approach (10% of consultations, mentioned by five out of seven surgeons) concerned discussions about high rehabilitation goals or expectations. Some surgeons held such discussions, in order to inhibit highly autonomous patients' goals and expectations, which they felt were often unrealistic.

Table 2.7 Interview excerpts illustrating orthopaedic surgeons' approaches to tailoring

Information provision
When she said 'with me, all that can go wrong will go wrong' and 'I'm part of the two percent' I started explaining more, specifically considering the postoperative pain, just to curb these things.(Surgeon D)
I explain things a bit more thoroughly to her, because I think she can handle this. And because I think she needs this. So, I discuss the MRI images and I use the terminology and I explain to her what this means, but I wouldn't do this with someone else. (Surgeon E)
I have to provide him less information, because he understands his condition. So that was relatively short and concise. (Surgeon B)
Well, I found her a bit insecure in that sense, I found her a bit anxious. She came across as a bit stressed. But yes, she was also looking for certainties. I suppose it's along the lines of: 'what's happening and what else could happen and where is this all going to end? Everything is worn out!'. Good grief. That's why I limited my explanation to what it specifically entailed for the shoulder and I that I think she'll be fine. A bit of reassurance. I had the impression that she responded positively to that. (Surgeon G)
Guidance trough insecurity and decision making
What I did adapt [in the consultation], was that normally I see patients for their wrist, and now I adapted my consultation to take in an extensive physical examination. Mostly to make him feel that we are working on it and that we are taking it seriously. (Surgeon D)
It is management: that means asserting that this [pain] is part of the problem and I try to reassure her in the most empathic way, but I don't think I have seen the last of her. (Surgeon C)
You just have to take them seriously and you shouldn't think 'well, I can't really help her, so she should go back to her general practitioner.' No, I really try to offer her some additional treatment, possibly secondary care. I discuss what the hospital can offer her, that's why I mentioned the pain clinic. Also because she tried so many different things herself. That was my idea. But as an orthopaedic surgeon there's not really a lot I can do. (Surgeon A)
Well, what I tried to do was to explore what she actually wants. Whether she wants to have surgery, or doesn't want have surgery. And, of course, it's also very interesting to know 'why is she really here? What does she want to happen? (Surgeon B)
Communication about personal circumstances
She's direct and amicable in her approach. And I accept that in some patients, but not in others. When certain people are that way, I just find it annoying. But with her it's okay. Because she's a realistic woman who is easy to communicate with … The way I talk to her is different. And in her case I can just say 'how shall we go about this?' (Surgeon E)
Our conversations are casual, very casual. Soon, we call each other by our first names. We make a joke here and there, and in that way we break the ice. Like you would meet someone on the market. Or in a bar, to give an example. (Surgeon A)
I find it fun to listen. I wish I could talk to them for half an hour, but I can't. So I try to schedule some time for talking, because essentially, my medical story is very simple. The shoulder is impaired and I can give an injection or I can replace the shoulder with a prosthesis. Those are all the available options. Nine out of ten times, I find that people don't want the prosthesis yet. But I can state that in thirty seconds and then part ways or I can, well, listen. And I like the latter best. (Surgeon G)

Inhibition of unrealistic goals and expectations
This lady, she wants to be perfect and that's not something I can provide to her. So that's why you heard me say things like 'I can't give you any guarantees' and 'maybe it has been said that you are in pain' and 'it has been reported, but the association is not crystal clear'. And the only reason why I do this is to protect myself because I don't think we can get her to a hundred percent. I hope I can improve her [function]. (Surgeon A)
There's no need for me to stimulate these people. On the contrary, I should inhibit them when they exercise too much instead of cheering them on. (Surgeon C)
I really try to make her reconsider [the surgery]. Because her wear was not that bad yet. I don't know whether this is a woman with a high tolerance for pain either. I think she might consider herself to have a high tolerance for pain, but honestly, I don't think she has. So I also think that the pain she experiences right now may be less. But we shall see. (Surgeon B)
Did not change his approach
No, no, no, this is all just according to the guidelines. So no, I did not. (Surgeon C)
No, this is all standard procedure. It is purely instrumental, not a different approach. (Surgeon E)

2.3.5 The association between perceived patient characteristics and tailored approaches

The tabular data of eighty interviews regarding characteristics, approaches, and visited surgeon were used in a multiple CA (see 2.2.4) to explore the association between perceived patient characteristics and reported tailored approaches. The resulting two-dimensional plot shows the pattern of associations between patient characteristics and tailored approaches (Figure 2.1). Given the exploratory nature of CA, all associations depicted are illustrative.

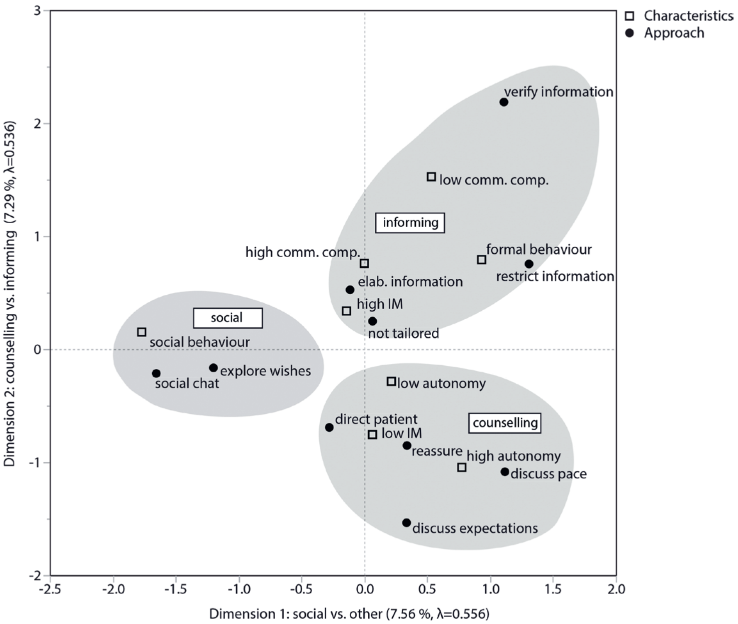

Figure 2.1 Three types of tailored consultations

Biplot of the association between perceived patient characteristics and surgeons' approaches to tailoring. Surgeon was entered in the multiple correspondence analysis as a supplementary variable (not displayed). Abbreviations: IM = illness management, comm. comp. = communication competence, elab. information = elaborate information.

From Figure 2.1, we identified two dimensions to distinguish between three types of tailored consultations. The first, horizontal, axis differentiates *social* consultations from all other consultations. The second, vertical, axis subdivides these remaining consultations in *informing* and *counselling* consultations.

Social consultations are characterised by social chats and exploration of patient's wishes, and are related to sociable patients. The other consultations, in contrast, do not include these social interactions and are mainly a means to informing or counselling the patient. The *informing* consultation is the default: patients are perceived as competent communicators with high illness management abilities, which are provided either elaborate information or no adjustments. During informing consultations surgeons can also restrict information in response to patients perceived as formal and with lesser communication competence, but this was rarely reported (upper-right corner of Figure 2.1).

We also distinguish the *counselling* consultation. It is characterised by direction and reassurance, and is associated with patients whose autonomy and illness management abilities are perceived as low. Counselling consultations were also reported with patients with high autonomy. Communication during these consultations focussed on discussing the pace of rehabilitation and to a lesser extent, expectations.

2.4 DISCUSSION AND CONCLUSION

This study explored whether and how orthopaedic surgeons tailor communication during medical consultations, based on their perception of a patient. We found that these physicians form their perception on the basis of the patient's abilities (to manage the illness and communicate clearly during the consultation), autonomy, and interpersonal behaviour. These characteristics are estimated from various subjective cues such as the communication's content and context, previous experiences of the surgeon, and the way a patient deals with illness-related issues such as pain. Consequently, surgeons report to tailor when and how they provide information, guide patients through insecurity and decision-making, communicate about personal circumstances, and discuss goals and expectations. We identified four associations between the surgeons' perception of the patient and specific approaches to tailoring communication: (1) higher perceived patient competence was associated with provision of extensive information or no changes in communication, (2) less perceived autonomy and competence were associated with reassurance and direction, (3) high perceived autonomy was associated with inhibitory discussions about pace and expectations, and (4) high perceived sociability was associated with communication about personal circumstances and exploration of wishes.

2.4.1 Discussion

In comparison to other medical specialists, we find that, like oncologists (Douma, Koning, de Haes, et al., 2012; Elit et al., 2015), orthopaedic surgeons report tailoring information provision. Information that is tailored in specificity and amount to a patient's preference can enhance patient health outcomes (Auerbach, Martelli, & Mercuri, 1983; Kiesler & Auerbach, 2006; Ludwick-Rosenthal & Neufeld, 1993). However, the current study demonstrated that information was tailored according to the surgeon's perception of a patient's autonomy and illness management capabilities, rather than the patient's preferences. It is uncertain whether this perception of the patient is accurate. In some circumstances, perceived characteristics may serve as proxies for patient preferences. We believe this is the case when observable characteristics are strongly associated to certain preferences. For example, a patient's information preference could be inferred from their anxious behaviour during a consultation, given that higher levels of anxiety correspond with a larger information preference (Davison & Breckon, 2012). However, such use of perception to determine preferences becomes problematic when evidence for strong associations is absent, mixed, or counterintuitive. We believe to have observed the latter issue when patients asked many questions during the consultation. Surgeons perceived these patients as insecure and restricted information to them, despite the available evidence that suggests that question-asking indicates high, rather than low, information preferences (Kinnersley et al., 2007).

This observation supports that physicians may tailor information to their perception of a patient, rather than the patient's actual preferences. If this is the case, it explains why previous studies observed changes in information provision that were not related to patient preferences (Douma, Koning, de Haes, et al., 2012; Zandbelt et al., 2006). Possibly, these physicians adjusted communication based on their perception of the patient's insecurity, autonomy, or formality, assuming that such characteristics accurately reflect patient preferences. Since this was not the case, the tailored information did not match. We therefore suggest that future research assesses both the physician's perception as well as a patient's (self-reported) preferences to determine under what conditions tailoring occurs.

The aim of this paper was not only to investigate how orthopaedic surgeons form a perception of a patient, but also to explore how these physicians perceive they tailor communication consequently. In pursuing this latter objective, we identified guidance, communication about personal circumstances, and discussions about goals as novel avenues for tailoring. Since responding to patients' emotions and partnership building are considered important elements of the medical consultation (Debra L Roter & Hall, 2006), it makes sense that physicians would intuitively tailor these aspects. However, while guidelines for tailoring information to different patients are available (see e.g. Back & Arnold, 2006a, 2006b), a similar framework for tailoring emotional support and personal talk has not yet been proposed. Some suggestions include additional talk about personal issues with patients who expect their doctor to develop a personal relationship with them (Farin, Gramm, & Schmidt, 2012; Ullrich, Hauer, & Farin, 2014) and guidance in accordance with patients' specific *reassuring cognitions* (Giroldi et al., 2014). However, the effect that such adjustments have on the quality of physician-patient communication has not yet been determined. It is recommended to investigate this effect, as this study demonstrated that surgeons do report to tailor these aspects already.

2.4.2 Strengths and limitations

A first limitation of the study is that the depth of the data collected in the short interviews may be superficial compared to in-depth interviews. If we'd invited the surgeons to reflect on tailoring in-depth, this might have provided more insight into *why* they tailor communication. However, for the principal aim of this work to describe *how* surgeons tailor, the methodological shortcomings of longer interviews (including the aforementioned recall bias) outweighed their potential benefit.

More substantial limitations of the study are related to the qualitative nature of the study and its small sample size. Like other interview studies have reported, physicians' accounts of the consultation may be different from the actual events that occurred (Elit et al., 2015). One of the strengths of the current study is the use of EMA to reduce the recall bias that contributes to this misinterpretation. Furthermore, as the researcher was present during the consultations, we were able to compare the surgeon's statements to behaviour he and the patient had displayed. In all cases in which tailoring was reported, notable changes in the consultation were observed. From this we conclude that surgeons' report of tailoring corresponds with actual tailored communication. However, we cannot assume that when surgeons did not mention a characteristic, cue, or approach this meant that the surgeon did not tailor, rather than simply not mentioning it when asked generally. This implies that the amount of tailoring reported in this study is likely an underestimate.

While we believe this study provides an interesting explorative insight into intuitive tailoring, we interviewed only seven orthopaedic surgeons from the same centre. The generalizability of these findings to other medical specialists may be limited. To validate our findings across other settings, a structured coding scheme for observation of physicians' tailored communication (e.g. a scheme to record patient behaviour and physicians' adjustments during the consultation) is needed. As this is not yet available, one focus of future research should be its development. If this effort is combined with an assessment of patient self-reported preferences, this would also contribute towards a better understanding of how preferences relate to observable patient behaviour.

2.4.3 Conclusion

The current study identified that orthopaedic surgeons consider the abilities, autonomy, and interpersonal behaviour of patients during the medical consultation, and intuitively use this perception to employ tailored approaches to communication. While most previous work has focused on tailored information provision by oncologists, this study was the first to identify the efforts of surgeons to also tailor guidance, chats about personal circumstances, and discussions about goals and expectations. These novel, intuitive, approaches to tailoring can be used to formulate and test formal guidelines for tailored communication.

Although the work is preliminary, analysis of coded interviews showed that the perception of certain characteristics (for example, high patient competence) was associated with the report of specific changes in communication (for example, more extensive information provision). These findings provide a first step in understanding under what conditions physicians tailor communication, and should be investigated in more diverse settings.

2.4.4 Practice implications

Tailoring communication can enhance the quality of physician-patient communication for a variety of patients. Physicians should be aware that their perception of the patient alters the communication that takes place during the consultation, while this may not always be appropriate. In order to facilitate patient-centred communication, the effect of intuitive approaches to tailoring should be assessed in relation to the physician's perception as well as the patient's explicit preferences for information and support.

Chapter 3

Profiles of total joint replacement patients by clinical, psychological, and communication characteristics

Summary

The main finding of Chapter 2 is that surgeons consider patients' abilities, preferences, and behaviour in illness management and communication relevant for tailored care. Yet, existing patient segmentation models do not include these characteristics. We expect that physicians will be better able to tailor healthcare services (specifically, communicative and educational services) if communication characteristics (e.g. communication style, preferences, and efficacy) are directly included in segmentation models.

Therefore, the aim of Chapter 3 is to investigate whether patient profiles can be defined holistically by concurrently examining patients' clinical, psychological, and communication characteristics. In addition, the chapter explores the possibility of generating a screening instrument to allocate patients to the appropriate profile. Existing segmentation models are discussed in section 3.1, section 3.2 describes cluster analysis and classification and regression trees as methods for segmentation. The results suggest three clusters of patients (Section 3.3.3) which were interpreted as the *managing, optimistic,* and *modest* patient profile (Section 3.4). This set of data-driven patient profiles summarizes three distinct ways through which TJR patients may experience their health, cope with major surgery and wish to communicate with their healthcare provider.

Parts of this chapter have been presented at the European Health Psychology Society 2018 as: Dekkers, T., Melles, M., Groeneveld, B. S., Porsius, J. T., Mathijssen, N. M. C., Vehmeijer, S. B. W., & de Ridder, H. (2018). Classification of patients by clinical, psychological, and communication characteristics: Patient profiles for personalized care.

ABSTRACT

Background. Communication between healthcare providers and patients who undergo total joint replacement (TJR) surgery may improve when communication is closer aligned to patients' preferences.

Questions/purposes. The purpose of this study was to (1) describe the communicative preferences of TJR patients and (2) to investigate whether distinctive groups ('patient profiles') of TJR patients could be defined on the basis of clinical, psychological, and communication patient characteristics.

Methods. Self-reported preference data of a consecutive sample of 191 TJR patients from a single hospital was collected and combined with data from the electronic patient record and patient-reported outcome measures (PROMs) registry. Patient groups were defined using cluster analysis and further explained through classification and regression trees. The resulting groups were compared on satisfaction and PROMs at three months.

Results. Patients considered open information most important, followed by participatory communication. Three distinct patient profiles were identified. Profile 1 (44%, 'managing') showed poor preoperative health, diverse coping strategies, and high communication preferences. Profile 2 (32%, 'optimistic') had the highest preoperative health, limited coping behaviour, and low communication preferences. Profile 3 (24%, 'modest') had moderate preoperative health and coping behaviour, but poor communication competences and potentially unaddressed emotional support preferences. This group also reported the least satisfaction with patient-provider communication (p = .001). Clinical outcomes differed only in hip (not knee) patients, with profile 2 reporting better outcomes (p = 0.002).

Conclusions. TJR patients value open information and participation but preferences are highly diverse. Three patient profiles summarize distinct ways through which TJR patients may experience their health, cope with major surgery and wish to communicate with their healthcare provider. Profiles can be used to develop more personalised approaches to communication, which is expected to improve the quality of TJR care.

3.1 INTRODUCTION

Total joint replacement (TJR) surgery is one of the most common and successful elective procedures in the Western world (de Fatima de Pina, Ribeiro, & Santos, 2011; Etkin & Springer, 2017). Yet, up to 30% of patients are unsatisfied after TJR surgery (Anakwe et al., 2011; Hamilton et al., 2013; Jones, Voaklander, Johnston, & Suarez-Almazor, 2000; Lane et al., 2016; Lim et al., 2015). Patient satisfaction is a cognitive evaluation and emotional reaction to care services (Urden, 2002) that is influenced by many different factors, including functional outcomes and pain relief (Ali et al., 2014; Bourne et al., 2010; Gunaratne et al., 2017; Halawi et al., 2019), the extent to which outcomes fulfil patients' expectations (Bourne et al., 2010; Culliton et al., 2012; Gunaratne et al., 2017; Halawi et al., 2019; Hamilton et al., 2013; Shirley & Sanders, 2013; Swarup et al., 2018), and the quality of patient-provider communication (Bjertnaes et al., 2012; Hamilton et al., 2013). The latter is the focus of the current paper.

Common complaints of patients are that patient-provider communication lacks attention for personal concerns, is one-way, and follows a standardized routine (Lane et al., 2016; Marcus-Aiyeku, DeBari, & Salmond, 2015; Moore et al., 2016; van Kasteren et al., 2018). All in all, patients feel that communication is poorly tailored to their specific preferences and needs. Research outside the orthopaedic field shows that patient satisfaction improves when communication matches patients' preferences, for example for the amount of medical information or level of participation in decision-making(Kiesler & Auerbach, 2006; Street, Elwyn, & Epstein, 2012). Such higher quality patient-provider communication may even contribute towards better health outcomes after TJR surgery (Black et al., 2014; Street, Makoul, Arora, & Epstein, 2009).

Unfortunately, little is known about the communication preferences of patients who undergo TJR surgery. Most healthcare providers find it difficult to estimate preferences during the medical consultation (Dekkers, Melles, Mathijssen, et al., 2018; Douma, Koning, de Haes, et al., 2012; Elkin, Kim, Casper, Kissane, & Schrag, 2007; Farin et al., 2012). Furthermore, there are no easily accessible (demographic) variables that accurately predict communication preferences (Johansson Stark et al., 2014; Kiesler & Auerbach, 2006). Thus, for communication to be more tailored towards patients' preferences, an explicit assessment of communication preferences in the TJR population is needed. Yet to fully understand the role of communication preferences, they should be determined alongside other factors that influence patient satisfaction. Some patient factors interact with both preferences and satisfaction rates, for example depression and anxiety (Ali et al., 2014; Anakwe et al., 2011). In general, less anxious patients report greater interest in (prognostic) information (Rodin et al., 2009) while more anxious patients look for emotional support from their healthcare provider (Van Dulmen & Van Den Brink-Muinen, 2004). However, it is unclear how the clinical and psychological characteristics of TJR patients relate to preferences, and how both may contribute toward dissatisfaction in the orthopaedic setting. Examining these relations could help understand if there are specific subgroups of patients that are at an additional risk of dissatisfaction after TJR given their clinical, psychological, and communicative characteristics.

Up to now, subgroups of TJR patients have been defined solely on the basis of their clinical (Dowsey, Smith, & Choong, 2015; Gutacker & Street, 2017; Swenson, Bastian, & Nembhard, 2016; van der Esch et al., 2015) or psychological (Cruz-Almeida et al., 2013; Murphy, Lyden, Phillips, Clauw, & Williams, 2011; Stecz, Wrzesińska, Tabała, & Nowakowska-Domagała, 2017) characteristics. A common assumption in these studies is that patients with similar clinical characteristics also share the same communication preferences. For example, Swenson and colleagues (2016) suggest that patients of different health market segments may hold different preferences for customer service and interaction with the electronic patient record (EPR). However, no data on communication preferences had been collected directly in study, which makes it difficult to verify whether patients indeed hold similar preferences. We expect that target groups could be more applicable to the purpose of tailoring communication and customer service if communication characteristics (e.g. style, preferences, and efficacy) are directly included in target group formulation.

Therefore, the first aim of this paper is to describe the communication characteristics (e.g. preferences and competences) of TJR patients. Second, we will investigate whether target groups of TJR patients can be defined holistically by concurrently examining patients' clinical, psychological, and communication characteristics. We present these so-called patient profiles specifically for the purpose of tailoring health communication, which may be interpersonal (e.g. patient-provider consultations) or mediated (e.g. web-based) (Patrick, Intille, & Zabinski, 2005; van Weert et al., 2011). Finally, we present a preliminary screening instrument to help physicians gain insight in individuals' patient profile.

3.2 PATIENTS AND METHODS

3.2.1 Participants and procedure

A consecutive sample of patients who had undergone primary total knee arthroplasty (TKA) or total hip arthroplasty (THA) at one Dutch regional hospital (Reinier de Graaf Hospital, Delft) between October 2015 and October 2016 was recruited (Figure 3.1). Patients who consented received a survey by email or post (patient preference). The study was examined by the medical ethical committee Zuidwest Holland (#16-120). The committee determined that the study was not subject to the Dutch Medical Research Involving Human Subjects Act (WMO) and the need to seek additional formal approval was waived. Measures were still taken to ensure the privacy and safety of all participants in the study: participants could withdraw from the study at any moment and all data was processed and stored anonymously.

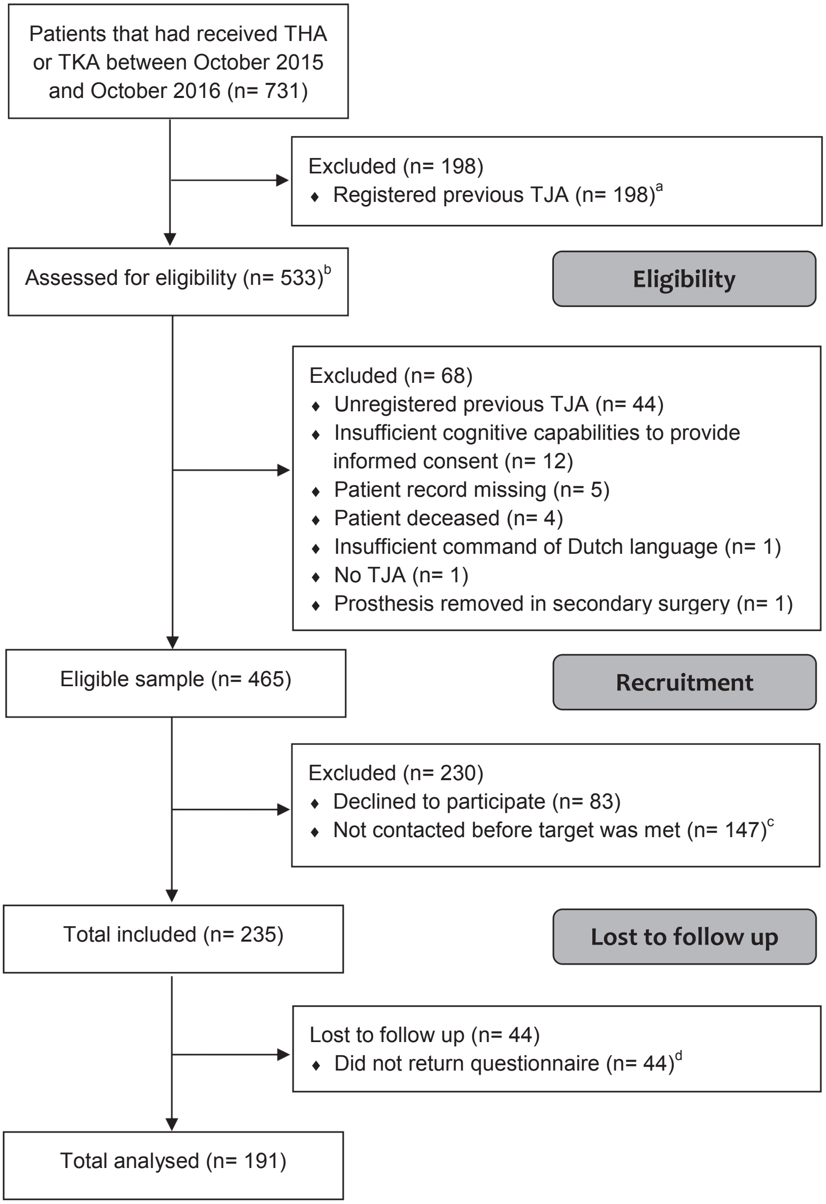

Figure 3.1 Participant flow diagram

[a] Registration of previous TJA was determined by screening for duplicate records in the Dutch Arthroplasty Register ('Landelijke Registratie Orthopedische Implantaten').

[b] Patient records were screened for eligibility in consultation with the treating orthopaedic surgeon.

[c] The target was 235. This was deliberately set higher than 180 (identified in a-priori power analysis) to allow for a 30% nonresponse rate common in survey research (R. M. Groves, 2006)

[d] Patients who had not yet returned the survey after four weeks were reminded once.

3.2.2 Data and measures

Three sources provided data for analysis: the Dutch onlinePROMs database, the Electronic Patient Record (EPR), and a survey. All measures are described in Table 3.1.

The onlinePROMs database (https://onlineproms.nl/) was used to retrieve patient-reported outcomes (PROMs) that were assessed as part of routine TJA care. PROMs capture the patient's own view of their health and quality of life (Devlin & Appleby, 2010). All PROMs were assessed preoperatively, six weeks postoperatively, and three months postoperatively. Other clinical characteristics (e.g. affected joint) were retrieved from the EPR. The survey containing questions related to psychological and communication characteristics was assessed postoperatively (median days after surgery: 266). Below some notable constructs from the survey are discussed in detail.

Table 3.1 Measures of clinical, psychological, and communication characteristics

Construct	Instrument	(Transformed) score
Clinical characteristics		
Health-related quality of life	EQ-5D-3L (R. Brooks, 1996)	0-1 Single summary index (0 = "worst health" 1 = "best health", <0 "worse than dead")
Self-reported health status	EQ VAS (R. Brooks, 1996)	0-100 (0 = "worst imaginable health state" to 100 = "best imaginable health state)
Pain	11-point Numerical Rating Scale (NRS) (Downie et al., 1978)	0-10 (0 = "no pain" to 10 = "worst pain possible")
Hip disability	Hip Disability and Osteoarthritis Outcome Score Physical Function Short-form (HOOS-PS) (Nilsdotter, Lohmander, Klässbo, & Roos, 2003)	0-100 (0 = "no difficulty" to 100 = "extreme difficulty)
Knee disability	Knee injury and Osteoarthritis Outcome Score Physical Function Short-form (KOOS-PS) (Roos, Roos, Lohmander, Ekdahl, & Beynnon, 1998; Roos & Toksvig-Larsen, 2003)	0-100 (0 = "no difficulty" to 100 = "extreme difficulty)
Hip function	Oxford Hip Score (OHS) (Dawson, Fitzpatrick, Carr, & Murray, 1996)	0-48 (0 = "worst" – 48 "best")
Knee function	Oxford Knee Score (OKS) (Dawson, Fitzpatrick, Murray, & Carr, 1998)	0-48 (0 = "worst" – 48 "best")
Affected joint	-	Hip or knee
Age	-	Age in years.
Psychological characteristics		
Anxiety	Hospital Anxiety and Depression Scale-Anxiety (HADS-A) (Spinhoven et al., 1997; Zigmond & Snaith, 1983)	0-21 (0 = "no anxiety" – 21 = "severe anxiety")
Pain catastrophizing [a]	Pain Catastrophizing Scale (PCS) (Sullivan, Bishop, & Pivik, 1995)	0-52 (0 = "best" – 52 = "worst")
Coping style [b]	Brief COPE (Carver, 1997)	0-3 (0 = "never" – 3 "very often")

Communication characteristics		
Preferences for patient-provider communication [c]	Communication preferences of patients with chronic illness questionnaire (KOPRA) (Farin, Gramm, & Kosiol, 2011)	0-100 (0 = "weak preference" – 100 "strong preference")
Preferences for shared decision making	Single question: After being informed about treatment options, some people prefer to leave decisions about their treatment up to their physician, whereas others prefer to make the decisions themselves. Please check the statement that best describes your preference in general. (Stiggelbout & Kiebert, 1997)	Passive = The physician should make the decisions using all that is known about the different treatments ***or*** The physician should make the decisions, but strongly consider my opinion Collaborative = The physician and I should make the decisions together on an equal basis Active = I should make the decisions, but strongly consider the doctor's opinion ***or*** I should make the decisions using all I know or learn about the treatments
Preferences for information sharing	Single question: In general, would you always want to be fully informed about all benefits and harms of a medical treatment? (Stiggelbout & Kiebert, 1997)	High = Yes, always Medium = In some cases Low = No
Communication competences [d]	Communication competence in the context of patient–provider interaction questionnaire (CoCo) (Farin, Schmidt, & Gramm, 2014)	0-5 (0 = "weak competence" – 5 = "strong competence")
Self-efficacy for health information	Consumer Health Information Preferences Scale-Self-Efficacy (CHIPS-SE) (Maibach, Weber, Massett, Hancock, & Price, 2006)	1-5 (1 = "low self-efficacy", 5 = "high self-efficacy")

[a] Including subscales helplessness, rumination, and magnification.

[b] Including subscales active coping, planning, positive reframing, acceptance, humour, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioural disengagement, and self-blame.

[c] Including subscales open information, patient participation, emotional support, and communication about personal circumstances.

[d] Including subscales adherent (attentive listening), critical (expressing doubt and disagreement), active (posing questions), and personal (discussing personal circumstances).

3.2.2.1 Stress, anxiety, and coping

Stress and anxiety are negative mood states that are common in patients undergoing TJR surgery (Duivenvoorden et al., 2013). They are produced when stressful events (e.g. pain) and resources to cope with such events are imbalanced (Carver, Scheier, & Weintraub, 1989; Lazarus & Folkman, 1984). Brief COPE is a validated instrument to assess 14 theoretically-based coping responses using 28 self-reported items (Carver, 1997; Carver et al., 1989). These include active coping ("I've been taking action to try to make the situation better"), acceptance ("I've been learning to live with it"), and denial ("I've been saying to myself 'this isn't real.'").

3.2.2.2 Patients' communication preferences and competences

We consider communication a transactional process between two people who exchange, create, and sustain shared meaning over time (Barnlund, 1970; West & Turner, 2008). This implies that physicians' communicative behaviour influences patients' communication and vice versa (Dekkers, Melles, Mathijssen, et al., 2018; Schöpf, Puy, Schmidt, & Farin, 2017; Street, 1991). Thus, even when a patient holds certain preferences, he or she might not enact these when physicians operate via a (non-preferred) relational model (Emanuel & Emanuel, 1992). Therefore, we assessed both the patient's preferences, as well as their behaviour during patient-provider communication (i.e. communication competence).

Preferences were assessed using the validated "Communication preferences of patients with chronic illness questionnaire" (KOPRA) instrument (Farin et al., 2011). Patients evaluated various communicative behaviours of physicians ("Your physician should… discuss the treatment plan with you"). It measures the relative importance patients attach to: patient participation and physicians' consideration of their opinion, open communication about information and negative events, physicians' empathy and emotional support, and a personal communication style that explores the patient's private life (Farin et al., 2011, 2012).

The original German instrument was translated into Dutch (with permission of E. Farin, personal communication, October 17 2016) according to the guidelines for cross-cultural adaptation of self-reported instruments (Beaton, Bombardier, Guillemin, & Ferraz, 2000; Sousa & Rojjanasrirat, 2011). Two certified translators independently performed a forward translation, a blinded backward translation and a comparison of the back-translated instrument to the original instrument. The resulting version was discussed by an expert committee, which covered researchers in psychology (TD, JP, HdR), psychometrics (JP), user-centred design (MM, BG) and orthopaedics (NM).

Communication competences were assessed using the validated "Communication behaviour of a patient in the context of patient-provider interaction" (CoCo) questionnaire (Farin et al., 2014). This instrument assesses four competences; adherence in communication (ADH), active disease-related communication (ACT), critical and participative communication (CRI), and personal communication (PER). The patient reflected on his or her performance of 28 behaviours on a 6-point scale. Items include: "I stuck to the subject during our talk" (ADH), "I posed questions regarding the treatment's goals" (ACT), I expressed my opinion of my therapy clearly to the doctor" (CRI), and "Sometimes the doctor and I laughed together" (PER). This instrument was also translated from German into Dutch following the previously discussed guidelines.

3.2.3 Statistical analyses

Descriptive statistics were used to report the demographic characteristics, internet usage, social support system, shared decision making, information sharing, and communication preferences and competences of participants.

The main methodology for developing target groups was cluster analysis. Cluster analysis is a technique for data reduction, which in the context of healthcare can be used to segment patients into clusters to identify homogenous patient groups (Clatworthy, Buick, Hankins, Weinman, & Horne, 2005; Kaufman & Rousseeuw, 1990; Sarstedt & Mooi, 2014; Swenson et al., 2016). Cluster analysis consists of four steps: selecting cluster variables, deciding the clustering procedure, determining the number of clusters, and validating the cluster solution. These steps are outlined below and, where applicable, supplemented with additional reporting as recommended by Clatworthy and colleagues (2005). All analyses were carried out in R3.3.1 (R Core Team, 2016).

3.2.3.1 Selection and pre-processing of clustering variables

Before processing, the combined dataset contained 81 variables. The final selection of clustering variables contained 23 variables. We removed administrative (e.g. surgery date, survey date) and sociodemographic variables (e.g. sex, social support). Age was kept in the clustering dataset as a clinical variable because age is often used in clinical decision making (Carr et al., 2012; R. W. Crawford & Murray, 1997). We removed joint-specific clinical variables (e.g. HOOS-PS, KOOS-PS, OHS, OKS) as including these would result two very small datasets (106 hip patients, 85 knee patients) that are not sufficient powered for cluster analysis. Finally, we reduced the coping variables from 14 to 7 subscales following a principal component analysis (PCA) with orthogonal rotation. This was to prevent multicollinearity which can skew the cluster solution (Ketchen & Shook, 1996; Punj & Stewart, 1995; Sambandam, 2003). For the same reason, we also removed the subscales of the PCS. After the final selection of variables, we imputed missing data using the "mice" package (Buuren & Groothuis-Oudshoorn, 2011) and scaled variables to account for the different measurement ranges.

3.2.3.2 Determination of the number of clusters

The appropriate number of clusters was determined in an exploratory hierarchical cluster analysis (Ward's clustering method with squared Euclidean distance) (Maechler, Rousseeuw, Struyf, Hubert, & Hornik, 2018; Punj & Stewart, 1995; Sarstedt & Mooi, 2014). The final cluster solution was based on confirmatory k-means cluster analysis and Euclidean distance as the similarity measure.

3.2.3.3 Validation of cluster solution

The external validity of the clusters was determined in a multivariate discriminant analysis with 'cluster' as the independent variable and patient satisfaction and outcomes at three months as dependent variables. Cluster stability was assumed when the same number of clusters continued to emerge in the exploratory hierarchical cluster analyses and similar clusters emerged over several random starts with different initial selections of the *k* centroids (Clatworthy et al., 2005).

3.2.3.4 Explanation of cluster solution

Classification and regression tree (CART) methodology was used to explain the cluster solution (Breiman, Friedman, Olshen, & Stone, 1984). CART is a supervised machine learning method to classify cases using a tree-based model (Lemon, Roy, Clark, Friedmann, & Rakowski, 2003; Loh, 2011; Swenson et al., 2016). The algorithm (package "RPART" (Therneau & Atkinson, 2018)) starts with the entire sample in one node and considers all variables to find which variable best differentiates the classes. When the optimal partition is identified, a decision rule is formulated (e.g. "self-reported health > 80") and two child nodes are created that further split the sample into two groups that (do not) satisfy the decision rule. Thereafter, the next variable that best differentiates the subsamples is determined and so on. This process continues until no further splits are made and the terminal node relays the predicted class.

Our first application of CART included only 23 variables of the clustering dataset and was used to explain why a patient is in one cluster rather than another. The second application of CART was to produce decision rules to classify future cases. Such tree-based classification instruments are user-friendly, easily interpretable, and as accurate as regression analyses (Breiman et al., 1984; Lemon et al., 2003; Swenson et al., 2016). In practice, such an instrument should preferably be applicable with minimum clinical burden. To develop this instrument we conducted a second CART analysis including all available data (including administrative variables, sociodemographic variables, and single questions from the survey). Since we only had access to a single dataset, we only tested the resulting decision-tree on (subsets of) the existing (i.e. training) dataset but not on new (i.e. testing) data. Therefore, we present this decision tree only as a preliminary screening instrument.

3.3 RESULTS

3.3.1 Participant characteristics

235 TJR patients were included and 191 returned the questionnaire (non-response rate 18%). The sample contained more female (60.8%) than male (39.2%) patients, and was mixed in respect to affected joint (hip: 55.5%, knee: 45.5%). A full description can be found in Table 3.2.

Table 3.2 Participant characteristics

	Total sample (N = 191)	
	Count	**%**
Age in years (mean, SD)	70.6	8.74
Sex		
Female	115	60.8
Male	74	39.2
Education		
Primary education	28	15.0
Lower secondary education	62	33.2
Higher secondary education	46	24.6
Tertiary education	51	27.3
Occupation		
Retired	113	59.8
Employed	25	13.2
Self-employed	20	10.6
Beneficiary	10	5.3
Other	21	11.1
Relationship status		
Married	129	68.3
Widowed	35	18.5
Divorced	16	8.5
Never married	8	4.2
Other	1	0.5
Social support [a]		
Partner	122	64.6
Child	60	31.7
Friend	30	15.9
Neighbour	17	9.0
No support	15	7.9
Family member	11	5.8
Group (church, sports)	4	2.1
Colleague	1	0.5
Other	7	3.7
Internet usage		
Daily	109	59.9
Never	31	17.0
Multiple times a week	29	15.9
Once a week	9	4.9
Monthly	4	2.2

Note. Sorted by prevalence. Sociodemographic data was missing for two participants.

[a] Patients could indicate multiple sources of social support.

Table 3.3 Characteristics of three profiles of total joint replacement patients

Variable	**Overall (N = 191)**		**Cluster 1 (N = 83)**		**Cluster 2 (N = 62)**		**Cluster 3 (N = 46)**		
	M	**SD**	**M**	**SD**	**M**	**SD**	**M**	**SD**	***p***
Clinical characteristics									
Health-related quality of life (0-1)	0.57	0.27	0.47	0.28	0.72	0.17	0.56	0.28	< .001
Self-reported health status (0-100)	69.84	16.85	64.34	18.15	76.76	15.29	70.46	12.62	.021
Pain (0-10)									
In rest	4.90	2.61	5.52	2.42	3.97	2.56	5.02	2.71	.018
Movement-evoked	7.31	1.79	7.66	1.57	6.68	2.04	7.52	1.59	.008
Age	70.51	8.67	68.53	8.09	69.40	8.64	75.59	7.83	< .001
Psychological characteristics									
Anxiety (0-21)	3.35	2.64	4.10	2.58	1.37	1.48	4.65	2.50	< .001
Pain catastrophizing (0-52)	15.20	9.20	17.53	8.35	8.61	5.61	19.89	9.78	< .001
Coping style (0-3)									
Positivity	1.55	0.59	1.86	0.51	1.33	0.63	1.30	0.41	.739
Self-distraction	1.48	0.86	1.93	0.72	0.92	0.77	1.43	0.76	< .001
Active support seeking	1.26	0.63	1.73	0.46	0.75	0.51	1.10	0.39	< .001
Venting	0.72	0.60	1.02	0.55	0.26	0.38	0.80	0.54	< .001
Religion	0.60	0.87	0.66	0.88	0.31	0.68	0.88	0.97	< .001
Maladaptive	0.52	0.46	0.67	0.51	0.22	0.24	0.67	0.38	< .001
Substance use	0.27	0.55	0.46	0.71	0.07	0.25	0.18	0.36	.143
Communication characteristics									
Communication preferences (0-100)									
Open information	69.11	16.41	80.12	12.05	62.82	14.78	57.72	12.89	.430
Patient participation	64.55	16.55	74.10	12.86	59.60	16.26	54.00	13.46	.298
Emotional support	48.01	17.40	54.37	17.02	38.84	15.33	48.91	15.53	< .001
Personal circumstances	32.09	19.52	39.94	19.36	23.15	17.54	30.00	16.77	.023
Preference for SDM (count, %)									
Collaborative role	97	50.8	41	50.00	34	55.74	22	51.16	0.882
Passive role	45	23.6	19	23.17	14	22.95	12	27.91	
Active role	44	23.0	22	26.83	13	21.31	9	20.93	
Preference for information sharing (count, %)									
High preferences	160	83.8	73	87.95	56	90.32	31	72.09	0.022
Low-medium preferences [a]	28	13.6	10	12.05	6	9.68	12	27.91	
Communication competences (0-5)									
Adherent	4.10	0.39	4.19	0.40	4.13	0.39	3.87	0.26	.001
Critical	3.41	0.71	3.79	0.56	3.36	0.64	2.77	0.57	< .001
Active	3.26	0.97	3.79	0.67	3.04	0.94	2.60	0.94	.089
Personal	2.88	0.99	3.16	0.94	3.03	0.97	2.16	0.71	< .001
Self-efficacy for health information (1-5)	3.46	0.57	3.63	0.55	3.51	0.53	3.06	0.44	< .001

Note. SDM=shared decision making. Multivariate analysis showed that clusters differed significantly on clustering variables (Wilks' λ = .453, F(24,166) = 8.36, p < .0001). The probability values from the univariate tests are reported in the last column. However, it should be noted that all p-values are exploratory and presented for interpretation only.

[a] Only 2 participants reported low information preferences. This was too low for correct approximation of chi-squared. Therefore, we aggregated low-medium preferences.

3.3.2 Communication preferences, competences, and self-efficacy of TJR patients

Patients considered open information most important (M=69.11, SD=16.41), followed by participatory communication (M=64.55, SD=16.55). Whether physicians explored and discussed personal circumstances was considered the least important (M=32.09, SD=19.52) on average, but preferences for this type of communication also varied most between patients. Half of the patients preferred to take a collaborative role in shared decision making, while 1 in 4 preferred either a more passive or active role. All communicative characteristics are described in Table 3.3.

3.3.3 Identification, validation, and interpretation of clusters

The exploratory hierarchical analysis suggested that three clusters best described the data. In the follow-up k-means cluster analysis a three-cluster solution was also selected as the final classification. The clusters differed significantly in their overall characteristics (Wilks' $\lambda = .453$, $F(24,166) = 8.36$, $p < .0001$). The characteristics of each cluster are shown in Table 3.3.

Cluster 1 (44%) was characterized by lower preoperative health, higher pain scores, use of multiple coping strategies (including self-distraction and actively seeking support), and the highest communication preferences, competences, and self-efficacy. Cluster 2 (32%) was characterized by higher preoperative health status, lower anxiety, limited coping behaviour, lower preferences for emotional support and discussion of personal circumstances, and moderate communicative competences. Cluster 3 (24%) was characterized by higher age, higher anxiety, a relatively high preference for emotional support, and lower communication competences and self-efficacy. Clusters differed significantly in satisfaction with communication and postoperative self-reported health (Wilks' $\lambda = .889$, $F(6,153) = 3.188$, $p = .006$). Cluster 2 was the most satisfied and had the best postoperative health at three months, while cluster 3 was the least satisfied and had the lowest health status (Table 3.4). Joint-specific disability and function after three months differed only between hip, but not knee, patients. Again, cluster 2 showed the best outcomes.

Table 3.4 Satisfaction and clinical outcomes three months after TJR surgery in three clusters of patients

Variable	**Cluster 1 (N = 83)**		**Cluster 2 (N = 62)**		**Cluster 3 (N = 46)**		
General outcomes	**M**	**SD**	**M**	**SD**	**M**	**SD**	***p***
Satisfaction with communication	8.28	1.35	8.74	0.96	7.86	1.57	0.001
Satisfaction with outcome	7.94	1.94	8.57	1.30	8.16	1.02	0.236
Self-reported health status	73.99	18.13	80.63	15.93	69.10	20.87	0.002
Pain in rest	1.74	2.12	0.94	1.43	1.78	2.20	0.074
Movement-evoked pain	2.71	2.24	2.07	2.21	2.95	2.47	0.106
Hip specific outcomes	**Cluster 1 (N = 47)**		**Cluster 2 (N = 36)**		**Cluster 3 (N = 23)**		
Hip disability	20.52	13.58	13.01	9.25	20.55	14.22	0.032
Hip function	39.13	6.95	43.16	3.72	37.05	7.86	0.002
Knee specific outcomes	**Cluster 1 (N = 36)**		**Cluster 2 (N = 26)**		**Cluster 3 (N = 23)**		
Knee disability	38.83	18.30	32.31	14.51	32.16	8.89	0.194
Knee function	34.58	8.12	36.71	8.53	35.68	6.8	0.633

Note. Multivariate analysis showed that clusters differed significantly on general outcomes (Wilks' $\lambda = .889$, $F(6,153) = 3.188$, $p = .006$). The probability values from the univariate tests are reported in the last column.

The first CART analysis identified that 'coping through active support seeking' best distinguished cluster 1 from cluster 2 and 3 (Figure 3.2). 76% of patients who reported this coping behaviour to some extent (>1.3 out of 3) were classified to cluster 1. The second-best discriminating feature was anxiety. Absence of anxiety (<3.5 out of 21) differentiated cluster 2 from cluster 3. 77% of the patients without anxiety were classified to cluster 2. Patients with anxiety scores above 3.5 were classified to cluster 3 (61%). Thus, the identified clusters mainly differ in their tendency to actively seek support and their levels of anxiety.

3.3.4 Preliminary screening instrument

The preliminary instrument for screening for TJR subgroup is presented in Figure 3.3. Three decision rules are used to assign patients to the appropriate cluster. In the current dataset the instrument achieved 76% accuracy with 95% CI [69%, 82%]. The instrument is slightly more accurate for cluster 1 (83%) and 2 (81%) compared to cluster 3 (78%).

The decision rules are based on presence of coping by planning ("I've been trying to come up with a strategy about what to do." > 0.5), absence of helplessness when faced with pain ("When I'm in pain, I feel I can't stand it anymore." < 1.5), and a preference for open communication about unpleasant effects ("Your physician should always tell you everything about your illness, even if it is unpleasant." >= 3.5).

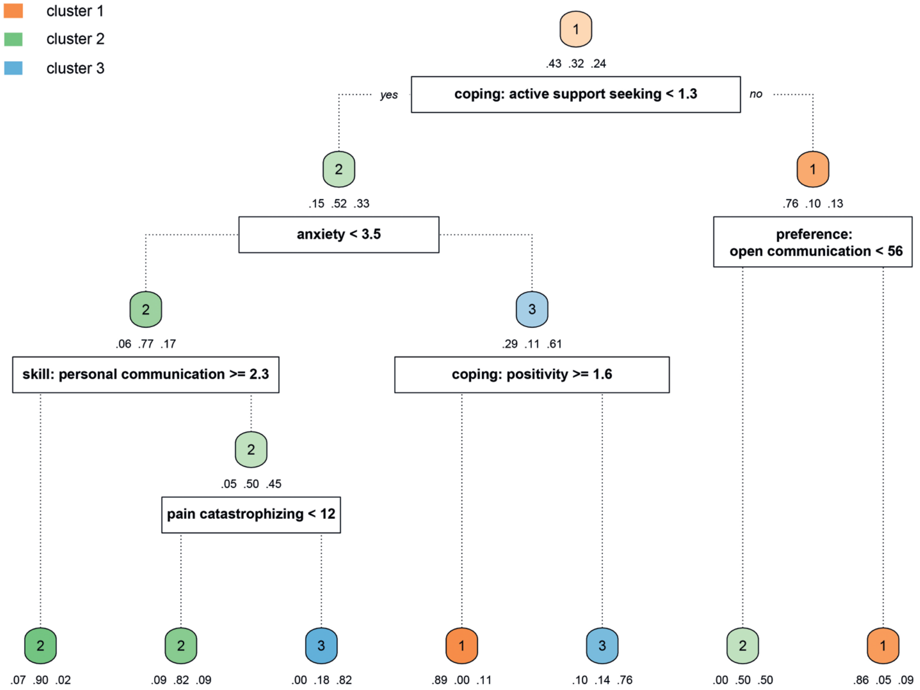

Figure 3.2 Tree diagram of characteristics that distinguish patient profiles

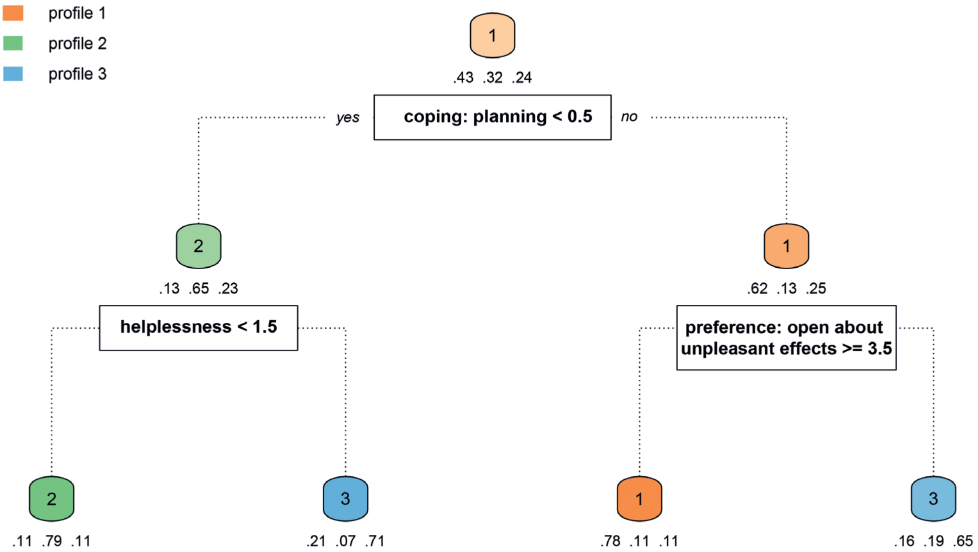

Figure 3.3 Preliminary screening instrument for determining patient profile

3.4 DISCUSSION AND CONCLUSION

The aim of this paper was to describe the communication preferences and competences of patients who undergo total joint replacement (TJR) surgery and investigate whether holistic target groups of patients could be defined by concurrently examining patients' clinical, psychological, and communication characteristics. These insights can be used to tailor health communication and improve satisfaction after TJR. We have identified three clusters ('patient profiles') with different communicative characteristics, clinical presentations, and psychological coping mechanisms. A screening instrument of three questions can be used to screen the most likely profile of a TJR patient.

3.4.1 Practice implications for personalised care

Most TJR patients were classified to cluster 1. These individuals expressed the strongest communication preferences, had the highest communication competences, practiced a diverse set of coping styles, and had the lowest preoperative health and quality of life. Due to the amount and diversity of resources they involve in managing TJR and the high demands they set for communication, we have named this group the managing profile. Managing patients report moderate-to-good satisfaction with communication and show large improvements in health and quality of life after surgery.

Patients who participate in the care process are more likely to be satisfied (Bot et al., 2014; Rost, 1990) which may explain why managing patients reported moderate-to-high satisfaction. At the same time, this profile's high expectations for openness, participation, and active decision making may not be easy to fulfil. As previously discussed, unfilled expectations may cause dissatisfaction (Culliton et al., 2012; Hamilton et al., 2013; Palazzo et al., 2014; Scott et al., 2012). Therefore, patients who present with high expectations of patient-provider communication may end up less satisfied if they are not offered opportunities to enact on their preferences.

To personalize communication towards this group we suggest two approaches: first, physicians should aim to meet the high communication preferences, for example by actively facilitating SDM and providing additional education and information through online platforms. Healthcare providers may also involve the managing patient's extensive social network (see Appendix 3A). Another priority to address is managing patients' lower satisfaction with outcomes. While not directly assessed in this study, we expect that since these patients had high expectations for communication, they may also hold strong outcome expectations. Therefore, discussing and aligning expectations for recovery may be an important activity to conduct with this group in particular.

The second most prevalent cluster comprised patients who did not have strong preferences for specific styles of communication nor demonstrated specific coping strategies. They had the highest preoperative health and quality of life. Due to their high health and low needs even when faced with a potentially stressful event such as TJR, we describe this group as the optimistic profile. Patients in the optimistic profile had the best absolute outcomes in health, quality of life, and satisfaction.

Several factors may explain the high satisfaction reported by optimistic patients First, from a clinical perspective, patients with good physical and mental health are more likely to be satisfied with TJR (Hamilton et al., 2013; Palazzo et al., 2014). Second, patients reflecting back on a surgery with successful outcomes may have simply thought more positively of their physician's communication in retrospect. Third, the current 'one-size-fits-all' care service may be 'personalised' de facto for optimistic patients. In a previous study we observed 171 consultations between orthopaedic surgeons and patients and found that most consultations focussed on providing elaborate medical information to patients who were perceived by surgeons as competent in terms of disease management and communication (Dekkers, Melles, Mathijssen, et al., 2018). This communication approach seems aligned with the preferences of optimistic patients who did not find the physician's communicative style particularly important, but do value open provision of information. The experience that their needs are met, notwithstanding through the surgeon's intuition and not a formal personalisation strategy, may explain why these patients were highly satisfied. We therefore tentatively suggest that personalised communication for optimistic patients may simply entail usual care.

Finally, the third and smallest cluster consisted of older patients with moderate preoperative health who reported significantly lower competences and self-efficacy for health communication. They reported lower communication preferences, but did have relatively large preferences for emotional support. As these patients had specific preferences but were less vocal in expressing them, we named this group the modest profile. Patients in the modest profile showed limited postoperative improvements and were the least satisfied with communication.

While none of the patients included in this study had clinically relevant levels of anxiety, modest patients were most likely have borderline anxiety disorders: 13% vs. 6% (managing) vs. 0% (optimistic). They were also more likely to demonstrate clinically relevant levels of pain catastrophizing (15% vs. 6% vs. 0%). This higher incidence of anxiety and pain catastrophizing may present specific difficulties for patient-provider communication. First, conveying health information to patients with limited communicative competences in distress requires a different approach from physicians. Additional emotional support or a more empathic communication style may be necessary, just as referrals to additional psychological care. This may be particularly important because modest patients' also report increased tendencies to catastrophize pain. According to the communal coping model, pain catastrophizing can be a way to elicit emotional support from others (Leung, 2012; Sullivan, Tripp, & Santor, 2000). Since modest patients had the most difficulties with communication, their catastrophizing tendencies may be a (subconscious) strategy to non-verbally signal emotional support needs. Perhaps, programs that help these patients to build communicative skills could address both limited communication competences directly, as well as reduce pain catastrophizing indirectly by diminishing the need for communal expressions of distress. Finally, we suggest that physicians determine modest patients' comprehension of medical information. We have shown that people with this profile have the most difficulties with understanding health information which is further complicated by their anxiety. Failing to comprehend information may limit these patients' capacity to actively participate in the care process, which in turn can negatively affect their satisfaction as well as their surgical outcomes (Altin & Stock, 2016; Street et al., 2012).

3.4.2 Limitations and further study

This study has several limitations. First, communication characteristics of patients were collected retrospectively. Intuitively, it makes sense that patients would enter the healthcare system with distinct preferences that affect satisfaction. However, preferences may change after encounters with care providers as patients find an opportunity to test, experience, and revalue their assumed preferences. Therefore, retrospectively assessed preferences may differ from prospective preferences (Black et al., 2014; Street et al., 2012). We have tried to address this limitation by excluding participants whom had had previous clinical encounters during prior TJR.

However, response shift and recall bias may have also affected patients' responses. Response shift refers to a change in evaluation of a construct resulting from recalibration of standards, reprioritization of values, and reconceptualization of the construct itself (Schwartz & Sprangers, 2014). We expect that patients whose outcomes were worse than anticipated (i.e. managing profile) or better (i.e. optimistic profile) may have reprioritized the value of patient-provider communication. In particular, managing patients may have reported higher preferences because they would have wanted to be better informed about the poor outcomes they experienced, while optimistic patients reported lower preferences because they less need to be informed since they already had achieved good outcomes. Possibly, preoperative communication preferences of TJR patients may thus be less diverse than outlined here. Furthermore, recall bias may have reduced patients' ability to accurately remember their communicative behaviour during patient-provider consultations. Therefore, they may have under- or overestimated their competences. However, we did not find that time between surgery and measurement had influenced self-reports. Still, the extent to which preferences and competences change throughout the TJR surgery trajectory and in turn affect patient profiles remain important issues for future research.

Second, it should be restated that cluster analysis is an exploratory method that is dependent of the researchers' subjective choices (Clatworthy et al., 2005). We have partly addressed this limitation by using objective indices to determine the appropriate number of clusters and by investigating cluster stability over a series of analyses. However, the cluster solution was not validated on a new data set. Now that we have demonstrated that three profiles accurately represented the clinical, psychological, and communication characteristics of this sample of TJR patients, the clusters should be validated over time and other (international) contexts. The presented screening instrument may contribute towards this goal as it gives physicians the opportunity to quickly gain insight in the distribution of profiles in their patient population. However, since the screening instrument was not tested on new data, researchers and clinicians should be mindful that it may be overfitted, i.e. closely fitted to the idiosyncratic characteristics of this particular sample, but poorly generalizable to other populations (Babyak, 2004). This potential concern highlights the need for future studies to further determine the accuracy of the instrument. Of course, as new information is collected on patient profiles in non-surgical or chronic populations, the descriptions of the profiles or the instrument may also need to be updated accordingly.

3.4.3 Conclusion

Tailoring health communication to the preferences and characteristics of patients may improve patient satisfaction and outcomes after TJR surgery. This research has shown that on average, patients value open information and participation but preferences are still highly diverse. Three patient profiles summarize distinct ways through which TJR patients may experience their health, cope with major surgery and wish to communicate with their healthcare provider. This may be used as a starting point to develop more personalized approaches to communication, which is expected to improve the quality of care.

Chapter 4

Patient profiles: A comparison of health consumers and patients

Summary

The previous chapter introduced a set of three patient profiles that represent the experienced health, psychological coping mechanisms, communicative preferences and competences of patients who had undergone total joint replacement (TJR) surgery. It also tentatively suggested that preferences may have changed over the course of treatment. In order to explore the variability of preferences over time, we now validate the set of profiles for prospective health consumers, i.e. people who experience chronic hip and knee complaints but are not yet under medical treatment.

Chapter 4 consists of two studies. Study 1 aims to describe the characteristics of prospective health consumers in comparison to treated patients and to examine whether the same set of three patient profiles accurately describes both populations. The findings from study 1 shows that while health consumers hold stronger absolute communication preferences than patients do (section 4.2.3), the relative differences in the health consumer population are still accurately described by the existing set of patient profiles (section 4.2.5). Building on these findings, study 2 combines patient and health consumer data to develop and test different instruments for accurate assessment of patient profiles throughout the TJR patient journey. Findings from this study show that neither the screening instrument presented in Chapter 3 nor patient self-selection are sufficiently accurate for profile allocation over time (section 4.3.3). Therefore, an updated patient profiling instrument is presented suitable for use with both patients and health consumers (section 4.3.4).

4.1 INTRODUCTION

By the time patients undergo a lower limb total joint replacement (TJR) surgery a long journey of conservative treatment, medical consultations, and surgical preparation has passed. The journey does not end with surgery either, as patients still await a rehabilitation period in which they may experience decreased muscle strength, limited flexibility, and gait problems for months to years after the surgical procedure (Brander & Stulberg, 2006; Meier et al., 2008). This extensive patient journey holds many opportunities in which healthcare services can be tailored to the preferences, needs, and competences of patients. For example, patient preferences can be incorporated into the clinical decision making process through interventions that support shared decision making (Bozic et al., 2013) or into the way that patient education is disseminated (Ackerman et al., 2016, Chapter 6). The main expectation of such tailored healthcare services is that they will improve patients' satisfaction with the service and increase adherence to treatment (Kiesler & Auerbach, 2006; Street et al., 2012). Since nonadherence to exercise and medication regimens may result in poor long-term outcomes after TJR surgery (Marks & Allegrante, 2005; Pisters et al., 2010; Wilke & Müller, 2010) improving satisfaction and adherence could ultimately improve patients' health.

In order to tailor healthcare services to the preferences of patients, patient preferences need to be known. In 2015-2016 we collected biopsychosocial data from 191 patients who had undergone TJR at one Dutch regional hospital (see Chapter 3). These included patients' experiences of their health, their psychological coping mechanisms, and their preferences and competences in health communication. After performing a series of exploratory and confirmatory cluster analyses, we found that the health experiences, preferences and competences of TJR patients could be represented in a set of three data-driven patient profiles: the *managing* profile, the *optimistic* profile, and the *modest* profile. While no individual patient is fully characterized by just one of these profiles, these distinct groups provide a starting point for healthcare and creative professionals to develop tailored care variants. However, this segmented approach to tailoring does make the implicit assumption that patient profiles will be stable over time and throughout the patient journey. This assumption of stability will be the target of the present study.

4.1.1 A theoretical account on the variability of preferences over time

Just as there are many opportunities to tailor care during TJR treatment, patients also have many opportunities to explore, enact, and revalue their preferences during the journey. For example, an athlete may believe that he or she will not want to hear the risks of the knee surgery. Yet as the prospect of surgery becomes more real and tangible, that same person may find out that they actually would have liked to have more information on how the surgery risk relates to their exercise behaviour. This process of revealed, constructed, and enacted preferences is articulated by Street et al. (2012) in their ecological model of patients' healthcare experience which poses that preferences are not only shaped by relatively stable macro-level factors (including the cultural, social, media, and economic context) but also by situational micro-level factors such as the clinical encounter and the experienced outcomes of care. This model does not consider patient preferences stable and immutable, but rather dynamic beliefs that evolve and shift over time. This dynamic character may also hold true for other aspects that underlie patient profiles, in particularly patients' communicative competences. Patients' may gain a better understanding of their disease and its management through experience or structured patient education (Kroon et al., 2014), or gain more confidence in asking questions as a result of a trusting and encouraging patient-provider relationship (Belcher, Fried, Agostini, & Tinetti, 2006; Fraenkel & McGraw, 2007).

If patient preferences and competences are indeed variable, the moment at which patient characteristics are assessed becomes a relevant factor. Assessed preferences may differ before and after a single consultation and across an accumulation of consultations over time, even when the same instrument is being used or the same patient is being assessed. In Chapter 3, patients reflected back on their patient journey and self-reported their preferences. This data was used directly to determine the set of patient profiles. Therefore, the same set of patient profiles may thus not accurately represent patients at other points in their journey. In particular, people who have not yet started treatment may report different preferences and competences, which would result in different profiles.

It is desirable that healthcare professionals and designers can estimate a patient's profile accurately, especially early in the care trajectory. This would allow healthcare services to be attuned to individual patients from the beginning of treatment. As mentioned earlier, accommodation of preferences can lead to better health outcomes by increasing patient adherence to the treatment plan and by supporting patient autonomy and satisfaction with care (Street et al., 2012). Providing care that continuously does so from the very beginning is likely even more beneficial. This may be especially true for TJR, in which multiple consultations with various health professionals occur over a long period of time and active participation and adherence to the rehabilitation plan is instrumental to optimize health outcomes (Andrawis et al., 2015; Franklin, McLaughlin, Boisvert, Li, & Ayers, 2006).

In summary, there are theoretical accounts which indicate that preferences and competences and thus patient profiles might change over time. By comparing the preferences of people who have not yet started treatment for their joint complaints to the preferences of patients, we can explore if and to what extent these vary across the TJR patient journey. This insight may be applied to the development and implementation of tailored healthcare services from the start and throughout TJR treatment, which is expected to increase adherence and patient satisfaction and subsequently, improve health outcomes.

This chapter is divided in two studies that cover three aims. In the first study we 1) describe the characteristics of health consumers and compare these to patients and 2) examine whether the same set of three patient profiles accurately describes data patterns in the health consumer population. The results from the first study are used in a second study in which we combine patient and health consumer data to 3) develop and test different instruments for assessing patient profiles throughout the TJR patient journey.

4.2 STUDY 1: COMPARING HEALTH CONSUMERS AND PATIENTS

4.2.1 Procedure, measures, and participants

We analysed a subsample of 235 participants with self-reported chronic hip or knee joint complaints of 633 participants that were recruited using a Dutch online consumer research service (respondenten.nl) as part of a larger study on tailored patient education. Excluded from the analysis were participants who did not respond to the survey invitation (N=130); responded to the invitation after the survey had closed (N=186); or failed to finish the survey (N=82).

Participants were provided a hyperlink to an online survey and filled out questionnaires regarding their perceived health status, anxiety, coping mechanisms, and communication preferences and competences (see Table 4.1). These measures were selected because they best differentiated profiles in the previous patient study. Participants were also asked to select their preferred role in the healthcare system (see 4.3.1) and provided sociodemographic background characteristics (sex, education, occupation, relationship status, social support, and internet usage) for comparison. The complete study took approximately 45 minutes and was conducted online. Participants received a small reimbursement for their participation. Throughout this chapter, we refer to the dataset above as the health consumer dataset. For comparing the health consumers to patients, we used the data of 191 patients collected in the study described in Chapter 3. We refer to this dataset as the patient dataset.

Table 4.1 Data collection in the health consumer population

Construct	Explanation	Instrument
Health experience		
Self-reported health	Rating of own current health state on a visual analogue scale from zero ('worst imaginable health state') to 100 ('best imaginable health state').	EQ5D-VAS (R. Brooks, 1996)
Pain in rest	Rating of joint pain in rest on a numerical rating scale from zero ('no pain') to 10 ('unbearable pain')	NRS (Downie et al., 1978)
Movement-evoked pain	Rating of movement-evoked joint pain on a numerical rating scale.	NRS (Downie et al., 1978)
Anxiety	10-item assessment of trait anxiety converted to a percentile rank score from 0-100 following the formula of Crawford and colleagues (J. R. Crawford, Cayley, Lovibond, Wilson, & Hartley, 2011; J. R. Crawford, Garthwaite, & Slick, 2009)	Short form STAI-A Trait scale (De Vries & Van Heck, 2013)

Psychological coping mechanisms		
Pain catastrophizing	13-item assessment of pain catastrophizing, an exaggerated negative mental state faced during an actual or anticipated painful experience which includes magnification of pain, ruminations about pain, and feeling helpless when in pain.	Pain Catastrophizing Scale (PCS) (Sullivan et al., 1995)
Active support seeking	8-item self-assessment of frequency of use of active support seeking as a coping response which includes taking action, making plans, and seeking emotional and instrumental support from others on a scale from zero ('never') to 3 ('very often').	Brief COPE (Carver, 1997)
Maladaptive coping	6-item self-assessment of frequency of use of a maladaptive coping response, which includes denial, behavioural disengagement (i.e. giving up), and blaming oneself.	Brief COPE (Carver, 1997)
Positivity	6-item self-assessment of frequency of use of a positive coping response, which includes positive reframing, humour, and acceptance.	Brief COPE (Carver, 1997)
Religious coping	2-item self-assessment of frequency of use of a religious coping response, which includes praying, spirituality, or mediation.	Brief COPE (Carver, 1997)
Venting	2-item self-assessment of frequency of use of venting as a coping response, which includes expression of negative feelings.	Brief COPE (Carver, 1997)
Substance use	2-item self-assessment of frequency of using substances as a coping response, including alcohol or other drugs.	Brief COPE (Carver, 1997)
Self-distraction	2-item self-assessment of frequency of use of self-distraction as a coping response, which includes seeking distraction in work or hobbies.	Brief COPE (Carver, 1997)
Preferences and competences in health communication		
Preference for open information	10-item assessment of the relative importance of communication aspects that relate to effective, direct, and open communication, including information about negative stressful aspects of the illness, converted to a percentile score from zero ('not important') to 100 ('very important').	Communication preferences of patients with chronic illness questionnaire (KOPRA) (Farin et al., 2011)
Preference for emotionally supportive communication	6-item assessment of the relative importance of communication aspects that relate to emotionally supportive communication, including being optimistic, addressing patient anxiety, and greeting warmly.	KOPRA (Farin et al., 2011)
Critical communication competences	9-item self-assessment of the patient's competence in critical and participative communication about health, which includes posing questions and expressing doubt and disagreements, expressed on a scale from 0 ('low competence') to 5 ('high competence').	Communication competence in the context of patient–provider interaction questionnaire (CoCo) (Farin et al., 2014)
Personal communication competences	5-item self-assessment of the patient's competence in communication about personal circumstances, which includes talking to the healthcare professional about things that are not directly related to the illness.	CoCo (Farin et al., 2014)
Self-efficacy for understanding health information	6-item assessment of the patient's belief in their ability to successfully for find and understand health information expressed on a scale from 1 ('low self-efficacy') to 5 ('high self-efficacy).	Consumer Health Information Prefe-rences Scale-Self-Efficacy (CHIPS-SE) (Maibach et al., 2006)
Demographics		
Age	Age in years.	-

Note. Measures that are taken with the same instrument (NRS, Brief COPE, KOPRA, CoCo) are measured on the same scale. The scale is provided with the first mention of the instrument.

4.2.2 Statistical analyses

Differences between health consumers and patients were explored using descriptive statistics. To test for significant differences between both populations we employed Analyses of Variance (ANOVA) tests for the characteristics measured on ordinal and interval scales (e.g. age, communication preferences, coping style) and chi-squared (χ^2) tests for nominal variables (e.g. gender, occupation).

One variable, anxiety, could not directly be compared between the two populations as it was measured using two different instruments: the Hospital and Anxiety Depression Scale (HADS) in the patient cohort and a short form of the State-Trait Anxiety Inventory (STAI-A Trait) in the health consumer cohort. Therefore, both scores were transformed to percentile rank scores using the formula of Ley (1972) as described in Crawford, Garthwaite, & Slick (2009):

$$\text{Percentile rank} = \left(\frac{m + .5k}{N}\right) 100$$

Formula 4.1 Percentile rank score transformation

Note. *m* is the number of members of a normative dataset scoring below the given score, *k* is the number obtaining the given score, and *N* is the size of the normative dataset.

For patients, we used the normative dataset of Crawford, Henry, Crombie, and Taylor (2001) to arrive at the rank score. For health consumers, no normative data was available for the STAI-A Trait short form yet. Therefore, we used the health consumer dataset itself as the normative dataset. As there were significant differences in anxiety between females and males in both health consumers and patients, percentile rank scores were calculated for each sex separately.

To examine whether health consumers could also be represented by three profiles we took a two-part approach. First, we wanted to validate whether (any) three-cluster solution would fit the health consumer data set. Since this was the case, we examined to what extent the three clusters of health consumers also exhibited similar characteristics as the three profiles of patients.

We followed the methodology of Kassambara (2017) to validate the three-cluster salutation. First, we determined the clustering tendency of the data using the Hopkins statistic (H) to evaluate whether the dataset contained any meaningful clusters. The Hopkins statistic is expressed as 1 – H (H_{min}= 0). Values close to 0 indicate significantly clusterable data while values > 0.5 indicate that the data is uniformly distributed and likely does not contain meaningful clusters (Kassambara, 2017; Kassambara & Mundt, 2017).

Clusters should be compact, well-separated, connected, stable, and meaningful (Brock, Pihur, Datta, & Datta, 2008). We evaluated the three cluster solution and five competing models (with 2 to 6 clusters) on the first four aspects. We were not able to evaluate the last aspect ‘meaningfulness’ because no ‘true’ external grouping (e.g. a species or diagnosis) is available for patient profiles. Compactness refers to the closeness of observations within the same cluster and separation to the separation of observations between different clusters. Compactness and separation are expressed by the average silhouette width (*S*i, range -1 to 1) and the Dunn index or cluster diameter (D, range 0 to ∞). Connectedness (i.e. placement of similar observations in the same cluster) is expressed by the connectivity index (C, range 0 to ∞). Lower values of C and higher values of *S*i and D indicate more compact, separated, and connected clusters.

A cluster solution is stable when removing one predictor from the dataset produces similar clusters as when the full dataset is used. Stability was assessed using the average proportion of non-overlap (APN), the average distance (AD), and the average distance between means (ADM). APN ranges from 0 to 1, with smaller values indicating more consistent clustering results. AD and ADM range from 0 to ∞ with smaller values indicating higher stability. We consider stability to be the most important aspect of cluster evaluation. This determines whether individuals are consistently placed in the same cluster regardless of potential measurement errors, which is necessary to make clinical decisions about appropriate treatments.

After validation of the three-cluster solution, we examined if the clusters in the health consumer dataset had the same characteristics as the clusters identified in patients. To determine which clusters to compare, we first calculated the distance between cluster centres for each health consumer and patient cluster. Each health consumer cluster was then assigned the label of the closest patient cluster centre (Swenson et al., 2016). Next, we compared the average characteristics of each cluster in a two-way ANOVA with cluster (1/2/3) and population (health consumer/patient) as independent variables and profile characteristics (clinical status, psychological coping, and communication preferences and competences) as dependent variables. All analyses were conducted in R version 3.5.1.

4.2.3 Clinical, psychological, and communication characteristics of health consumers

Health consumers were younger, more likely to be employed, and used the internet more often than patients (Table 4.2). They also reported significantly less preoperative pain yet experienced more anxiety. Furthermore, they reported more coping mechanisms and higher communication preferences for both open information as well as emotional support.

Table 4.2 Clinical-, psychological-, communication-, sociodemographic-, and internet-related characteristics of health consumers in comparison to patients

	Health consumers (N=235)		**Patients (N=191)**		
	Mean, %	**SD**	**Mean, %**	**SD**	**Δ**
Experience of health					
Self-reported health	68.80	17.75	70.06[a]	16.47	-1.26
Preoperative pain in rest	3.73	2.59	4.79[a]	2.58	-1.06*
Preoperative movement-evoked pain	4.84	2.23	7.27[a]	1.84	-2.43***
Anxiety	50.43	28.86	28.09	22.37	+22.34***
Coping behaviour					
Pain catastrophizing	14.00	9.27	14.94	9.13	-0.94
Active support seeking	1.63	0.52	1.26	0.63	+0.37***
Maladaptive coping	0.76	0.43	0.52	0.46	+0.24***
Positivity	1.66	0.54	1.55	0.60	+0.11
Religious coping	0.60	0.85	0.58	0.86	+0.02
Venting	1.15	0.60	0.72	0.60	+0.43***
Substance use	0.48	0.69	0.27	0.55	+0.21*
Self-distraction	1.82	0.67	1.48	0.86	+0.34**
Preferences and competences in health communication					
Preference open information	77.74	13.36	69.40	16.25	+8.34***
Preference emotionally supportive communication	51.72	17.93	47.77	17.38	+3.95*
Critical communication competences	3.53	0.73	3.41	0.71	+0.12
Personal communication competences	2.71	1.01	2.88	0.99	-0.17
Self-efficacy for health information	3.67	0.60	3.46	0.57	+0.21
Sociodemographics					
Age in years	57.11	7.81	70.55	8.74	-13.44***
Sex (% female)	71.06%	-	60.85%	-	+16.78%
Education (% higher education)	52.77%	-	37.43%	-	+40.98%*
Occupation (% employed)	55.74%	-	23.81%	-	+134.10%***
Relationship status (% married or relationship)	61.97%	-	68.25%	-	-9.20%
Social support [b]					
From family (% recipients of support)	69.79%	-	85.19%	-	-18.08%**
From other sources (% recipients of support)	41.63%	-	25.93%	-	+60.55%**
No support (% recipients of no support)	12.34%	-	7.94%	-	+55.42%
Internet usage					
Usage (% daily users)	100%	-	59.89%	-	+66.97%***
Device usage [b]					
PC or laptop (% users)	87.55%	-	71.12%	-	+23.10%***
Phone (% users)	81.11%	-	39.57%	-	+104.98%***
Tablet (% users)	45.06%	-	44.92%	-	+0.31%

Note. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. All p-values are corrected for multiple comparisons (Holm correction).

[a] Self-reported health and preoperative pain of patients were assessed prior to the total joint replacement surgery. All other characteristics were assessed after surgery.

[b] Participants could indicate multiple sources of support and use of multiple devices.

4.2.4 Evaluation of three cluster solution

Hopkins statistic (0.393) was below 0.5, indicating that the health consumer dataset contained meaningful clusters. Table 4.3 shows the results of the evaluation of the three cluster solution. Compactness, separation, and connectedness of the three cluster solution was limited, indicated by the low average silhouette width (0.091), low Dunn index (0.202), and high connectivity index (180.46) scores. In comparison, a two and six cluster solution produced marginally better results. Still, the three cluster solution was more stable than any other cluster solution, as indicated by both a low average proportion of non-overlap and low average distance between means.

Overall, a two cluster solution would provide somewhat better separated clusters and a six cluster solution more compact clusters. However, neither solutions would consistently produce stable clusters. Therefore, we decided to retrain the original three-cluster solution. The limitations of this solution in terms of compactness and separation are further discussed in section 4.4.

Table 4.3 Evaluation of three cluster solution in comparison to k[2:6] solutions

		K=2	K=3	K=4	K=5	K=6
Compactness and separation	*S*i (-1–1)	**0.115**	0.091	0.078	0.076	0.065
	D (0–∞)	0.227	0.202	0.239	0.232	**0.248**
Connectedness	C (0–∞)	**115.366**	180.463	225.970	243.764	265.839
Stability	APN (0–1)	0.219	**0.198**	0.314	0.390	0.447
	AD (0–∞)	5.641	5.383	5.328	5.278	**5.241**
	ADM (0–∞)	0.8360	**0.7255**	1.0961	1.3142	1.4708

Note. Bold-faced values indicate the best clustering results.

C=Connectivity index, *S*i=Silhouette width, D=Dunn index, APN=average proportion of non-overlap, AD=average distance, ADM=average distance between means.

4.2.5 Comparison of profiles in health consumer and patient population

Based on the distance between cluster centres, 56 health consumers were assigned to the managing profile, 100 to the optimistic profile, and 79 to the modest profile. Figures 4.1 to 4.3 show the differences between the experience of health, psychological coping mechanisms, and communication preferences and competences per profile in the health consumer and patient populations.

Most interactions between profile and population were not significant (57%)[13] and the relative patterns in the health consumer data correspond remarkably well overall with patterns seen in the patient data. For example, while patients had more movement-evoked pain than health consumers on average, the relative ordering between profiles remained consistent: optimistic patients (M=6.6, SD=2.1) and health consumers (M=3.8, SD=2.3)

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[13] The full results of the analysis of variance are reported in Appendix 4A.

had the lowest pain scores, followed by managing (M=7.6, SD=1.6; M=5.5, SD=2.3) and modest (M=7.6, SD=1.7; M=5.6, SD=1.6) patients and health consumers.

In 13 out of 17 characteristics an interaction effect between profile and source population was found. Most of these interactions (54%) can be considered concordant variations. With this is meant that the relative data pattern is similar in both populations, but of smaller or larger magnitude in one. For example, both optimistic patients and health consumers both report less pain in rest than patients and consumers of any other profile, but optimistic health consumers (M=2.2, SD=2.1) reported much less pain than optimistic patients (M=3.8, SD=2.4, *p* =.001).

Six of the interaction effects can be considered discordant, meaning that the data patterns in both populations are opposed. For example, while managing patients report moderate coping through religion compared to optimistic and modest patients, managing health consumers report the highest levels of coping through religion compared to optimistic and modest health consumers. Most discordant characteristics concerned the optimistic profile and demonstrated that optimistic health consumers report higher levels of anxiety (Δ=+22.96, *p* <.001) and active support seeking (Δ=+0.92, *p* <.001) compared to optimistic patients. At the same time, optimistic health consumers report lower personal communication competences (Δ=-0.44, *p* <.05).

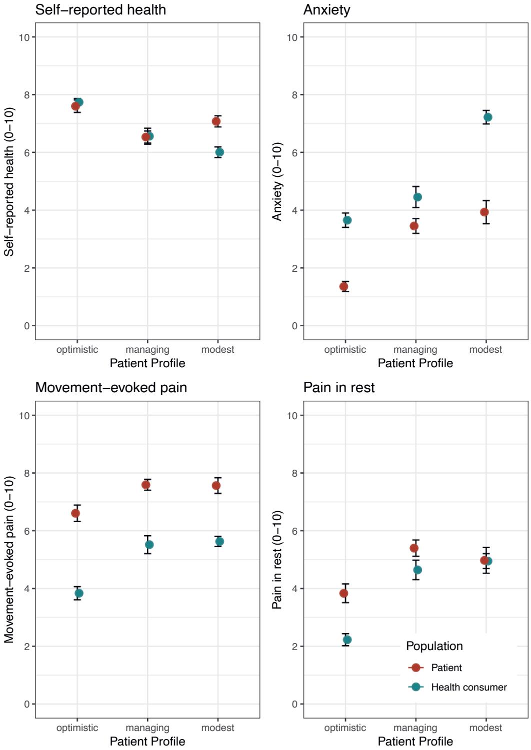

Figure 4.1 Comparison of health experience characteristics between health consumers and patients

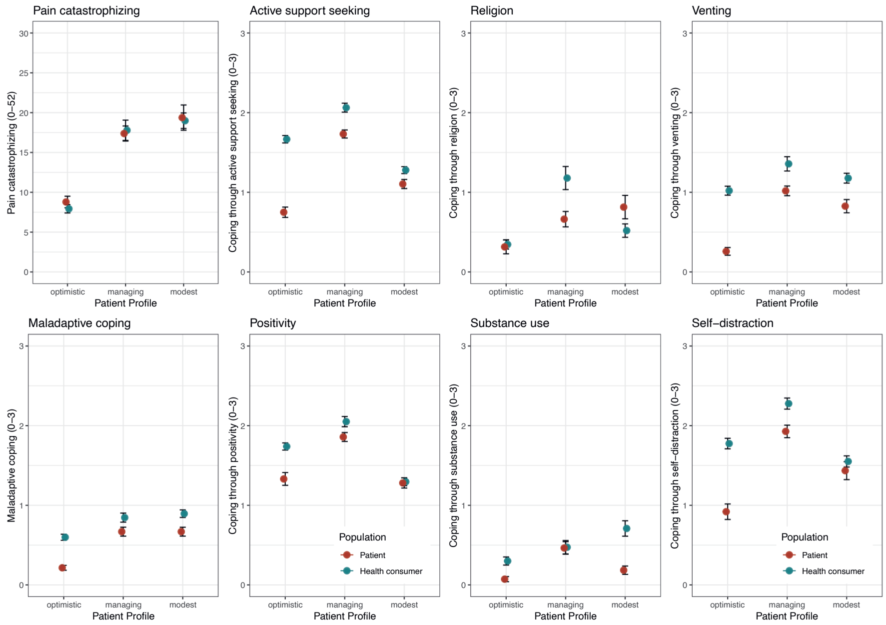

Figure 4.2 Comparison of psychological coping mechanisms between health consumers and patients

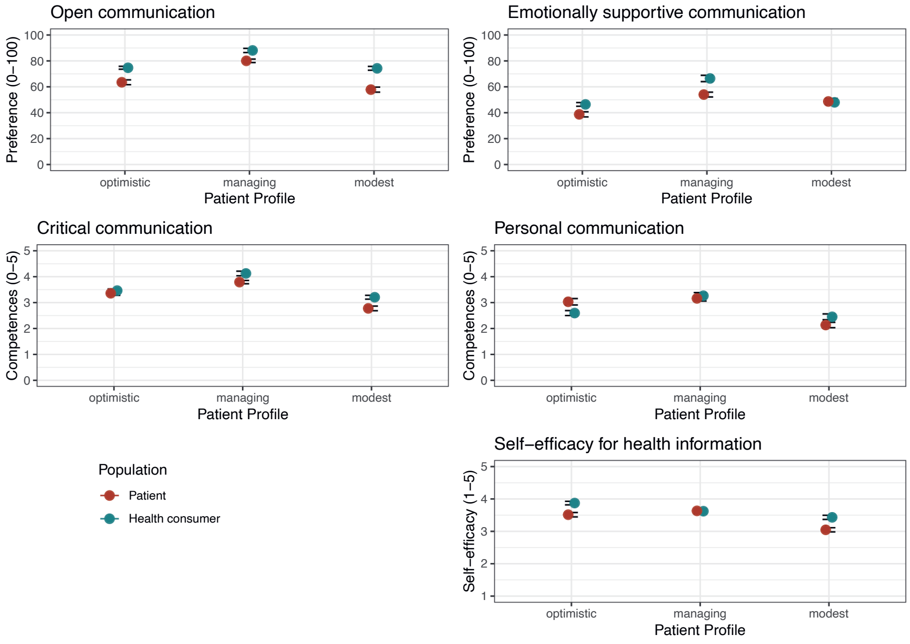

Figure 4.3 Comparison of communication preferences and competences between health consumers and patients

4.2.6 Discussion study 1

Compared to patients, health consumers experience less preoperative pain and more anxiety, exhibit more coping mechanisms, and have higher preferences for both open as well as emotionally supportive communication. Health consumers could be represented in two, six, or three profiles. A two-profile classification resulted in a dichotomous partition of health consumers with high scores (higher preferences and competences, more coping mechanisms) and low scores. This may be informative for patient selection, as patients with suboptimal coping strategies achieve worse outcomes after hip and knee surgery (Ayers, Franklin, Trief, Ploutz-Snyder, & Freund, 2004; Lopez-Olivo et al., 2011; Rosenberger, Ickovics, Epel, D'Entremont, & Jokl, 2004). However, we consider a binary partition to provide limited information for tailoring specific aspects of healthcare services. The six-profile solution may form a more interesting alternative as it nuances the existing three profiles. Yet, this solution was less stable, meaning that participants were sometimes categorized to one cluster and to another cluster in a second or third analysis. This creates uncertainty over which profile best represents an individual patient and increases the risk that a patient is allocated to a tailored healthcare services that is misaligned with their preferences. While this has not been studied in the context of tailored healthcare services, studies on tailored health promotion interventions indicate that the disadvantages of mismatched interventions (e.g. reactance, decreased adherence) outweigh the potential benefits of matched interventions (Godinho, Alvarez, Lima, & Schwarzer, 2015). Therefore, we retained a three cluster solution.

The characteristics of these three clusters corresponded closely to the characteristics of the original patient profiles. Specifically, the relative ordering between profiles remained consistent. For example, both optimistic patients and health consumers reported significantly less maladaptive coping than people who exhibited a managing or modest profile. However, the absolute values did differ between health consumers and patients: optimistic health consumers reported more maladaptive coping behaviour than optimistic patients. The current instrument available for patient profile allocation uses decision rules that rely heavily on absolute values to determine which profile best describes an individual patient (e.g. presence of coping by planning > 0.5 + a preference for open communication about unpleasant effects > 3.5 = managing profile). Because these absolute values differ across population and thus timing of assessment, new instruments are needed for accurate patient profile allocation.

4.3 STUDY 2: DEVELOPING AND EVALUATING INSTRUMENTS TO CLASSIFY PATIENTS AND HEALTH CONSUMERS

As previously discussed, the instrument that is currently used for patient profile allocation determines the profile from the absolute values of preferences, competences, and experiences that people report. It does not take into account the relative patterns in these aspects. For example, since preoperative anxiety levels are higher on average, “high levels of anxiety” at that point in the patient journey may be reflected by a score of 70. Postoperatively, high levels of anxiety correspond to scores of 40. If these relative differences are not taken into account, patient profiles cannot be accurately determined both before and after surgery, which may result in mismatched interventions. Personalised interventions that are mismatched can instead lead to reactance and thereby decreased adherence (Godinho et al., 2015). Therefore, it is important that an instrument used to make decisions about which tailored healthcare services are appropriate for whom is as accurate as possible.

Furthermore, we want to explore alternative options for patient profile allocation. Specifically, whether patients themselves could determine which patient profile best reflects their preferences, and if so, to what extent this corresponds to their formally assessed profile. Letting patients determine their own profile would be an attractive option both because it involves patients more directly and because it would save time in the clinic. Therefore, study 2 compares self-selection and various ways of patient profiles allocation to develop the most accurate and parsimonious classification instrument.

4.3.1 Procedure and data preparation

To prepare the data, the health consumer and patient data were merged to one dataset with an additional variable denoting source population. Because machine learning problems require complete datasets, we imputed missing data (6.6.%) using a multivariate imputation approach (Buuren & Groothuis-Oudshoorn, 2011). We refer to the resulting dataset (N=426) as the merged dataset.

Each participant in the merged dataset was allocated to one of three profiles using three different methods. First, we assigned profiles based on the confirmatory three cluster analysis described in section 4.2.2. We refer to these profiles as the ‘assigned profile’. Next, we assigned profiles using the three question screening instrument presented in Chapter 3. These profiles are referred to as ‘screened profile’. Third, participants self-selected the profile that they felt best represented them. Participants could choose from three short role descriptions based on the original profiles (Table 4.4). The role descriptions were written by main author Tessa Dekkers, in collaboration with co-authors Marijke Melles, Huib de Ridder, and various designers from Panton B.V. following a workshop on patient profiling (Dekkers et al., 2018). They were also pilot tested for comprehensibility with 14 patients and informal caregivers (see Chapter 6). These profiles are referred to as the ‘self-selected profile’. The concordance between the self-selected, screened, and assigned profiles was calculated to determine if self-selection or screening could be used for accurate profile allocation.

Table 4.4 Role descriptions used for self-selection of profile by participants

Profile (% of patients)	Role description
Managing (44%)	"I find it very important to have accurate information about all possible treatment options. I prefer to decide how, which, and where I receive treatment. I like to be in control: for example, I would look for a second opinion if I think that is necessary. I would like my doctor to be just as involved with my health and treatment as I am."
Optimistic (32%)	"I find it very important that care is fast and efficient. It's great to be aware of my health, but I do not want to know everything. I prefer to make important decisions about my treatment together with my doctor. I would like to contribute to my health independently. For example, I would like to keep track of my rehabilitation progress."
Modest (24%)	"I find it very important to take time for my health. Sometimes I find it difficult to process all the information you get, so I would like to receive support from the doctor in that aspect as well. I do want to be aware of what is being discussed about my health, but I prefer to leave important decisions about the treatment to my doctor. I would like to visit or talk to my doctor often."

Note. The profile self-selection task was introduced with the following text: *People have different opinions about what is important for their health. Below you can find the opinions of three people regarding the way that they interact with their healthcare providers. Please read the three opinions and select the opinion that best represents your opinion about health.* Patients only saw the role description and did not see the patient profile label (e.g. 'managing') or prevalence of each profile in the patient population. Role descriptions and question are translated from Dutch.

4.3.2 Methodological approach to development and evaluation of updated patient profiling instrument

To develop a new version of the patient profiling instrument which would be sensitive to changing preferences over time, we used the package 'caret' to train, tune, and evaluate a machine learning model (Kuhn, 2008). We approached this problem as a supervised learning problem meaning that training data was labelled with a known class (in the case of patients, their original profile and in case of health consumers, their assigned profile). The task of a supervised learning model is to extrapolate information about the training cases to make predictions for unseen cases, also known as the testing data (Mohri, Rostamizadeh, & Talwalkar, 2018). In the specific context of the study, the aim of the model was to predict patient profile both at the beginning (using the health consumer data) and later in the patient journey (using the patient data) while maximizing accuracy and parsimony of the instrument. Accuracy was defined as the overall concordance between the observed and predicted profile and the concordance corrected for expected agreement by chance, i.e. the Kappa statistic (Dimitriadou, Hornik, Leisch, Meyer, & Maintainer, 2011). For both measures, higher values indicate better accuracy. Parsimony was defined as the overall number of variables used for prediction.

First, 70% of the data was denoted as 'training data' and 30% as 'testing data'. The testing data was withheld to later evaluate the predictive performance of the models. Next, various models were trained on the training data using 10-fold cross-validation and 3 repeats (Kuhn, 2008). Many different algorithms are available to do so; we tested three types which could fit the patient profiling problem. First, we considered a linear discriminant analysis (LDA) which is commonly used to develop predictive functions after cluster analysis (Clatworthy et al., 2005). Second we considered classification and regression trees (CART) which was the approach we used to develop the original screening instrument. Third, we considered ensemble algorithms (e.g. random forest, parallel random forest, and boosted random forest) as an extension of the CART approach. Ensemble learning algorithms develop multiple tree-based models and are thereby better equipped against issues of overfitting (Breiman, 2001). The results of each model were compared in the training data after which the best performing models were evaluated in the testing dataset. Finally, we looked at the importance of each predictor to the model[14] and included only the most important variables to optimize parsimony. This final optimized classifier was tested again on the testing data to evaluate its performance.

4.3.3 Evaluation of self-selection and screening allocation methods compared to profile assignment

Table 4.5A-C shows the incidence of each profile using the three allocation methods. Screened (concordance = 39%) and self-selected (35%) profiles had limited concordance with assigned profiles. In particular, the screening instrument overestimated the prevalence of the modest profile and underestimated the prevalence of the optimistic profile. These misclassifications may be explained by the previous finding that absolute values of active support seeking and open information preferences were higher in the health consumer cohort (Table 4.2).

When self-selection was used as the allocation method, prevalence of the managing profile was overestimated and the modest role underestimated. Concordance between self-selected profile and assigned profile did not differ between participants who reported high agreement with their self-selected profile (concordance = 36.18%) and participants who felt indifferent to their self-selected profile (33.33%).

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[14] See Kuhn (2008) for an in-depth discussion of how variable importance is defined for each of the algorithms used in the study.

Tables 4.5A-C Prevalence and cross tabulation of profiles using screening, self-selection, and assignment allocation methods

A: Prevalence and concordance to assigned profile

	Profile			Concordance to assigned profile [CI]
	Managing	Optimistic	Modest	
Screened profile	93	6	136	38.72% [32.46%-45.27%]
Self-selected profile[a]	112	73	33	35.32% [28.99%-42.06%]
Assigned profile	56	100	79	

B: Cross tabulation of assigned profile and screened profile

		Screened profile		
		Managing	Optimistic	Modest
Assigned profile	Managing	37	0	19
	Optimistic	29	4	67
	Modest	27	2	50

C: Cross tabulation of assigned profile and self-selected profile

		Self-selected profile[a]		
		Managing	Optimistic	Modest
Assigned profile	Managing	27	13	8
	Optimistic	49	37	12
	Modest	36	23	13

Note. CI= confidence interval

[a] 17 participants did not select any of the three profiles.

4.3.4 Development and evaluation of updated patient profiling instrument

The results from section 4.3.2.1. show that the screening as well as self-selection methods have limited concordance with assigned patient profiles. These methods are not considered accurate enough to allocate health consumers to profiles. Therefore, we developed an updated version of the patient profiling instrument using both the health consumer and patient data.

Figure 4.4 shows the performance of the linear-, tree-based-, and ensemble- machine learning models. The ensemble methods demonstrated the highest accuracy. The stochastic gradient boosting method performed the best in the training set, achieving a median of 87.1% (IQR= 86.7-92.3) correct classifications. In comparison, linear and tree-based methods achieved 80.6% (IQR= 73.3-83.9) and 63.3% (IQR= 59.4-69.2) accuracy respectively.

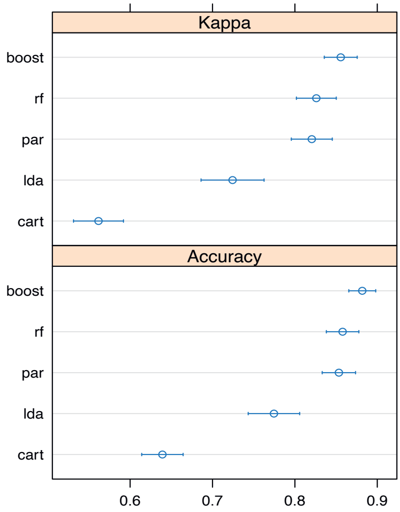

Figure 4.4 Accuracy of prediction models in training data

Next, the ensemble models were used to predict patient profile in the testing data set. On the unseen data, the parallel random forest model and random forest methods achieved the highest accuracy of 86.3% (IQR= 79.0-91.8) and 85.5% (IQR= 78.0-91.2). The previously best performing stochastic gradient boosting method performed poorer on new cases (83.1% accuracy, IQR= 75.3-89.2). Therefore the parallel random forest and random forest models were used as a starting point to develop a more parsimonious model that could predict patient profile using less predictors.

Figure 4.5 shows the relative importance of each predictor to both classification models. In both models, preoperative status was the most important predictor. This is to be expected, as the preoperative status denotes the population (patient/health consumer) against which the individual's scores need to be interpreted. Furthermore, both models attach higher importance to the same set of variables including coping through active support, age, anxiety, pain catastrophizing, and preference for open communication. In both models, predictors that have low prevalence (such as the uncommon coping behaviours substance use and religious coping) or high average scores (such as self-efficacy) contribute the least to correct classification.

We considered 3 models that included a combination of 7 to 9 of the most important predictors. Of these models, a random forest classification model that used 9 predictors, namely preoperative status, coping through active support seeking, anxiety, age, pain catastrophizing, preference for open communication, critical communication competences, and movement-evoked pain, most accurately predicted patient profile. With an accuracy of 79.8% (IQR=75.5-86.5) and a parsimony of 9 included predictors measured over 59 items, this model was selected as the final patient profile allocation instrument (see Appendix 4B). The estimated patient burden for completion of this questionnaire is

10-15 minutes, which is a significant reduction over the full instrument of 91 items (20-25 minutes).

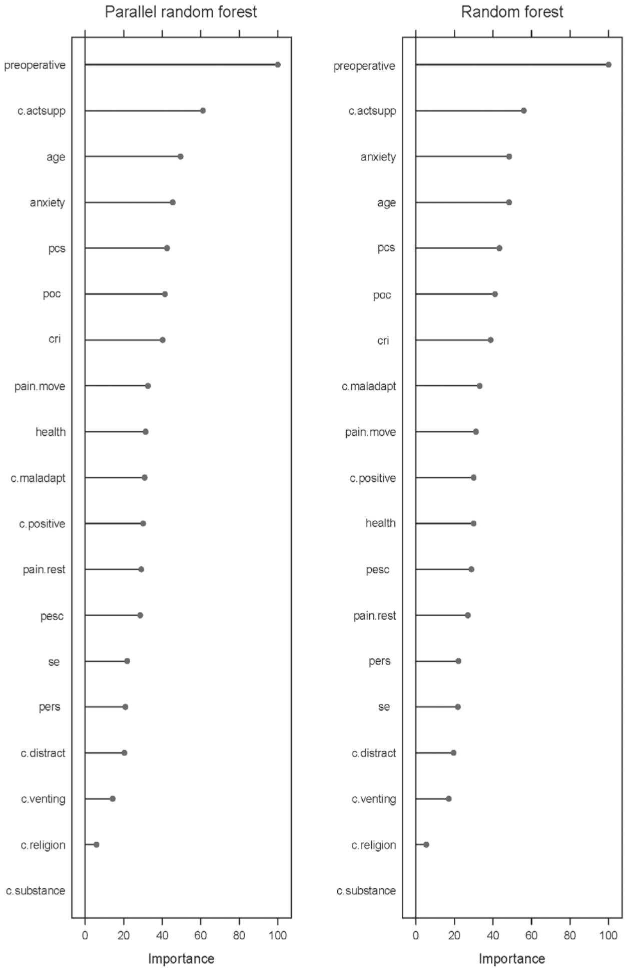

Figure 4.5 Variable importance in the (parallel) random forest models

4.3.5 Discussion study 2

The findings from study 2 show that self-selection or screening are not accurate methods for allocating individual patients to patient profiles throughout the patient journey. Therefore, we developed a new classification instrument. This instrument is able to determine patient profile in both health consumers and patients with 80% accuracy. As such, it can be used to allocate tailored healthcare services to individual patients.

4.4 GENERAL DISCUSSION

The patient journey of total joint replacement (TJR) surgery presents many opportunities to tailor healthcare services to the preferences, needs, and competences of patients. Tailoring healthcare services may improve patient satisfaction and adherence and subsequently optimize health outcomes (Street et al., 2012). In order to develop tailored services, healthcare and creative professionals need insight in the preferences, needs, and competences of patients. Patient profiles (i.e. representations of the common characteristics of a specific subgroup of patients that are unique compared to the overall patient population) may offer this insight but have not yet been validated in untreated health consumers at the beginning of their patient journey. This study provides insight the characteristics of health consumers in comparison to patients and tested the representativeness of the set of patient profiles (Chapter 3) in this population. Furthermore, we evaluated various methods for profile allocation and developed an accurate and parsimonious classification instrument suitable for assessing patient profiles throughout the TJR patient journey.

4.4.1 Do preferences change over time?

Health consumers were found to experience less pain and more anxiety, to exhibit more coping mechanisms, and to have higher preferences for both open as well as emotionally supportive communication. When interpreting these findings, it is important to note that pain and self-reported health are the only items that were assessed prior to the surgery in the patient cohort. As pain is considered the principal indication for joint replacement surgery by both surgeons (Crawford & Murray, 1997; Frankel et al., 2016) and patients (Frankel et al., 2012) it is to be expected that people who have sought treatment (i.e. the patient cohort) were experiencing more pain than people who have not yet done so. Furthermore, despite transforming the anxiety measurement in a percentile score to be able to compare anxiety across the two cohorts, discrepancies in instruments and norm scores used may have distorted the findings.

Of greater interest are the differences between health consumers and patients in communication preferences which indicate that communication preferences in TJR may have decreased over time. This finding is not in line with recent research that suggests that patients' information needs increase after discharge (Billon et al., 2017). These contradictory findings may be explained as a devaluation of the importance of information under conditions of incomprehension.

Most TJR consultations tend to focus on oral information provision (Dekkers, Melles, Mathijssen, Vehmeijer, & de Ridder, 2018; Chapter 2) yet patient comprehension of such information is limited (Giudici, Gillois, Coudane, & Claudot, 2015). In this case, the patient preference (i.e. high information preferences) is initially accommodated. This service will be evaluated by the patient based on the perceived outcomes it has delivered (Street et al., 2012). For some patients, the outcome will be the valued outcome of comprehension. However, one in four patients may instead experience increased anxiety because of the obtained knowledge (Agozzino et al., 2019). Others may fail to comprehend the information fully, resulting in confusion, disappointment, or misunderstanding. Such negative outcomes are expected to result in a shift on the initial preference (Street et al., 2012). As information provision did bring the anticipated benefits (e.g. comprehension, reassurance) future information preferences will decrease. This process may repeat over time, resulting in the decreased information preferences observed in the current study. A further observation that supports this interpretation is that information preferences declined most in more anxious individuals with lower communicative competences.

It is important to keep into consideration that the cross-sectional study presented in this chapter does not provide conclusive evidence for changing preferences over time. A major limitation of this study is that while the two cohorts differed in surgical status and phase in their patient journey, participants also differed in age, educational attainment, and experience with technology. Furthermore, health consumers reported on their expected preferences while patients reflected on their actual enacted preferences. Both assessments may have been influenced by response shifts or recall biases (Schwartz & Sprangers, 2014). Therefore, we cannot conclude that the identified differences in preferences and competences are necessary due to a passage of time, the surgery, or contact with healthcare providers. However, the findings do suggest that time may affect preferences which warrants further examination of this topic. In particular, longitudinal study of preferences, competences, and comprehension is needed to understand if and why preferences change throughout the TJR patient journey.

4.4.2 Do the three patient profiles represent both health consumers and patients?

Despite differences between health consumers and patients, the set of patient profiles previously based solely on patient data corresponded well to the health consumer data. These findings indicate that the set of managing, optimistic, and modest patient profiles may be used to represent the broad differences in health experience, psychological coping mechanisms, and communication preferences and competences between TJR patients throughout their patient journey. Of the three roles, the optimistic profile does appear to be the least consistent over time. Prior to surgery, health consumers classified as optimistic reported more coping mechanisms (particularly, they reported more active coping, planning, and support seeking) and lesser communication competences (i.e. more difficulties communicating about personal circumstances with physicians) compared to patients. Possibly, these findings indicate that optimistic patients are able to improve communicative competences more or quicker compared to patients of other profiles. The decrease in coping behaviour may be explained using the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984). This theory posits that coping behaviour only occurs when a stressor (i.e. threatening event) is appraised as sufficiently significant. Optimistic consumers prior to surgery may have considered surgery to be a potentially stressful event and as such report more coping mechanisms. However, optimistic patients may later experience the surgery as less stressful than expected, reducing the need to practice the anticipated coping mechanisms. It would be of interest to examine how optimistic patients exactly reduce anxiety and gain communicative competences over the course of TJR surgery, as these patients also obtain the best surgical outcomes (Chapter 3). Insight in this process could help define what changes in healthcare services are needed for managing and modest patients to achieve similar results.

4.4.3 How can individual patients be allocated to a patient profile accurately?

In the discussion of Chapter 3, we indicated that the short tree-based screening instrument may be *overfitted*, i.e. closely modelled to the idiosyncratic characteristics of the specific patient sample, but poorly generalizable to other populations such as health consumers (Babyak, 2004). The present research confirms this apprehension as it shows that neither screening (using the decision tree) nor self-selection were accurate methods for determining the patient profile. The new instrument presented in this chapter addresses the previous limitations as it is trained on more data from two diverse populations, evaluated on previously unseen (i.e. testing) data, and uses more advanced, ensemble learning algorithms. However, these changes have increased the length of the questionnaire considerably in comparison to screening or self-selection. The prospected 10-15 minutes may be too long for routine use in orthopaedic practice, especially if the instrument is used repeatedly to examine preferences and competences over time. To address this limitation, we provide three suggestions. First, we envision a secondary use of the tree-based instrument as a conversation tool rather than a classification tool. Specifically, by removing the cut-off scores, physicians could approach the three questions on planning, unpleasant information, and pain catastrophizing as discussion topics to initiate a conversation about the patient's coping mechanisms and communication preferences. The medical and creative professionals in the Tailored Healthcare project have also reported success with the use of journey metaphors that encapsulate these topics. For example, one orthopaedic surgeon now asks patients what they do when they prepare for a holiday; research everything themselves extensively (managing), buy a concise guidebook (optimistic), or hire a tour guide (modest). Such metaphors may be a comprehensible way to discuss preferences. However, the current study has also shown that people are ill-equipped at self-selecting a profile, so this metaphorical approach should be further tested.

Secondly, the new instrument could be strategically employed only when patient preferences are expected to have changed, namely after clinical encounters and after the outcomes of care are assessed (Street et al., 2012). In TJR, this could be prior to surgery, after discharge, and at 6 and 12 months after surgery.

Finally, we see promising developments in computerized adaptive testing (CAT) that could reduce patient burden. CAT is a computerized approach to testing based on Item Response Theory (IRT) in which respondents answer a subset of items that are adaptively selected based on their previous answers (Edelen & Reeve, 2007). For example, patients who report severe difficulties with walking 100 metres, will no longer be asked to assess their ability to walk 500 metres, or a kilometre. This reduces the number of questions administered to each respondent while increasing measurement precision (Giesinger, Kuster, Holzner, & Giesinger, 2013). CAT has successfully streamlined Patient Reported Outcome Measures (PROM) assessment (Papuga et al., 2017; Petrillo, Cano, McLeod, & Coon, 2015) including PROMs used in the orthopaedic context (Giesinger et al., 2013). Recent research shows that the method may also be extended to the assessment of non-cognitive constructs, such as personality traits (Stark, Chernyshenko, Drasgow, & White, 2012). While no CAT versions of patient preferences questionnaires exists that the authors are aware of, the instrument developed in the current study may lend itself to this method as most of the scales used (e.g. communication preferences, Farin et al., 2011) are already based on IRT models.

4.5 CONCLUSION

Patients' preferences and competences may change over the course of their patient journey. We found that health consumers who experience chronic joint complaints but are not yet in treatment report higher communicative preferences and competences than patients who have undergone total joint replacement (TJR) surgery. Still, the set of three patient profiles was representative of the overall health consumer population. We present an updated instrument that can accurately allocate individual patients to a patient profile that is sensitive to the absolute and relative differences between that emerge between individuals and over time. This instrument can be used for longitudinal examination of how profiles, preferences, and competences of patients change throughout the patient journey.

Part B

Implementation of patient profiling for the design of tailored orthopaedic healthcare services

Chapter 5

Web-based patient education in orthopaedics: Systematic review

Summary

Chapters 2 to 4 describe the development and validation of a set of three data-driven patient profiles. Chapter 5 and 6 now turn to the implementation of patient profiles for the design of a tailored healthcare service. In order to determine the added benefit of *tailored* web-based patient education (the service under study) the effect of standardized web-patient education is assessed.

The objective of Chapter 5 is to examine the effects of standardized Web-based patient education interventions on patients with orthopaedic conditions in comparison with traditional patient education and publicly available health information websites. 10 trials that examine web-based patient education in the orthopaedic context were identified (sections 5.2.1 to 5.2.6). Web-based patient education was found to improve patients' knowledge and satisfaction (section 5.2.7) but these findings may not be representative for the whole orthopaedic patient population as most trials included only considerably younger, higher-educated, and internet-savvy participants (section 5.3). This suggest that web-based patient education is a service that should be tailored to the preferences, needs, and competences of patients.

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ABSTRACT

Background. Patients with orthopaedic conditions frequently use the Internet to find health information. Patient education that is distributed online may form an easy-accessible, time- and cost-effective alternative to education delivered through traditional channels, such as one-on-one consultations or booklets. However, no systematic evidence for the comparative effectiveness of web-based educational interventions exists.

Objective. The objective of this systematic review was to examine the effects of web-based patient education interventions for adult orthopaedic patients and to compare its effectiveness to generic health information websites and traditional forms of patient education.

Methods. CINAHL, the Cochrane Library, EMBASE, MEDLINE, PsycINFO, PubMed, ScienceDirect, Scopus and Web of Science were searched covering the period 1995 to 2016. Peer-reviewed English and Dutch studies were included if they delivered patient education via the Internet to the adult orthopaedic population, and assessed its effects in a controlled or observational trial.

Results. A total of 10 trials reported in 14 studies involving 4172 patients were identified. Nine trials provided evidence for increased patients' knowledge after web-based patient education. Seven trials reported increased satisfaction and good evaluations of web-based patient education. No compelling evidence exists for an effect of web-based patient education on anxiety, health attitudes and behaviour, or clinical outcomes.

Conclusions. Web-based patient education may be offered as a time- and cost-effective alternative to current educational interventions when the objective is to improve patients' knowledge and satisfaction. However, these findings may not be representative for the whole orthopaedic patient population as most trials included considerably younger, higher-educated, and internet-savvy participants only.

5.1 INTRODUCTION

Patient education is a valuable part of care that enables patients to be informed, active participants in their own treatment (Fernsler & Cannon, 1991; Gruman et al., 2010; Hoving et al., 2010). Traditionally, it is provided through face-to-face teaching methods by healthcare professionals (Hoving et al., 2010; Lübbeke, Suvà, Perneger, & Hoffmeyer, 2009; Pellino et al., 1998). These methods are often supplemented with written booklets or pamphlets (A. Cheung, Finegan, Torok-Both, Donnelly-Warner, & Lujic, 2007; Pellino et al., 1998), or multimedia channels such as audiotapes, DVD, and video (Daltroy, Morlino, Eaton, Poss, & Liang, 1998; Lin, Lin, & Lin, 1997). However, as both internet access and the availability of health information on public websites increases, it is now common for patients to also use the Internet to learn about health and illness (Colledge, Car, Donnelly, & Majeed, 2008). People with orthopaedic conditions, such as osteoarthritis, rheumatic arthrosis, or trauma, form no exception to this trend. Internet-use among this group increases rapidly: 79% of patients had internet access in 2012 and among them, 23% in 2010 to 65% in 2012 had used the Internet to research their orthopaedic condition or upcoming treatment (Baker et al., 2010; Fraval et al., 2012).

Patients themselves are positive about using the Internet to find health information. They perceive online health information to produce health benefits and social benefits (e.g. improved self-care behaviour and better social support) in a manner that is easy-accessible, cost-effective, and time-effective (Win, Hassan, Oinas-Kukkonen, & Probst, 2016) Reactions of healthcare professionals however, have been mixed. It is recognized that health information that is distributed online can incorporate unique features such as tailored information, multimedia, and interactivity to keep patients engaged with the educational material (H. Q. Nguyen, Carrieri-Kohlman, Rankin, Slaughter, & Stulbarg, 2004; Win et al., 2016). For example, McKay and colleagues incorporated interactive elements in their internet-based diabetes self-management support intervention by allowing patients to live chat with each other and healthcare professionals (McKay, Glasgow, Feil, Boles, & Barrera, 2002). That such elements can ultimately enhance the education's effectiveness is demonstrated, for example in the fields of breast cancer and general surgery: web-based patient education increases patients' knowledge and satisfaction (Hering, Harvan, Dangelo, & Jasinski, 2005; Ryhanen, Siekkinen, Rankinen, Korvenranta, & Leino-Kilpi, 2010), improves the physician-patient relationship (Wald, Dube, & Anthony, 2007), and creates awareness about health issues in the general population (Idriss, Alikhan, Baba, & Armstrong, 2009). Despite these initial successes, concerns with web-based education have been voiced in orthopaedic practice as well. Most of these stress the poor quality of online health information, which is deemed overly commercialized and poorly readable even when produced by qualified health care professionals (B. A. Brooks, 2001; Cassidy & Baker, 2016; Hungerford, 2009). Furthermore, despite increasing Internet access in the population as a whole, clinicians fear the generalizability of previous findings to elderly patients who may be inexperienced with

Internet usage (Jariwala, Kandasamy, Abboud, & Wigderowitz, 2004; H. Q. Nguyen et al., 2004; Wald et al., 2007). To acknowledge these potential downsides while meeting patients' demands for online patient education, it is important to systematically examine and evaluate the effects of web-based educational interventions that are currently in place.

The current review follows the definition of Roter and colleagues (1998, p. 1141) in defining educational interventions as "pedagogic interventions, verbal or written, with a knowledge-based emphasis designed to convey information". This distinguishes educational interventions from behavioural and affective interventions, which focus on shaping behavioural patterns and appealing to feelings and emotions respectively. The core aim of educational interventions is knowledge acquisition by patients (Daltroy et al., 1998; Hungerford, 2009; Idriss et al., 2009; Jariwala et al., 2004). With knowledge, the patient can participate in decision making and build skills for self-care (B. A. Brooks, 2001). In this way, increased knowledge can result in better clinical outcomes and ultimately improve the patient' quality of life (Feudtner, 2001).

5.1.1 Web-based patient education in comparison to traditional patient education

When evaluating web-based patient education, it is inevitable to compare its effectiveness to that of traditional patient education. Therefore, the first aim of this review is to compare the effectiveness of web-based patient education to the more traditional methods for patient education such as face-to-face teachings or the use of print materials. In order to make an accurate comparison between the two we will provide a brief overview of the effectiveness of traditional patient education as identified in previous systematic reviews below.

In orthopaedic practice, positive effects following traditional patient education include increased knowledge regarding surgical procedures and the informed consent process, improved self-management skills, and reduced length of stay (Johansson, Nuutila, Virtanen, Katajisto, & Salanterä, 2005; McDonald, Page, Beringer, Wasiak, & Sprowson, 2014; Ronco, Iona, Fabbro, Bulfone, & Palese, 2012; Schenker, Fernandez, Sudore, & Schillinger, 2011). Yet, educational interventions are no more effective than other interventions such as attention control or physiotherapy (Kroon et al., 2014). Furthermore, clinical outcomes, such as pain and functioning, do not improve following patient education (Johansson et al., 2005; Louw, Diener, Butler, & Puentedura, 2013; McDonald et al., 2014), just as patient education also does not decrease anxiety in a clinically meaningful way (Johansson et al., 2005; McDonald et al., 2014). Finally, there is insufficient evidence currently available to determine the effect of education on patients' empowerment and self-efficacy (Johansson et al., 2005) and no systematic reviews have examined the effect of patient education on patient satisfaction. From these findings, we hypothesize the following:

> H1: Web-based patient education interventions will have a positive effect on patients' knowledge, but not on anxiety or clinical outcomes.

5.1.2 Web-based patient education in comparison to generic health information websites

As outlined earlier in this introduction, educational interventions are no longer the sole source of knowledge for patients as an abundance of health information is also freely available on the Internet. When patients make use of generic health information while included in the experimental arm of a web-based patient education intervention trial, online health information forms a potential strong co-intervention (H. Q. Nguyen et al., 2004). Thus, to accurately evaluate web-based patient education it is important to not only compare its effect to that of traditional interventions, but also to that of public health information websites. Therefore, the second aim of this study is to compare web-based patient education interventions to health information websites.

Health information websites are often broader in scope than educational interventions, as they typically target the general population as well as patients, while patient education targets patients or other members of the healthcare system only (Padilla & Bulcavage, 1991). This means these websites are also unlikely to involve healthcare providers, or make use of clinical measurements or other information about patients that is derived from the healthcare system. Furthermore, health information websites are generally not theory-based. In contrast, patient education interventions are often developed and implemented using various theoretical frameworks (Glanz, Rimer, & Viswanath, 2008). While we recognize that use of theory in intervention development is varied and may be absent from some patient education interventions as well (Glanz et al., 2008; Padilla & Bulcavage, 1991; Syx, 2008), embedment of theory in general does set apart educational interventions from generic health information websites. Therefore, we expect that:

> H2: Theory-based and/or professionally-facilitated web-based patient education interventions perform better than generic health information websites.

5.1.3 Review objective

Concluding, promising results of web-based patient education interventions have been reported, but a systematic review of web-based patient education specifically for orthopaedic practice has not yet been carried out. The effects of web-based patient education can be evaluated in itself, but should also be compared to other interventions currently in place: first to traditional patient education interventions, that are theory-based and professionally-facilitated, but are provided through different channels (such as verbally, written or by using multimedia) and secondly to publicly accessible, generic health information websites, which share the same channel of information provision (the Internet) but are generally not theory-based or professionally-facilitated. The overall aim of this systematic review is to tackle these comparisons, by examining the effects of web-based patient education interventions on patients with orthopaedic conditions as reported in controlled and observational trials, in comparison to traditional patient education and health information websites. The questions that guided us in examining the comparative effectiveness were 1) ‘what are the effects of web-based patient education on adult patients with orthopaedic conditions?’ and ‘what are the effects of web-based patient education in comparison to the effects of 2) traditional patient education and 3) generic health information websites?’

5.2 METHODS

5.2.1 Protocol and registration

This systematic review has been written according to the requirements of the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) statement (Liberati et al., 2009; Moher et al., 2009). The review’s protocol has not been published.

5.2.2 Eligibility criteria

We included peer-reviewed, controlled and observational trials reported in English or Dutch, that self-defined as studying the effects of patient education interventions delivered via an online environment, including mobile devices, websites and online systems, to adult people with any orthopaedic illness or condition and/or currently receiving treatment for such conditions. Following our definition of educational interventions, we excluded behavioural or affective interventions. These may include educational components but differ from educational interventions as they specifically target behavioural patterns or appeal to feelings or social relationships to change patients’ outcomes (D L Roter et al., 1998). As our focus lay with studying interventions, we did not include studies that only discussed generic, not theory-based, not professionally-facilitated health information websites and did not compare their effectiveness to web-based patient interventions. No mandatory principal outcomes were defined for studies to be eligible for inclusion in the review. No restrictions on publication date were imposed in the search for eligible studies. However, in the final selection of studies we excluded studies that were published before 1995 to ensure the review represented current evidence.

5.2.3 Information sources

Studies were initially identified by searching the electronic databases CINAHL, Cochrane Central Register of Controlled Trials, EMBASE, MEDLINE, PsycINFO, PubMed, ScienceDirect, Scopus and Web of Science between September 1st 2015 and November 30th 2015. As an example, the search strategy for the PubMed database can be found in Textbox 5.1. Search strategies for the other databases are available in Appendix 5A. The search was repeated in September 2017 to ensure the latest evidence was included. This search strategy was complemented by reviewing the bibliographies of included studies to identify additional studies of interest. We contacted one author for a full text copy of an eligible study which was subsequently provided to the review team. For all other articles, full text copies were available and no further contact with the original authors was made.

(internet OR "world wide web" OR online OR web-based OR "computer assisted" OR e-health OR network OR "web services") AND ("patient education" OR "patient education as topic" [MeSH Terms] OR "consumer health informati*" OR "medical education" OR "health education" OR "health knowledge, attitudes, practice"[MeSH Terms]) AND (orthopedic* OR orthopaedic* OR "joint replacement" or "arthroplasty" OR "hip" OR "knee") AND (Adult OR Aged) AND (Effect OR efficacy OR performance OR result OR outcome)

Textbox 5.1 PubMed search strategy for the identification of studies assessing the effects of Web-based patient education interventions for the adult orthopaedic population

5.2.4 Study selection

The first author assessed the identified studies for eligibility by title and abstract. The predefined selection criteria were applied to full-text reports of potentially eligible studies primarily by the first author, in discussion with two review authors (MM, HdR) until consensus was reached. A third review author (BSG) was available for arbitration but this was not required.

5.2.5 Data collection process

A structured data extraction sheet was employed to extract data from included studies. The data extracted included: (1) study characteristics (i.e. author, year of publication, design, population, timing of outcome measures); (2) intervention characteristics (i.e. content and duration of intervention and control intervention, total sample size and sample sizes in separate conditions); (3) patient characteristics (i.e. socio-demographic variables, health status, experience with internet); and (4) outcomes (i.e. type of outcome measure, instrument, effect). For each study, the effect of the intervention was coded as a) significant result (positive + or negative –); b) non-significant result =; or c) not reported (×).

To provide a structured overview of the components in each intervention, we employed Barak and colleagues' (Barak, Klein, & Proudfoot, 2009) framework for internet-supported interventions. This framework provides guiding definitions for four components that make up a web-based education intervention including: 1) program content (educational or behaviour change content), 2) multimedia use (type of media used to convey program content), 3) interactive online activities (activities offered to increase patient interest, understanding, and engagement), and 4) guidance and supportive feedback (if and how patients can obtain automated or human support and feedback).

5.2.6 Risk of bias in individual studies

To appraise the risk of bias in included studies, data regarding reporting, external validity, internal validity, and statistical power was extracted independently by two review authors (TD, BSG) using a modified version of Downs and Black tool for assessment of methodological quality (Downs & Black, 1998). This tool was selected for its high internal consistency and reliability and its applicability to both randomized and observational studies (Downs & Black, 1998; Hootman, Driban, Sitler, Harris, & Cattano, 2011). In line with previous studies, the ambiguous item regarding statistical power was modified to indicate the presence of a statistical power analysis or sample group calculation by allocating 1 (present) or 0 (absent) points (Cindy Ng, Mackney, Jenkins, & Hill, 2012; Eng et al., 2007; Robbins, Houghton, Woodbury, & Brown, 2006). The range of the modified tool is 0-28, with higher scores indicating higher methodological quality. Studies were not excluded on the basis of their methodological quality; however, findings from medium and poor quality studies were given less weight in the qualitative synthesis than studies of high methodological quality.

5.2.7 Synthesis of results

We examined the effectiveness of web-based patient education interventions by describing and comparing the characteristics and results of the included studies, as summarized in the structured data extraction sheet (see 5.2.5) through qualitative synthesis (Tranfield, Denyer, & Smart, 2003). No meta-analysis was attempted due to the small number of included studies and considerable variability in the outcome measures employed.

5.3 RESULTS

5.3.1 Study selection

The search identified 1032 eligible studies of which 10 trials, reported in 14 papers, met the inclusion criteria and were included in the review (Figure 5.1). Five of the included studies (Heikkinen, Helena, Taina, Anne, & Sanna, 2008; Heikkinen, Salanterä, & Leino-Kilpi, 2009; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Heikkinen, Leino-Kilpi, Vahlberg, & Salanterä, 2012; Heikkinen, Salanterä, Leppänen, Vahlberg, & Leino-Kilpi, 2012) concern separate reports of the same trial. To account for potential inconsistencies in reporting, all five reports of the trial were included in the review (Liberati et al., 2009).

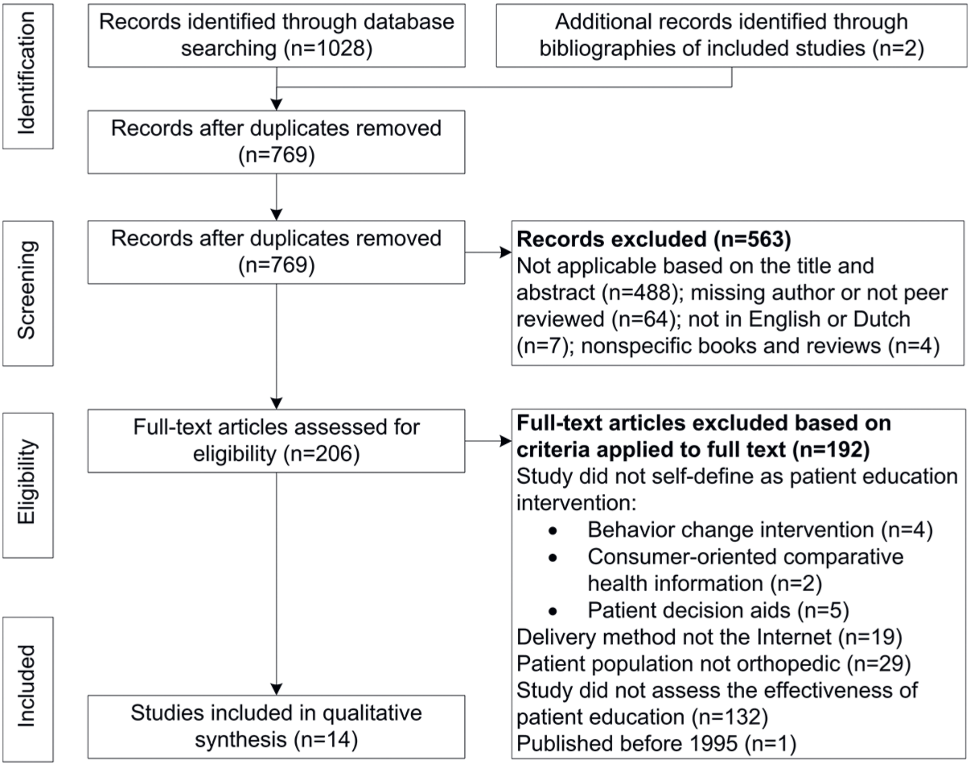

Figure 5.1 Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) flow diagram presenting identification and selection of articles for the systematic review of effectiveness of Web-based patient education in orthopedics

5.3.2 Study characteristics

Seven of the ten trials employed a randomized controlled design, two an observational design and one a quasi-experimental design. Four trials assessed the effect of web-based patient education in comparison to traditional patient education channels including face to face education with a nurse or physician (Fraval et al., 2015; Heikkinen et al., 2008, 2009; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Heikkinen, Leino-Kilpi, Vahlberg, et al., 2012; Heikkinen, Salanterä, et al., 2012; Yin, Goldsmith, & Gambardella, 2015); and patient information sheets (N. D. Groves, Humphreys, Williams, & Jones, 2010). Three trials compared web-patient education to health information websites (Drieling, Ma, Thiyagarajan, & Stafford, 2011; Goldsmith & Safran, 1999; Nahm et al., 2010) and three assessed the interventions' effects but did not compare these to either traditional patient education or health information websites (Meesters, De Boer, Van Den Berg, Fiocco, & Vliet Vlieland, 2012; Sobel & Popp, 2006; Umapathy et al., 2015).

5.3.3 Patient characteristics

Most of the studies provided web-based patient education to patients undergoing surgical treatment including: total knee arthroplasty (TKA) (Fraval et al., 2015; N. D. Groves et al., 2010); total hip arthroplasty (THA) (Fraval et al., 2015; N. D. Groves et al., 2010; Sobel & Popp, 2006); knee arthroscopy (Fraval et al., 2015; Heikkinen et al., 2008, 2009; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Heikkinen, Leino-Kilpi, Vahlberg, et al., 2012; Heikkinen, Salanterä, et al., 2012; Yin et al., 2015); shoulder arthroscopy (Fraval et al., 2015; Heikkinen et al., 2008, 2009; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Heikkinen, Leino-Kilpi, Vahlberg, et al., 2012; Heikkinen, Salanterä, et al., 2012); anterior cruciate ligament (ACL) reconstruction (Fraval et al., 2015); and unspecified ambulatory orthopaedic surgery (Goldsmith & Safran, 1999). Two studies provided web-based patient education to patients with chronic conditions including: rheumatoid arthritis (RA) (Meesters et al., 2012) and osteoarthritis (OA) (Umapathy et al., 2015). Two studies provided web-based patient education to populations at risk for orthopaedic conditions such as: osteoporosis (Drieling et al., 2011) and hip fracture (Nahm et al., 2010). The mean age of participants across studies was 56.3 years and the sample was predominantly female (average 71.3% females in studies reporting gender). Most studies (70%) reported 'access to the Internet' as an explicit inclusion criterion and some also required participants to also have an unspecified level of comfortableness (Yin et al., 2015) or skill (Goldsmith & Safran, 1999; Heikkinen et al., 2008, 2009; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Heikkinen, Leino-Kilpi, Vahlberg, et al., 2012; Heikkinen, Salanterä, et al., 2012; Nahm et al., 2010) in using the Internet.

5.3.4 Intervention characteristics

The intervention characteristics of all included studies are described in Table 5.1. Most interventions consisted of a single website which was developed specifically for study purposes, while one study provided patient education by sharing multiple websites that are publically available (N. D. Groves et al., 2010). We did not identify any studies that used mobile devices for patient education.

Program content was specific to each intervention. Most interventions offered practical information about the orthopaedic condition or treatment, such as the procedures planned for the day of surgery or instructions for postoperative monitoring (Fraval et al., 2015; Goldsmith & Safran, 1999; N. D. Groves et al., 2010; Heikkinen et al., 2008, 2009; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Heikkinen, Leino-Kilpi, Vahlberg, et al., 2012; Heikkinen, Salanterä, et al., 2012; Sobel & Popp, 2006; Umapathy et al., 2015; Yin et al., 2015). Others focused on providing information regarding behavioural determinants (Drieling et al., 2011; Goldsmith & Safran, 1999) and local health care services (Meesters et al., 2012). Only two studies explicitly reported using content that was not primarily educational: patient testimonials/narratives (Nahm et al., 2010; Umapathy et al., 2015).

Half of the interventions conveyed content in a moderate to highly dynamic manner, meaning that they used three or more multimedia formats such as text, pictures, videos, animations, or audio (Drieling et al., 2011; Heikkinen et al., 2008, 2009; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Heikkinen, Leino-Kilpi, Vahlberg, et al., 2012; Heikkinen, Salanterä, et al., 2012; Nahm et al., 2010; Sobel & Popp, 2006; Umapathy et al., 2015). The other interventions primarily used text and pictures to convey the content. We did not find consistent evidence for the obvious assumption dynamic multimedia use increases the intervention's success. For example, both the static orthoanswer.org website (primarily text) used by Fraval and colleagues (Fraval et al., 2015) and the highly dynamic social cognitive theory (SCT) website (text, pictures/graphics, audio, animation, video) of Nahm and colleagues (Nahm et al., 2010) increased patients' knowledge. On the other hand, the similarly dynamic website of Drieling and colleagues (Drieling et al., 2011) did not do so.

While half of the interventions could be considered dynamic in terms of multimedia use, only one also provided highly dynamic activities (meaning, more than three interactive online activities were offered) (Drieling et al., 2011). Activities offered to the patient on the dynamic Bone Health Improvement Project website included problem solving exercises, goal setting exercises, and self-assessment. Among the more static websites, self-assessment was the most common interactive activity (Nahm et al., 2010; Umapathy et al., 2015). Because of the limited use of interactive online activities, we were not able to assess the influence interactivity might have on patient outcomes.

Most websites offered some human-support or feedback as part of the intervention (Drieling et al., 2011; Heikkinen et al., 2008, 2009; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Heikkinen, Leino-Kilpi, Vahlberg, et al., 2012; Heikkinen, Salanterä, et al., 2012; Meesters et al., 2012; Nahm et al., 2010; Umapathy et al., 2015). Examples of extensive support include a moderated message board (Nahm et al., 2010) and highly tailored automated feedback (Drieling et al., 2011; Umapathy et al., 2015). Other interventions offered fairly limited support by only sharing contact details of a nurse or other health professional (Heikkinen et al., 2008, 2009; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Heikkinen, Leino-Kilpi, Vahlberg, et al., 2012; Heikkinen, Salanterä, et al., 2012; Meesters et al., 2012). Again, there was no clear evidence that the level of support or feedback provided had an influence on the interventions' success.

In terms of duration and frequency of website usage, we observed considerable variation. This ranged from single 20-minute visits (Yin et al., 2015) to eighteen 60-to-90-minute visits over the course of 6 months (Drieling et al., 2011). As duration and frequency were not consistently reported, we were not able to assess a dose-response relationship between usage of a web-based intervention and outcomes.

Table 5.1 Intervention characteristics of studies evaluating the effects of Web-based patient education in orthopedics (alphabetical order)

Authors, year, country	Name of intervention	Components in intervention (Barak et al., 2009)				Theoretical basis of intervention	Duration and frequency of intervention
		Program content	**Multimedia use**	**Interactive online activities**	**Feedback support provision**		
Drieling et al. (2011), United States	Bone Health Improvement Project	Tailored messages about risk factors, knowledge, attitudes, and behaviors. Nontailored educational materials including recipes, exercise examples, and safety recommendations.	Text, graphics. Links to videos and other resources.	Tutorials include activities to facilitate behaviors, including problem-solving and goal-setting exercises.	Tailored automated feedback in the form of a personalized subset of intervention messages on the home page and in tailored tutorials.	Sender-message-channel-receiver communication model. Social Cognitive Theory (SCT). Transtheoretical model.	Intervention duration 6 months, 10 tailored tutorials (length 60-90 min) during first 3 months and 8 tailored tutorials during second 3 months.
Fraval et al. (2015), Australia	Orthoanswer	Walkthrough overview of procedures of diagnosis and indications for surgery; complications; and preoperative, intraoperative, and postoperative care. Frequently asked questions.	Text, graphics.	Not specified.	Not specified.	Not specified.	Duration not specified. Website visited once.
Goldsmith and Safran (1999), United States	Ambulatory Surgery Nursing website	Information on surgery practicalities and discharge information. Password-protected access to pain management information section.	Not specified.	Not specified.	Not specified.	Not specified.	Not specified.
N.D. Groves et al. (2010), United Kingdom	Your Spinal Anaesthetic, the Health library, NHS Direct	Information about anesthesia, particularly with respect to total knee arthroplasty and total hip arthroplasty.	Text, graphics.	Not specified.	Not specified.	Not specified.	Not specified.

Heikkinen et al. (2008; 2009; 2012a; 2012b; 2012c), Finland	Not specified	Information about nine topics on surgery including instructions for preparing to the surgery, events of the surgery day, follow-up care, and financial aspects. Frequently asked questions.	Text, graphics, video.	Self-selection of the amount, depth and dimension of the knowledge provided by structuring information to knowledge level (basic, intermediate, and advanced).	Option to contact nurse via email or phone.	Cognitive empowerment.	Website use 10-300 min (mean=80.7, SD=66.7), 4-6 times (mean=2.3).
Meesters et al. (2012), Netherlands	Not specified	Information regarding practical aspects of health care services divided in six areas: “health care services,” “health professionals,” “rheumatic diseases and physical activity,” “information and support,” “local consumer organization,” and “assistive devices”.	Text, graphics.	Option to subscribe to a newsletter to receive the announcement of relevant regional events.	Contact details of health services and health professionals. Telephone and email helpline to contact clinical nurse specialist.	Not specified.	Website online for 30 months. Duration and frequency of visits not specified.
Nahm et al. (2010), United States	Social Cognitive Theory (SCT)–based, structured HPF website	Structured Web learning modules on osteoporosis, falls and hip fractures, dietary or supplementary calcium intake, and exercise. Patient testimonials.	Text, graphics, audio, animation, video.	Self-assessment quizzes.	Discussion board moderated by research nurse.	SCT.	2 weeks, 2 modules of 20-30 min per week.
Sobel and Popp (2006), United States	EMMIPrep tool	Information about the surgical experience from preoperative to postoperative, including risks, benefits, and alternatives.	Text, animation, other unspecified learning modalities.	Option to type in questions.	Not specified.	Not specified.	Duration of online education 20 min. Frequency not specified.

Umapathy et al. (2015), Australia	My Joint Pain	Information for management of knee and hip osteoarthritis (OA) on treatment and management options and health care providers. Patient narratives (in video format). Customized management plan based on assessment.	Text, graphics, videos.	Hip or knee OA risk assessment. Monitoring of OA through weekly, monthly, and biannual pain assessment.	Tailored reinforcement messages based on assessment. Detailed report that could be discussed with health care team.	Criteria for judging the quality of patient decision aids as specified by the International Patient Decision Aids Standards Collaboration.	Website online for 12 months. Duration and frequency of visits not specified.
Yin et al. (2015), United States	ExplainMySurgery.com, custom knee arthroscopy module	Explanation of relevant anatomy, pathology, and general perioperative instructions for knee arthroscopy.	Not specified.	Not specified.	Not specified.	Not specified.	20 min, once.

Note. Heikkinen et al. 2012a = Heikkinen, Leino-Kilpi, Vahlberg, et al. (2012), Heikkinen et al. 2012b = Heikkinen, Leino-Kilpi, & Salanterä (2012), Heikkinen et al. 2012c = Heikkinen, Salanterä,Leppänen, Vahlberg, & Leino-Kilpi (2012).

5.3.5 Methodological quality of included studies

The methodological quality of the studies was moderate, based on a mean Downs and Black score of 17.67 ± 5.42 out of 28 (Table 5.2) (Downs & Black, 1998; Hootman et al., 2011). Most studies adequately reported intervention and sample characteristics, but the external validity was often problematic, as was the lack of power analyses.

Table 5.2 Methodological quality of included studies (ordered by quality)

	Downs & Black (1998) subscales[a]					
	Reporting	**External validity**	**Bias**	**Confounding**	**Power**	**Overall study quality[b]**
Heikkinen et al. (2008)	10	1	5	6	1	High
Fraval et al. (2015)	8	2	5	6	1	High
Drieling et al. (2011)	10	1	5	5	0	High
Nahm et al. (2010)	9	1	6	4	1	High
Heikkinen et al. (2012a)	10	1	4	6	0	High
Heikkinen et al. (2012c)	10	1	4	6	0	High
Heikkinen et al (2012b)	9	1	4	6	0	High
Umapathy et al. (2015)	10	1	5	3	1	High
Yin et al. (2015)	9	1	5	5	0	High
N.D. Groves et al. (2010)	6	1	6	5	1	High
Meesters et al. (2012)	9	1	5	1	0	Medium
Goldsmith & Safran (1999)	7	0	5	2	0	Medium
Heikkinen et al. (2009)	5	1	3	3	0	Medium
Sobel & Popp (2006)	3	0	1	0	0	Low
Median study quality	9/11	1/3	5/7	5/6	0/1	High

Note. Heikkinen et al. 2012a = Heikkinen, Leino-Kilpi, Vahlberg, et al. (2012), Heikkinen et al. 2012b = Heikkinen, Leino-Kilpi, & Salanterä (2012), Heikkinen et al. 2012c = Heikkinen, Salanterä, Leppänen, Vahlberg, & Leino-Kilpi (2012).

[a] Lowest to highest possible score for reporting (0-11), external validity (0-3), bias (0-7), confounding (0-6), power (0-1), overall quality (0-28).

[b] Percentage scores were calculated by dividing the final score by the maximum score and multiplication by 100. The percentage scores were used for ordinal categorization of the studies as low quality (≤33%), medium quality (33.4% - 66.7%) and high quality (≥66.8%) (Hootman et al., 2011).

5.3.6 Outcome measures of included studies

Most studies assessed knowledge acquisition (Drieling et al., 2011; Fraval et al., 2015; N. D. Groves et al., 2010; Heikkinen et al., 2008; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Heikkinen, Leino-Kilpi, Vahlberg, et al., 2012; Meesters et al., 2012; Nahm et al., 2010; Sobel & Popp, 2006; Umapathy et al., 2015; Yin et al., 2015) (90% of trials) and patient satisfaction, sometimes through qualitative feedback (Drieling et al., 2011; Fraval et al., 2015; Goldsmith & Safran, 1999; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Nahm et al., 2010; Sobel & Popp, 2006; Yin et al., 2015) (70% of trials). Other reoccurring outcome measures included anxiety (Fraval et al., 2015; N. D. Groves et al., 2010; Yin et al., 2015), functional outcomes (Goldsmith & Safran, 1999; Heikkinen, Leino-Kilpi, & Salanterä, 2012), and self-efficacy (Drieling et al., 2011; Heikkinen et al., 2009; Nahm et al., 2010).

Many studies employed custom instruments that were designed by the researchers to assess the outcomes of their specific intervention. This resulted in a broad assortment of instruments that are difficult to interpret and compare (Table 5.3). To illustrate this diversity, consider instruments used to assess knowledge acquisition. Only one validated instrument (the Osteoporosis Health Belief Survey) was used in more than one study (Drieling et al., 2011; Nahm et al., 2010). Four other studies also employed validated instruments, but not the same ones, as the topics of study (informed consent, anaesthesia, and empowerment) differed considerably (Fraval et al., 2015; N. D. Groves et al., 2010; Heikkinen et al., 2008; Umapathy et al., 2015). Four other studies employed instruments that had been developed specifically for each intervention, though the authors had pilot-tested or used these before (Heikkinen et al., 2008; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Meesters et al., 2012; Nahm et al., 2010). Finally, two studies did not report anything regarding the validity or testing of their custom instruments (Sobel & Popp, 2006; Yin et al., 2015).

Table 5.3 Patient outcomes and instruments used to assess the effect of web-based patient education (alphabetical order)

Outcome measure	Instrument	Used in
Knowledge acquisition		
	Deaconess Informed Comprehension Test	Fraval et al., 2015
	Hip Fractures Knowledge Test	Nahm et al., 2010
	Knowledge Test	Heikkinen et al., 2008, 2012b
	Modified Standard Anaesthesia Learning Test	N.D. Groves et al., 2010
	Osteoporosis Health Belief Survey	Drieling et al., 2011; Nahm et al., 2010
	Orthopaedic Patients Knowledge Questionnaire	Heikkinen et al., 2008
	Osteoarthritis Quality Indicator	Umapathy et al., 2015
	Sufficiency of Knowledge	Heikkinen et al., 2008, 2012b
	Custom instrument (no name provided)	Meesters et al., 2012; Sobel & Popp, 2006; Yin et al., 2015
Patient satisfaction & patient feedback[a]		
	Client Satisfaction Questionnaire	Fraval et al, 2015
	Patients' Evaluations of Education	Heikkinen et al., 2009
	Perceived Health Website Usability Questionnaire	Nahm et al., 2010
	Custom instrument (no name provided)	Yin et al., 2015
Anxiety		
	Emotions Questionnaire	Heikkinen et al., 2012c
	State-Trait Anxiety Index	Fraval et al., 2015
	Patients' Evaluations of Education	Heikkinen et al., 2009
	Custom instrument (no name provided)	Yin et al., 2015

Empowerment, self-efficacy, and health attitudes		
	Calcium subscale of Osteoporosis Self-efficacy Scale	Nahm et al., 2010
	Osteoporosis Health Belief Scale	Drieling et al., 2011; Nahm et al., 2010
	Outcome Expectations for Exercise Scale	Nahm et al., 2010
	Patients' Evaluations of Education	Heikkinen et al., 2009
	Self-efficacy for Exercise	Nahm et al., 2010
	Web-based Learning Self-efficacy Measure	Nahm et al., 2010
Self-management and behaviour change		
	Behavioral Risk Factor Surveillance System	Drieling et al., 2011
	Block-National Cancer Institute Health Habits and History Questionnaire	Nahm et al., 2010
	Brief Physical Activity Survey	Drieling et al., 2011
	Health Education Impact Questionnaire	Umapathy et al., 2015
	Yale Physical Activity Survey	Nahm et al., 2010
Clinical outcomes		
	The Symptoms	Heikkinen et al., 2012a
	Verbal Rating Scale of McGill Pain Questionnaire	Goldsmith & Safran, 1999

Note. Heikkinen et al. 2012a = Heikkinen, Leino-Kilpi, Vahlberg, et al. (2012), Heikkinen et al. 2012b = Heikkinen, Leino-Kilpi, & Salanterä (2012), Heikkinen et al. 2012c = Heikkinen, Salanterä, Leppänen, Vahlberg, & Leino-Kilpi (2012).

[a] Qualitative feedback methods (Drieling et al., 2011, Goldsmith & Safran, 1999, Sobel & Popp, 2006) are not included in the table.

5.3.7 The effects of web-based patient education interventions in orthopaedics

A summary of the effects of web-based patient education interventions is provided in Table 5.4.

5.3.7.1 Knowledge acquisition

Web-based patient education significantly increased patients' knowledge about orthopaedic conditions and orthopaedic treatment (Drieling et al., 2011; Fraval et al., 2015; Heikkinen et al., 2008; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Meesters et al., 2012; Nahm et al., 2010; Sobel & Popp, 2006; Yin et al., 2015). Web-based interventions were more effective than interventions provided through traditional channels (Fraval et al., 2015; N. D. Groves et al., 2010; Heikkinen et al., 2008; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Yin et al., 2015) and these effects persisted over 2 weeks (Heikkinen, Leino-Kilpi, & Salanterä, 2012). Increased knowledge levels also resulted in patients feeling more knowledgeable (Heikkinen et al., 2008; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Meesters et al., 2012; Sobel & Popp, 2006; Yin et al., 2015). However, feelings of knowledgeability did not significantly increase more after web-based education (Heikkinen et al., 2008; Heikkinen, Leino-Kilpi, & Salanterä, 2012), except when provided in addition to face-to-face sessions (Yin et al., 2015).

Patients who received educational interventions did not acquire more knowledge than those who independently reviewed health information websites. One trial reported that a theory-based intervention produced higher knowledge levels regarding osteoporosis than a health information website in healthy older females (Drieling et al., 2011) but another found no significant difference between both interventions in the same target group (Nahm et al., 2010).

5.3.7.2 Patient satisfaction and patient feedback

Patient satisfaction was a main outcome in two studies (Fraval et al., 2015; Yin et al., 2015). Both found that web-based patient education had a positive effect on patients' satisfaction. Yin and colleagues (2015) report a persistent increase in satisfaction with information and teaching on the day of surgery ($M_i = 8.7$ vs. $M_c = 7.7$, $p = .03$) and at the first post-operative visit ($M_i = 9.2$ vs. $M_c = 8.1$, $p = .01$) after exposing knee arthroscopy patients to a custom online teaching module with explanations of anatomy, pathology, and perioperative instructions. Fraval and colleagues (2015) report that satisfaction increased more in orthopaedic outpatients who consulted both the online module and received verbal counselling with their surgeon compared to those who had only received the latter.

Seventy percent of trials investigated patient satisfaction or collected qualitative patient feedback but had not defined it as a principal outcome. Feedback on the online interventions was generally positive: patients described them as "very effective" (Goldsmith & Safran, 1999), "easy to use" (N. D. Groves et al., 2010; Heikkinen, Leino-Kilpi, Vahlberg, et al., 2012; Sobel & Popp, 2006) and "worth the time" (Yin et al., 2015). Compared to face-to-face education and health information websites, web-based education was mostly evaluated better (Fraval et al., 2015; Nahm et al., 2010). Only Heikkinen and colleagues (2009) report worse evaluations in terms of clarity of the content for the web-based intervention ($M = 79.75$) compared to the face-to-face session with a nurse ($M = 86.41$), $p = .001$. However, both methods were considered clear enough to warrant further use.

5.3.7.3 Anxiety

In the three studies that assessed patients' anxiety following web-based patient education, no significant effects on anxiety were found. Knee arthroscopy patients reported few distressing emotions in general, and anxiety was not influenced by web-based patient education or verbal education (Heikkinen, Salanterä, et al., 2012). After visiting a website providing an overview of the preoperative, intraoperative and postoperative care processes orthopaedic outpatients were not less anxious about the planned surgery than patients who had discussed the same content with their surgeon (Fraval et al., 2015). For knee arthroscopy patients, using a web-based educational tool did also not decrease anxiety about the surgery, but did decrease anxiety about recovery (Yin et al., 2015).

5.3.7.4 Empowerment, self-efficacy, and health attitudes

Two studies included self-efficacy as a primary outcome measure and reported contradicting evidence (Drieling et al., 2011; Nahm et al., 2010). One study showed that both patients who used a structured SCT-based educational intervention and those who browsed health information websites had increased self-efficacy for calcium intake, the health behaviour of interest (Nahm et al., 2010). In contrast, these effects were not replicated in a similar study, which reported that self-efficacy was not influenced by patient education at all (Drieling et al., 2011). A lower quality report of the larger randomized controlled trial of Heikkinen and colleagues (2009) reported results that indicate that web-based patient education may even adversely influence self-efficacy. When participants were asked how well they could act based on the knowledge received in the education, the intervention group perceived their abilities significantly lower (M= 82.77) than the control group (M= 88.86), p = .001. Thus, the extent to which web-based educational interventions impact self-efficacy remains unclear.

5.3.7.5 Self-management and health behaviour change

Only one study assessed the effect of web-based patient education on self-management (Umapathy et al., 2015). In Umapathy and colleagues' 2015 study patients with self-assessed osteoarthritis used a tailored information tool to enhance self-management for twelve months. Users of the tool reported increased health-directed activity, engagement with life, self-monitoring, skill acquisition and social integration but not significantly more so than non-users. Users did acquire more knowledge about self-management and lifestyle as measured with the osteoarthritis quality indicator and showed a significant reduction in weight (change score: -6.3%) compared to non-users (change score: 2.5%), p = .03. While these results are promising, confounds in the study's design contaminate its findings: participants in this study were not randomized to the conditions and this opportunity for patients to self-select may have resulted in motivated users and demotivated non-users.

5.3.7.6 Clinical outcomes

The evidence for an effect of web-based patient education on clinical outcomes is limited and contradictory: while access to a pain management section of an ambulatory surgery web site resulted in a significant decrease in 'discomforting' pain scores after ambulatory surgery (Goldsmith & Safran, 1999), web-based tutorials about knee arthroscopy had no effect on pain after surgery (Heikkinen, Leino-Kilpi, Vahlberg, et al., 2012). In fact, the second study's findings suggest that pain may be less effectively decreased after web-based patient education in comparison to face-to-face education. Four weeks after the surgery patients who had received web-based education reported more pain in other areas (15.7% moderate-high pain) in comparison to the control group (7% moderate-high pain). However, three-way interactions between pain, group and time failed to reach significance. The same study also reports that other postoperative symptoms (including tiredness, problems with digestion, swelling of the operation area) decreased regardless of the patient education method used.

Table 5.4 Summary of the effects of Web-based patient education (ordered by comparison then by quality)

Authors	Design	Quality assessment	Patient population	Intervention, sample size (n), age (years)	Control, sample size (n), age (years)	Timing of outcome measures	Outcome measures, instruments	Intervention effects[a]	Intervention effects relative to control[a]
No comparison									
Umapathy et al. (2015)	Quasi-experimental study	High	Patients with self-assessed hip or knee osteoarthritis N=195	Online tailored information tool, n=104, age=mean 60.9 (SD 9.1)	Nonusers, n=91, age=mean 60.5 (SD 8.3)	Pre test, post test (12 months)	Knowledge	=[b]	=
							Self-management	+	=
Meesters et al. (2012)	Observational study	Medium	Patients with rheumatoid arthritis N=400 (160 paired observations analyzed)	Informational website, n=160, age=mean 60.4 (SD 9.9)	Not applicable (N/A)	Pre test, post test (24 months)	Knowledge insufficiency	–	N/A
							Information needs	–	N/A
Sobel and Popp (2006)	Retrospective survey analysis	Low	Patients undergoing total hip arthroplasty (THA) and other surgeries (gastric bypass, colonoscopy) N=2423	Online education tool, n=2423, age not reported	N/A	Post test	Knowledge (general)	+	N/A
							Knowledge (risks)	+	N/A
							Confidence in provider	+	N/A
							Perceived usefulness	Positive evaluation	N/A

Comparison to health information websites

Drieling et al. (2011)	Pilot Randomized Controlled Trial (RCT)	High	Healthy females at risk of osteoporosis N=121	Internet-based risk- and stage-tailored health education program, n=61, age=mean 59.9 (SD 6.7)[c]	Independent review of online health information, n=60, age=mean 58 (SD 8.6)[c]	Pre test, post test (3 months), follow-up (6 months)	Knowledge (osteoporosis)	×	+[d]
							Knowledge (calcium)	×	+
							Knowledge (exercise)	×	=
							Self-efficacy	×	=
							Beliefs	×	=
							Exercise	×	=
							Calcium intake	×	=
							Vitamin D intake	×	=
Nahm et al. (2010)	RCT	High	Older adults from general population at risk of hip fracture N=245	SCT-based structured hip fracture prevention website, n=125, age=mean 69.3 (SD 7.7)[e]	Conventional hip fracture prevention website, n=120, age=mean 69.3 (SD 7.7)[e]	Pre test, post test (2 weeks), follow-up (3 months)	Knowledge (hip fracture)	+	=
							Knowledge (osteoporosis)	+	=
							Self-efficacy (calcium intake)	+	=
							Self-efficacy (exercise)	=	=
							Self-efficacy (online learning)	×	–
							Expectations (calcium intake)	+	=
							Expectations (exercise)	=	=
							Calcium intake	+	=
							Exercise	=	=
							Satisfaction	×	+

Goldsmith and Safran (1999)	Prospective RCT	Medium	Patients scheduled for preoperative screening for orthopedic, gynecological, and laparoscopic ambulatory surgery N=195	Preoperative interview + informational website + password-protected access to pain management section, n=98, age=mean 45.2 (range: 19-82)	Preoperative interview + limited access to information website (n=97, age=mean 44.5 (range: 18-74)	Post test (arrival at home), 1st follow-up (night after surgery), 2nd follow-up (day after surgery)	Pain Utilization Perceived usefulness	× × +	– + ×
Comparison to traditional patient education								
Fraval et al. (2015)	RCT	High	Orthopedic outpatients scheduled for five common orthopedic procedures: total knee arthroplasty (TKA), THA, knee arthroscopy, shoulder arthroscopy, and anterior cruciate ligament reconstruction N=211	Standard verbal consent discussion + online patient education tool, n=103, age=mean 54.29 (SD not reported)	Standard verbal consent discussion, n=108, age=mean53.7 (SD not reported)	Post test	Knowledge Anxiety Satisfaction	× × ×	+ = +
N.D. Groves et al. (2010)	Double-blind RCT	High	Patients presenting to the orthopedic preadmission clinic before admission for TKA or THA N=118	Written patient information sheet + online health information websites, n=59, age=mean 58.7 (SD 10.4)	Written patient information sheet, n=59, age= mean 62 (SD 9)	Pre test, post test (at admission for surgery or 2 weeks after clinic appointment)	Knowledge Choice for neuraxial	+ +	+ +

Yin et al. (2015)	Prospective RCT	High	Adult patients undergoing first-time knee arthroscopy for primary diagnosis of meniscal tear N=55	Standard verbal preoperative education and counseling with surgeon + Web-based tutorial, n=26, age=mean 49.9 (SD 10.3)	Standard verbal preoperative education and counseling with surgeon, n=29, age=mean 47.5 (SD 13.3)	Post test (preoperative visit), 1st follow-up (day of surgery), 2nd follow-up (1st postoperative visit)[f]	Knowledge	×	+
							Knowledge sufficiency	×	+
							Anxiety	×	=[g]
							Satisfaction	×	+
							Perceived usefulness	Positive evaluation	×
Heikkinen et al. (2008)[h]	RCT	High	Ambulatory orthopedic surgery (shoulder or knee arthroscopy) patients N=149	Web-based education via website, n=72, age=mean 44.2 (SD 12.7)	Verbal education with nurse, n=75, age=mean (SD 12.7)	Pre test, post test, follow-up (2 weeks after surgery)	Knowledge (overall, functional, ethical)	+	+
							Knowledge (bio-physiological, experiential, social, financial)	+	=
							Knowledge sufficiency (ethical)	+	+
							Knowledge sufficiency (overall, bio-physiological, functional, experiential, social, financial)	+	=
Heikkinen et al. (2012c)[h]	-	High	-	-	-	Pre test, post test, follow-up (surgery day, 1st and 3rd postoperative day, 2 and 4 weeks postoperative)	Emotions	=	=

Heikkinen et al. (2012b)[h]	-	High	-	-	-	Pre test, post test, follow-up (2 weeks after surgery)	Knowledge	+	+
							Knowledge sufficiency	+	=
Heikkinen et al. (2012a)[h]	-	High	-	-	-	Pre test, post test, follow-up (surgery day, 1st and 3rd postoperative day, 2 and 4 weeks postoperative)	Pain (symptoms)	=	=
							Function (symptoms)	+	=
Heikkinen et al. (2009)[h]	-	Medium	-	-	-	Post test	Information needs	×	=
							Understanding	×	=
							Self-efficacy	×	–
							Anxiety	×	+
							Clarity of content	×	–
							Satisfaction	×	=

Note. Heikkinen et al. 2012a = Heikkinen, Leino-Kilpi, Vahlberg, et al. (2012), Heikkinen et al. 2012b= Heikkinen, Leino-Kilpi, & Salanterä (2012), Heikkinen et al. 2012c = Heikkinen, Salanterä,Leppänen, Vahlberg, & Leino-Kilpi (2012).

[a] Statistically significant results: (+), positive effect; (=), not significant; (–), negative effect; (×), not reported.

[b] Although overall knowledge improvement was not significant, it did significantly improve for subscales self-management, lifestyle, and physical activity (+).

[c] To increase ease of comparison, mean age and SD were approximated from the frequency tables reported in the original studies.

[d] Mean age and SD were not provided separately for each group. The mean age and SD of the overall sample is reported.

[e] Change from baseline to 6 months was significant; however, change from baseline to 3 months was not significant.

[f] Measures from post test to follow-up were rephrased over the study period.

[g] Change was significant at 2nd follow-up; however, change at post test or 1st follow-up was not significant.

[h] All papers by Heikkinen and colleagues report different outcome measures following the same intervention. As such, the study design, intervention group, control group, and sample sizes as described for Heikkinen et al. (2008) are identical to Heikkinen et al. (2009,2012a,2012b,2012c)

5.4 DISCUSSION

The current review set out to examine the effects of web-based patient education in the care for adult orthopaedic patients. This is an important subject, as orthopaedic patients are commonly using the Internet to find health information (Baker et al., 2010; Fraval et al., 2012) and perceive this to have an impact on both their health and social environment (Win et al., 2016), while these effects have not yet been systematically examined. The comparative evaluation of web-based educational interventions is especially relevant: to generic health information websites which potentially form a strong co-intervention (H. Q. Nguyen et al., 2004), and to traditional patient education interventions which may be more effective, but have higher costs (Win et al., 2016).

This review identified 14 studies that reported the effects of ten different web-based patient education interventions targeted towards the orthopaedic patient population. Although the amount of studies is limited, the overall methodological quality of the included studies is high. Still, the different studies could not be compared on a meta-analytic level given the wide variety in scope, primary outcomes, and means of outcome assessment. Furthermore, the reported findings may be limited to patients who were already able to use the Internet as 70% of the studies included in this review established criteria that excluded inexperienced, less skilled patients with limited access to the Internet to the trials. Hence, it is difficult to draw definitive conclusions about the effectiveness of web-based patient education interventions.

While keeping these limitations in mind, the currently available evidence does suggest that patients who are offered web-based patient education find the service both usable and satisfactory (Drieling et al., 2011; Fraval et al., 2015; Goldsmith & Safran, 1999; Heikkinen, Leino-Kilpi, Vahlberg, et al., 2012; Nahm et al., 2010; Sobel & Popp, 2006; Yin et al., 2015). It increases their knowledge levels (Fraval et al., 2015; N. D. Groves et al., 2010; Heikkinen et al., 2008; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Meesters et al., 2012; Nahm et al., 2010; Sobel & Popp, 2006; Yin et al., 2015), which also results in patients who feel knowledgeable (Fraval et al., 2015; N. D. Groves et al., 2010; Heikkinen et al., 2008; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Yin et al., 2015) and are able to participate in the informed consent process (Fraval et al., 2015; Sobel & Popp, 2006; Yin et al., 2015). Web-based education appeared to be more effective in these aspects than traditional education methods (Fraval et al., 2015; N. D. Groves et al., 2010; Heikkinen et al., 2008; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Yin et al., 2015). In spite of their knowledge gain, the provision of online information to patients does not subsequently reduce patients' anxiety (Fraval et al., 2015; Heikkinen, Salanterä, et al., 2012; Yin et al., 2015). These findings support our first hypothesis that web-based patient education interventions would have a positive effect on patients' knowledge, but not on anxiety. Contrary to second hypothesis however, web-based education was not found more effective than generic health information websites (Goldsmith & Safran, 1999; Yin et al., 2015). A possible explanation for this finding is that both web-based patient education materials and generic health information websites suffer from issues such as poor readability (Eltorai, Sharma, Wang, & Daniels, 2015; Jariwala et al., 2004; Keller, 2014; Nassiri, Bruce-Brand, O'Neill, Chenouri, & Curtin, 2014).

There is still insufficient evidence to determine the effect of web-based patient education on self-efficacy, self-management, or clinical outcomes. Only two studies investigated self-efficacy (Drieling et al., 2011; Nahm et al., 2010); one observational study investigated self-management (Umapathy et al., 2015); two studies investigated pain (Goldsmith & Safran, 1999; Heikkinen, Leino-Kilpi, Vahlberg, et al., 2012); and no studies have assessed patients' functioning using standardized patient-reported outcome measures for orthopaedic practice, such as the Western Ontario and McMasters Universities Osteoarthritis Index (WOMAC) or Hip Disability and Osteoarthritis Outcome Score (HOOS). Therefore, we were unable to test our hypothesis that web-based patient education would not have an effect on clinical outcomes.

This review illustrates the typical web-based patient educational intervention that is currently offered to people with orthopaedic conditions. These are mostly websites focused on practical, informational content that is presented using multiple media formats including text, pictures, and video. Most offer some form of (human) support to patients using the programs, but are still static in terms of interactivity. Still, it seems that online self-assessment is being recognized as an appropriate strategy to make educational content more engaging. At this point, there was not enough evidence to conclude that either of these intervention characteristics – content, media use, support, interactivity, or duration – has a consistent effect on the interventions' success. However, regarding support provision, it should be noted that almost all studies that did not specify the level of support offered on the website did include some form of provider contact as part of the usual care given to both the experimental and control groups (Fraval et al., 2015; Goldsmith & Safran, 1999; N. D. Groves et al., 2010; Yin et al., 2015). Patients may have received feedback and support during these meetings, which makes it difficult to estimate the effects that added online support or feedback may have. Therefore, future work should report whether (ICT) support or feedback was provided as part of usual care.

Most of our findings are in line with previous reviews of web-based patient education. We found further support for the idea that changing the channel of communication in patient education can increase patient satisfaction, as was tentatively hypothesized in Nguyen and colleagues' 2004 review. Web-based patient education is also equally effective in orthopaedics as in oncology practice (Ryhanen et al., 2010). Similarly to orthopaedic patients, breast cancer patients' knowledge and satisfaction increased following web-based education, while their anxiety was not affected. Furthermore, in both fields a wide variety of study outcomes and corresponding instruments was identified. Thus the current review can only further endorse the need for standardized instruments in the evaluation of web-based interventions as previously addressed by Ryhanen and colleagues in 2010.

Despite the above-mentioned replications, we could not determine whether self-care behaviour of orthopaedic patients increased due to web-based patient education, an effect that has been identified in cardiovascular patients who were offered online educational interventions (Fredericks, Martorella, & Catallo, 2015). Because the Internet can be used without constant professional supervision, online interventions may play a continuous role in the education and support of chronically ill orthopaedic patients (Irvine et al., 2015; Trudeau et al., 2015; Wilkinson & Whitehead, 2009). Despite this potential, we found only one study that specifically evaluated education within the context of an online self-management intervention (Umapathy et al., 2015). This may have been because we have excluded behavioural or affective interventions from review. This narrow scope allowed us to precisely examine the effectiveness of education alone, but a next step for web-based interventions would be report separately on educational, behavioural, and affective content. This will allow those who are tasked with developing interventions to study the interplay between these components to determine the 'ideal' dose for a specific population or condition. Taxonomies to facilitate such in-depth examination of intervention components have already been developed for behaviour change techniques (Michie et al., 2013) and computer-tailoring (Lustria, Cortese, Noar, & Glueckauf, 2009). Slowly, similar efforts are done for web-based interventions as well, such as Barak and colleagues' internet-supported interventions model (Barak et al., 2009) used in this review to describe intervention components and Win and colleagues' online patient education features model (Win et al., 2016). Still, a consensus on an appropriate taxonomy has not yet been reached, and until this is in place, it will be difficult to estimate the specific role education can play in enhancing complex outcomes such as self-management capabilities.

5.4.1 Limitations

This review has several limitations which relate to the representativeness of the samples included in the studies, the limited number of included studies, and the lack of a meta-analysis.

First, the quality of the reported studies was higher than previous reviews of web-based interventions have documented (Bessell et al., 2002; H. Q. Nguyen et al., 2004). Most studies provided an elaborate description of the control groups and interventions, including the specific interactive elements designed into the programs. Still, the external validity of the included studies is low; no studies provided evidence that the included sample was representative of the entire population. This is concerning considering that most studies had criteria in place that excluded participants with less Internet use and experience. Compared to these selected samples, the entire population was likely older (Baker et al., 2013; Fraval et al., 2012; Thorne, Mackenzie, & Wilson, 2017; Walsh, Rehman, & Goldhirsh, 2014), lower educated (Baker et al., 2013; Fraval et al., 2012; Walsh et al., 2014) and more likely to receive public care (Fraval et al., 2012; Gutierrez, Kindratt, Pagels, Foster, & Gimpel, 2014). On the other hand, younger patients are also the ones who expect more information (Klemetti et al., 2016; Ryhanen et al., 2010), value online services (Ackerman et al., 2016; Berendsen et al., 2010) and are most likely to benefit from educational interventions (Fredericks, Guruge, Sidani, & Wan, 2010). Thus, while we cannot conclude that it serves the whole orthopaedic population, web-based patient education may be an excellent way to cater to this younger patients' specific needs.

Second, we were able to evaluate only a limited number of studies. Although the initial search identified over a thousand potential studies, only ten trials specifically evaluated web-based patient education interventions in a sufficiently controlled setting. As a result, we were not able to draw any reliable conclusions about the effect of web-based patient education on patient reported outcomes, including postoperative pain and functioning, while reviews of traditional patient education show that these outcomes may be affected (Kroon et al., 2014; Louw et al., 2013; McDonald et al., 2014).

Third, the studies employed a wide variety of outcome measures which did not allow for a meta-analysis of the findings. Though the qualitative synthesis does indicate that web-based patient education increases patients' knowledge levels and satisfaction, we were not able to determine the extent of these effects. Therefore, their clinical relevance has yet to be determined.

5.5 CONCLUSION

In summary, offering patient education interventions via the Internet to adult people with orthopaedic conditions increases their knowledge about their condition and its treatment (Drieling et al., 2011; Fraval et al., 2015; N. D. Groves et al., 2010; Heikkinen et al., 2008; Heikkinen, Leino-Kilpi, & Salanterä, 2012; Heikkinen, Salanterä, et al., 2012; Meesters et al., 2012; Nahm et al., 2010; Sobel & Popp, 2006; Yin et al., 2015). Online educational interventions are typically instructional websites, that make use of multimedia but offer limited interactivity. They are considered usable and can increase patient satisfaction (Fraval et al., 2015; Goldsmith & Safran, 1999; N. D. Groves et al., 2010; Heikkinen, Leino-Kilpi, Vahlberg, et al., 2012; Nahm et al., 2010; Sobel & Popp, 2006; Yin et al., 2015). However, the provision of online information to patients does not subsequently reduce patients' anxiety (Fraval et al., 2015; Heikkinen, Salanterä, et al., 2012; Yin et al., 2015).

Given these findings, we tentatively conclude that web-based patient education may be offered as a time- and cost-effective alternative to current educational interventions when the primary aim of the intervention is to increase patients' knowledge and satisfaction. However, there is too little evidence to advocate for web-based patient education to replace existing interventions that aim to improve other outcomes, including self-management skills, pain, and function. Furthermore, it should be kept in mind that web-based interventions currently cater to younger patients who may not be comparable to the general patient population. A solution for hospital administrators or health care policy makers currently planning an educational intervention for orthopaedics patients is to provide web-based education in addition to verbal or written components, which allows patients to select the platform they are most comfortable with while ensuring satisfactory results.

Chapter 6

The effect of information architecture on the effectiveness and user experience of web-based patient education: A randomized experiment with middle-aged and older adults

Summary

Chapter 5 demonstrated that web-based patient education increases patients' knowledge about their disease and its treatment and their satisfaction with the care process. However, patients who are older, lower-educated, or less experienced with the internet may not be able to use online education effectively. Information architecture (IA) design may support patients in using a patient education website effectively independently. Tailoring IA can make a website more accessible for a larger variety of patients with different communicative preferences and competences.

To support intervention designers in making informed choices that enhance patients' learning, Chapter 6 describes a randomized experiment concerning the effect of (tailored) IA on the effectiveness, use, and experience with a web-based patient education website. We identify five working mechanisms by which IA can affect patients' experience and learning (section 6.1.2) and outline the design process of the website variants in relation to the patient profiles (section 6.2.2). We found that a matrix IA design is perceived to provide more active control to users, while a tunnel IA increases the perceived personal relevance of the educational content. Both increase satisfaction (sections 6.3.1 and 6.3.2). Tailoring IA provides additional benefits for *managing* patients, but not for *optimistic or modest* patients (section 6.3.3).

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ABSTRACT

Background. Web-based patient education is increasingly offered to improve patients' ability to learn, remember, and apply health information. Efficient organization, display, and structural design, i.e. information architecture (IA), can support patients' ability to independently use web-based patient education. However, the role of IA in the context of web-based patient education has not been examined systematically.

Objective. To support intervention designers in making informed choices that enhance patients' learning, the current paper describes a randomized experiment concerning the effect of IA on the effectiveness, use, and user experience of a patient education website and examines the theoretical mechanisms that explain these effects.

Methods. Middle-aged and older adults with self-reported hip or knee joint complaints were recruited to use and evaluate one of three patient education websites. Each website contained the same textual content based on an existing leaflet but differed in the employed IA design (tunnel, hierarchical, or matrix design). Participants rated the websites on satisfaction, engagement, relevance, control, trust, and novelty and completed an objective knowledge test. Analyses of variance and structural equation modelling were used to examine the effects of IA and construct a theoretical model.

Results. We included 215 participants in our analysis. IA did not affect knowledge gain (p =.361) or overall satisfaction (p =.069) directly. However, tunnel (M=3.22, SD=0.67) and matrix (M=3.17, SD=0.69) architectures were found to provide more emotional support compared to hierarchical architectures (M=2.86, SD=0.60) (p =.002). Furthermore, increased perceptions of personal relevance in the tunnel IA (β=.11) were found to improve satisfaction (β=.17) indirectly. Increased perceptions of active control in the matrix IA (β=.18) also improved satisfaction (β=.27) indirectly. The final model of IA effects explained 74.3% of the variance in satisfaction and 6.8% of the variance in knowledge and achieved excellent fit: $\chi^2(17,215)=14.684$, p =.618, RMSEA=0.000 [CI 0.000-0.053], CFI=1.00, SRMR=0.044.

Conclusions. Web-based patient education designers should employ tunnel IA to guide users through sequentially ordered content or matrix IA to offer users more control over navigation. Both improve user satisfaction by increasing user perceptions of relevance (tunnel) and active control (matrix). Hierarchical IA designs are not recommended, as hierarchical content is perceived as less supportive, engaging, and relevant which may diminish the usage, and in turn the effect of the educational intervention.

6.1 INTRODUCTION

Verbal and written patient education methods are often supplemented with web-based education to improve patients' ability to learn, remember, and apply health information. Such improvements are needed because patients' recall of traditional education is generally poor (Fagerlin et al., 2010; Langdon, Hardin, & Learmonth, 2002; Turner & Williams, 2002) which negatively affects their satisfaction with care, ability to self-manage, and emotional well-being (Kinnersley et al., 2007; Krupic, Määttä, Garellick, Lyckhage, & Kärrholm, 2012).

There are many options to engage patients with web-based education ranging from animations and interactive exercises to tailored health advice (Morrison, Yardley, Powell, & Michie, 2012). But in order for education to be the most effective, patients have to be able to use such functions independently. An efficient information architecture (IA) supports independent usage (Arden-Close et al., 2015; Kebede, Liedtke, Möllers, & Pischke, 2017) yet few studies have systematically examined IA in the context of online health education. In order to support intervention designers in making informed choices that enhance patients' learning, the current paper describes a randomized experiment concerning the effect of information architecture on the effectiveness, use, and user experience of a patient education website and the theoretical mechanisms that explain these effects.

6.1.1 Information architecture

IA concerns "the structural design of a shared information environment" (Morville & Rosenfeld, 2006). It describes "the way in which digital content is organized and displayed, which strongly impacts users' ability to find and use content" (Pugatch, Grenen, Surla, Schwarz, & Cole-Lewis, 2018). IA has a pervasive role in website design as it affects the user's ability to find information with no or very limited training and helps save long-term costs. Online environments with effective IAs are typically more scalable, easier to maintain and update, and require fewer redesigns (Morville & Rosenfeld, 2006). Yet despite the importance of IA, there is a lack of primary research that examines IA specifically in the context of web-based health education. A recent review on this subject even revealed that to date just one study has empirically manipulated IA in isolation from other design features (Pugatch et al., 2018). This study, conducted in 2012 by Crutzen and colleagues to examine online hepatitis information, investigated whether providing users with the opportunity to skip pages (or not) affected website usage and user perceptions of efficiency, effectiveness, and enjoyment. It showed that an architecture that provided users with less control over navigation increases both website use and knowledge gain (Crutzen, Cyr, & De Vries, 2012). While this study demonstrated that IA influences online learning experiences, it examined only one particular IA design (the tunnel). Therefore, we argue that a more comprehensive examination of IA is due. For this purpose, we use Danaher and colleagues' taxonomy of four archetypes of IA; the tunnel, hierarchical, matrix, and hybrid architecture (Danaher, Brendryen, Seeley, Tyler, & Woolley, 2015; Danaher, McKay, & Seeley, 2005). For clarity, the current study focusses on the three non-hybrid IA designs (i.e. tunnel, hierarchical, matrix). The features, advantages, and disadvantages of each design are outlined below and examples of each IA design are presented in Figures 6.2A-C (Methods).

The tunnel IA design is the most common IA in health interventions: 90-100% of interventions for chronic illness or mental health support include some form of tunnelling (Kelders, Kok, Ossebaard, & Van Gemert-Pijnen, 2012). In a typical tunnel IA users follow a step-by-step approach to access content in sequential order. A possible advantage of this IA is that it reduces the complexity of information. However, it also reduces the perceived control of users, which may decrease engagement and lead to non-adherence and attrition (Perski, Blandford, West, & Michie, 2017). The second IA archetype is the hierarchical design. In this design, information is organized hierarchically. Users are shown chunks of information from which they select nested content to review in detail, hereby offering users control over content selection. Assumed advantages of this IA include familiarity and simplicity. Yet, usability may be limited when users are unable to locate deeply-nested content. The third IA concerns the matrix design. This IA design presents all available content on one homepage or dashboard. It allows users to freely navigate through the content in their preferred order and duration. The matrix IA design is considered engaging yet disorienting, and particularly appropriate for highly educated and experienced users (Lynch & Horton, 2016; Perski et al., 2017).

6.1.2 What explains effects of information architecture?

Many scholars have condemned the ‘black box’ approach to eHealth which offers little understanding of the underlying mechanisms through which online interventions (and the tools, techniques, and strategies embedded in them) exert their effects (Danaher et al., 2015; Kelders et al., 2012; Whitton et al., 2015). IA design suffers from the same issue. While there are several assumed benefits (e.g. increased usability, increased user control) to each IA design as outlined above, there is no overarching conceptual model of IA effects. This makes it difficult to determine how IA can improve the effectiveness and user experience of a health education website. Therefore, we examine five aspects of the user experience – user engagement and user perceptions of control, personal relevance, trustworthiness, and novelty - that may be influenced by IA design in depth. These are depicted in the conceptual model (Figure 6.1).

6.1.2.1 User engagement

First, we hypothesize that IA design affects user engagement. User engagement is defined as “a quality of user experience characterized by the depth of an actor’s investment when interacting with a digital system” (O’Brien, 2016; O’Brien, Cairns, & Hall, 2018, p. 28). Several recent reviews suggest that user engagement is pivotal for creating an effective and enjoyable online experience (Ludden, van Rompay, Kelders, & van Gemert-Pijnen, 2015; Perski et al., 2017). IA design, and tunnelling in particular, is thought to increase engagement because it persuasively guides users through the online process (Crutzen et al., 2012; Kelders et al., 2012). In a study of an online smoking cessation intervention, users who viewed content in a set order accessed more relevant content, and viewed this content longer and more often (McClure et al., 2013). Therefore, we hypothesize that IA design affects engagement, with tunnel IA design resulting in higher levels of user engagement, which will in turn positively influence knowledge acquisition and user satisfaction.

6.1.2.2 Perceived user control

User control is a "user's ability to voluntarily participate in and instrumentally influence a communication" (Liu, 2003, p. 208; Liu & Shrum, 2002). Previous studies have already shown that IA influences user perceptions of control (Crutzen et al., 2012). Yet, user control may affect the user experience in two ways. First, less user control may increase engagement, as detailed above. However, *more* user control may also increase engagement, because it provides users with a sense of dominance and autonomy (Ludden et al., 2015). Furthermore, online environments over which users can exert more control are seen as more interactive (Liu, 2003; Liu & Shrum, 2002). Interactive interventions in turn show greater and longer lasting effects, as they are typically used more often (Morrison et al., 2012; Vandelanotte et al., 2016). Important to note here is that *perceived* interactivity and control are of bigger influence than actual website interactivity (Song & Zinkhan, 2008; Voorveld, Neijens, & Smit, 2011). Therefore, we focus on perceived user control, which we expect is highest in a matrix IA design. Increased perceptions of control are expected to lead to greater effectiveness and a more positive user experience.

6.1.2.3 Perceived personal relevance

Perceived personal relevance refers to the extent that people feel that information is relevant to themselves and their situation (Kreuter et al., 1999; Lustria et al., 2016; Strecher et al., 2008). Some IA designs (matrix, hierarchical) allow users to select content; allowing them to determine which content they consider personally relevant. People are more motivated to process personally relevant content, leading to deeper processing and a greater susceptibility any persuasive attempts the content makes (A. Dijkstra, 2008; Hawkins et al., 2008; Lustria et al., 2016). We expect that perceived personal relevance may increase knowledge acquisition from educational content through the same motivational pathway. Perceptions of relevance have also been linked to educational enjoyment (Ryan & Deci, 2000). Thus, we expect that IA design improves perceived personal relevance of health information and that this leads to both greater knowledge acquisition and greater satisfaction.

6.1.2.4 Perceived trust

Perceived trust is a belief that influences whether a patient is willing to engage with health education (Yi, Yoon, Davis, & Lee, 2013). Trust in health information is influenced by source, message, channel, and recipient (Hesse et al., 2005; Wathen & Burkell, 2002) as well as structural website features (Rains & Karmikel, 2009). We therefore hypothesize that IA design influences participants' trust in the health information presented and in turn the knowledge and satisfaction derived from education content.

6.1.2.5 Perceived novelty

Finally, we considered perceived novelty as a potential explanatory variable. Since the tunnel IA design is the norm in health interventions, users may perceive other IA designs to offer more novel ways to access health information. Novelty in the context of interfaces can "act as a curiosity generating mechanism that arouses the imaginations of users and captures their interest in a site" (Huang, 2003). Users pay greater attention and effort to novel media (R. E. Clark, 1983) subsequently leading to a greater uptake of information. Novelty has also been related to enjoyable experiences of flow and engagement (Huang, 2003; O'Brien, 2016). We therefore expect that IA design (in particular, the less common hierarchical and matrix designs) will affect user perceptions of novelty and that increased novelty will improve both user satisfaction, and through increased attention to the content, knowledge acquisition.

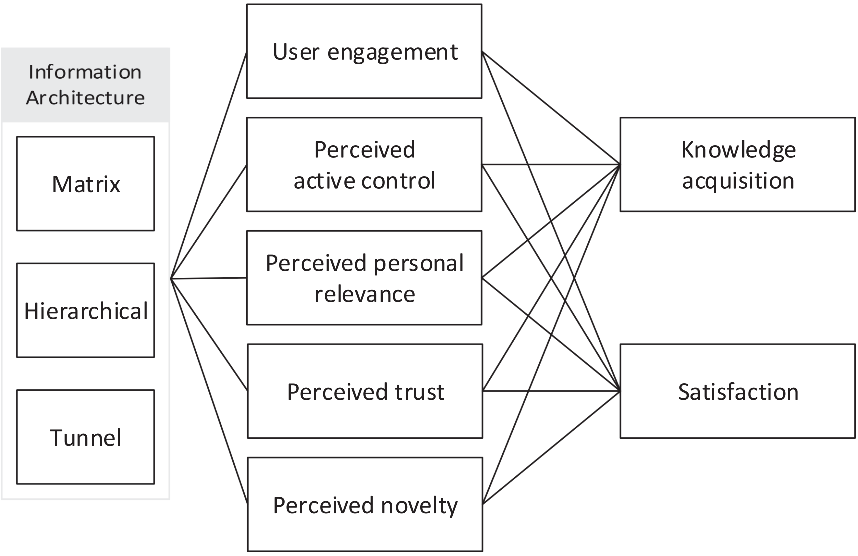

Figure 6.1 Conceptual model of information architecture

6.1.3 Does one IA design fit all?

A final consideration to make in examining the effects of IA is the role of individual preferences and capabilities. Many recommendations regarding IA design take user characteristics into account. For example, Lynch and Horton (2016) describe matrix IA designs (which they refer to as 'webs') as more suitable for highly educated users with a high level of prior knowledge about the content. It has also been suggested that perceived control over website navigation may be more important to some users than to others (Crutzen et al., 2012). However, the influence of individual differences on the effectiveness and experience with different IA design has not been empirically tested.

The current study uses a previously defined set of user profiles of total joint replacement (TJR) surgery patients (Groeneveld et al., 2019, Chapter 3) to explore the potential benefit of tailored IA design (Table 6.1). Each profile represents one of three ways through which communicative preferences and competences may manifest in patients. So-called *managing* patients prefer to more open, participative communication and have high competences and self-efficacy for understanding and applying health information. In comparison, *optimistic* patients have similar competences, but no clear preferences for the tone of communication. Finally, *modest* patients value both open information as well as emotional support, but have limited self-efficacy and competences for health communication. With these profiles and the recommendations for each IA design in mind, we hypothesise that users with higher preferences for open communication (i.e. managing patients) will prefer IA designs that offer more control (i.e. matrix), optimistic patients will not prefer any IA design in particular, and modest patients will prefer more supportive IA designs that guide them through the educational content step by step (i.e. tunnel).

Table 6.1 Description of communicative preferences and competences of three patient profiles

Optimistic profile 42% of health consumer population	**Modest profile** 34% of health consumer population	**Managing profile** 24% of health consumer population
• Moderate preference for open communication	• Moderate preference for open communication	• High preference for open communication
• Low preference for emotionally supportive communication	• Moderate preference for emotionally supportive communication	• High preference for emotionally supportive communication
• Moderate critical communication competences	• Low critical communication skills	• High critical communication competences
• Moderate personal communication competences	• Low personal communication skills	• High personal communication competences
• High self-efficacy for health information	• Low self-efficacy for health information	• Moderate self-efficacy for health information

6.1.4 Study objectives

The aims of the current study are threefold: (1) to test the effect of information architecture in the context of a total joint replacement surgery patient education website on knowledge acquisition and satisfaction with the online education, (2) to test possible working mechanisms of information architectures, including user engagement, perceived user control, perceived personal relevance, perceived trust, and perceived novelty and (3) to explore the potential of tailored information architectures.

6.2 METHODS

In July 2018 we conducted a between-subject experiment comparing the knowledge and satisfaction gained from a patient education website with three different IA designs. Ethics approval for this study was obtained from the Human Research Ethics Committee TU Delft. Participants provided written consent and signed a data processing agreement formulated in concordance with the EU General Data Protection Regulation (GDPR).

6.2.1 Participants and procedure

Participants were recruited using a Dutch online consumer research service (respondenten.nl). Middle-aged to older adults (40-80 years) with self-reported chronic hip or knee joint complaints (including arthrosis, wear and tear, chronic inflammations, birth deficits, or unknown causes) were eligible for participation. To detect a small-to-medium effect (f^2= 0.15-0.25) on satisfaction and knowledge using an alpha of 0.05 and a power of 0.80, a sample size between 159 and 432 participants was needed (Faul, Erdfelder, Lang, & Buchner, 2007; Selya, Rose, Dierker, Hedeker, & Mermelstein, 2012). We aimed to recruit at least 100 participants per condition for a total sample of 300 participants. Participants received monetary reimbursement (€15) for their participation.

The complete experiment was conducted online via survey software (Qualtrics). Each eligible participant was provided a hyperlink to the survey. After providing consent, participants filled out questionnaires regarding their communication preferences and skills, health, anxiety, and coping behaviour, which were used to determine the patient profile (Groeneveld et al., 2019, Chapter 3). Participants also stated the extent to which they already felt knowledgeable about TJR surgery (part A). In part B participants were randomly assigned to one of three experimental conditions using Qualtrics' built-in randomizer. The allocation sequence and assignments were concealed from all participants, the researchers, and the consultant hired for patient recruitment until all data was collected. Participants were initially asked to focus on either the website's design or content. After reviewing the website's design, participants reported satisfaction and user perceptions. They were then asked to view the website a second time whilst focusing on content. Then they filled out a knowledge test designed for the purpose of this study. The order of focus (design vs. content) was counter-balanced. Finally, participants shared their socio-demographic information and received a code for reimbursement (part C). Eligible participants who had not started or completed the survey after three weeks were reminded via email once.

6.2.2 Materials

6.2.2.1 Design process

The three websites were designed between March and June 2018 by a design agency specializing in the design of products, services and processes for healthcare (Panton B.V.) under supervision of the first author. The lead designer was provided literature on IA (Danaher et al., 2005) and given access to patient profile role descriptions and anonymized data about patients' communication preferences and competences collected in an (unpublished) earlier study. In June, prototypes of the websites were pilot-tested. To discuss progress and ensure accuracy and quality of health information shared on the patient education websites the design team met with the first author ten times throughout the design process. At two points in the design process (after first conceptualization and after the pilot tests) the design team also met with the full research team, including an orthopaedic surgeon.

6.2.2.2 Pilot usability study

Prototypes of the three websites were pilot tested with seven patients (mean age 64.7 years) scheduled for TJA and seven informal caregivers (mean age 63.3 years) in June 2018. Interested patients present at the clinic for scheduled group-based patient education were shown the prototypes after they provided written consent. They first freely explored the websites while mentioning aloud any (positive or negative) aspects that stood out. They were then asked to find information about the first check-up after surgery. This assignment was used to identify usability issues and software bugs (Wiklund, Kendler, & Strochlic, 2010). Finally, patients were asked to report engagement using the User Engagement Scale-Short Form (UES-SF, see 6.2.3.2). Throughout the pilot test, the cursor of the participants was tracked using screen capture software (CamStudio Recorder v2.7, Rendersoft Development). Screen captures were used both to identify unclear navigational cues and to get an initial impression of whether the users navigated through the IAs as intended (e.g. whether patients explored more pages in the matrix design, made use of the table-of-contents in the hierarchical design, and moved step-by-step using the next and prior buttons in the tunnel design, etc.). The input of patients and caregivers was shared with the lead designer and implemented in the following iteration of the design. This led to significant improvements in usability including less scrollable text, more prominently displayed contact information, vivid colour accents, and larger buttons.

6.2.2.3 Websites

All websites contained the same textual content based on an existing patient education leaflet titled 'Instructions after an outpatient Total Hip Prosthesis (THP)' [*Instructies na een Totale Heup Prothese (THP) in dagbehandeling*] used by the local hospital (Reinier de Graaf Gasthuis, the Netherlands). The leaflet addressed practical concerns before and after outpatient THR surgery including preparation for surgery, pain, medication, and physiotherapy. All graphic design elements (including photos, fonts, colour) were equivalent across websites.

The tunnel IA website design had a chronological sequential ordering of topics presented as a time-line, starting with 'the day of the operation' and ending with 'three month follow-up' and 'frequently asked questions'. Navigation was limited to 'next' and 'previous' buttons placed below the text and in the time-line. Topics that were not yet accessible to the user were greyed out (see Figures 6.2A-C). The hierarchical IA website design presented participants with a choice menu in which they selected the phase of their 'patient journey' (e.g. in the hospital, able to walk a few steps, etc.). After selecting an option, users were presented with topics grouped in a table-of-contents menu. Participants could further investigate their chosen topic using the menu and could return to the homepage using the buttons or navigation path (i.e. 'bread crumb trail'). The matrix IA website design showed all topics in tiles on the homepage and provided no suggested reading order. By clicking the topic tiles or hyperlinks in the body of text, participants could switch between topics. Offline copies of the experimental websites are available on request by contacting the first author.

A Tunnel

Pijn en zwelling na de operatie

Vaak verdwijnt de wondpijn in de eerste week, maar de spierpijn kan na de operatie best nog enige weken aanhouden. Ook kan er een grote bloeduitstorting ontstaan in het operatiegebied. Het bloed kan in de dagen na de operatie uitzakken naar uw tenen. Uw lichaam ruimt dit bloed zelf weer op, maar het kan, vooral in de eerste week na de operatie een gespannen gevoel geven. Ook hierbij helpt het om regelmatig korte stukken te lopen.

Om te voorkomen dat uw geopereerde been te dik wordt na de operatie is het verstandig om in de eerste week na de lunch één tot twee uur op bed te gaan liggen met de benen omhoog op een kussen. Het dik worden van het been is niet helemaal te voorkomen.

Bij koorts (boven 38,5 °C), vragen en/of onduidelijkheden kunt u op werkdagen tussen 08.30 en 16.30 uur telefonisch contact opnemen met de consulente. Het telefonisch spreekuur is van 8.30u-10u. U kunt buiten deze tijden de voicemail inspreken en u wordt dan zsm teruggebeld. In de avond en nacht en weekend uren kunt u bij calamiteiten altijd contact opnemen met de Spoedeisende Hulp.

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B Hierarchical

Pijn en zwelling na de operatie

Vaak verdwijnt de wondpijn in de eerste week, maar de spierpijn kan na de operatie best nog enige weken aanhouden. Ook kan er een grote bloeduitstorting ontstaan in het operatiegebied. Het bloed kan in de dagen na de operatie uitzakken naar uw tenen. Uw lichaam ruimt dit bloed zelf weer op, maar het kan, vooral in de eerste week na de operatie een gespannen gevoel geven. Ook hierbij helpt het om regelmatig korte stukken te lopen.

Om te voorkomen dat uw geopereerde been te dik wordt na de operatie is het verstandig om in de eerste week na de lunch één tot twee uur op bed te gaan liggen met de benen omhoog op een kussen. Het dik worden van het been is niet helemaal te voorkomen.

C Matrix

Pijn en zwelling

Meestal is de pijn die u voor uw operatie had direct weg na de operatie. Er ontstaat echter wel operatiepijn die voornamelijk bestaat uit spierpijn en wondpijn. Voor en na de operatie hebben wij u medicatie gegeven die deze 'operatiepijn' moet verminderen. Sommige patiënten hebben door het gebruik van de pijnmedicatie helemaal geen pijn. Indien u wel pijn hebt, helpt het vaak om de heup te bewegen. U kunt bijvoorbeeld wat oefeningen doen in bed, maar vooral lopen vermindert de pijn. Niet bewegen maakt de pijn erger doordat de heup stijf wordt.

Vaak verdwijnt de wondpijn in de eerste week, maar de spierpijn kan na de operatie best nog enige weken aanhouden. Ook kan er een grote bloeduitstorting ontstaan in het operatiegebied. Het bloed kan in de dagen na de operatie uitzakken naar uw tenen. Uw lichaam ruimt dit bloed zelf weer op, maar het kan, vooral in de eerste week na de operatie een gespannen gevoel geven. Ook hierbij helpt het om regelmatig korte stukken te lopen. Om te voorkomen dat uw geopereerde been te dik wordt na de operatie is het verstandig om in de eerste week na de lunch één tot twee uur op bed te gaan liggen met de benen omhoog op een kussen. Het dik worden van het been is niet helemaal te voorkomen.

Figures 6.2A-C Tunnel, hierarchical, and matrix information architecture (IA) design of a (Dutch) patient education website

All screenshots depict the same content about 'pain and swelling' [pijn en zwelling]. Annotations A-H indicate typical design elements of the specific IA design. A= Next/previous buttons (tunnel IA), B= Next/previous buttons (tunnel IA), C= Not yet accessible greyed-out text (tunnel IA), D= table-of-contents (hierarchical IA), E= major grouping by recovery phase (hierarchical IA), F= return to main menu, G= topic matrix (matrix IA), H= hyperlink (matrix IA).

6.2.3 Measurements

The primary outcomes of interest are knowledge acquisition and website satisfaction. Satisfaction with the online education captures both the attitude of patients towards website functioning (e.g. satisfaction with comprehensibility and with emotional support derived from the website) as well as their affective attitude (e.g. satisfaction with website attractiveness) (Bol et al., 2013, 2014). The secondary outcomes used to test the conceptual model include user perceptions of engagement, control, personal relevance, trust, and novelty. We also measured usage by capturing the total time spent on the website in seconds. Finally, we collected short qualitative feedback forms on the perceived (dis)advantages of the website.

6.2.3.1 Knowledge acquisition and satisfaction with website

Five multiple choice (MC) questions and three open questions about (self-)care after TJR surgery were used to assess knowledge acquisition. The questions followed from the content of the websites and included: 'After the surgery, it is important to strengthen the muscles surrounding the hip joint. Which ways to do so are recommended by orthopaedic surgeons?'. Each question included the following answer options: 'not been discussed', 'discussed, but I can't remember the details', a correct answer, and an incorrect answer (distractor) (Jansen et al., 2008). For each correct MC answer participants scored 1 point and for each open question an answer sheet was developed that assigned points from 0 (incorrect), 1 (partly correct), to 2 (fully correct). All points were summed and converted to reflect the percentage correct answers (0 – 100% correct).

Satisfaction with the patient education was measured using the Website Satisfaction Scale (WSS) (Bol et al., 2013, 2014) comprising three subscales: satisfaction with the 1) attractiveness of the website, 2) comprehensibility of the information, and 3) emotional support received from the website. All items were measured on a 5-point Likert scale (1 = 'totally disagree', 5 = 'totally agree'). Questions included 'the website looks nice', 'the website is understandable', and 'the website gives ease of mind'. Both an overall index score of satisfaction and the separate subscales achieved excellent reliability (α= .82-.98).

6.2.3.2 User perceptions of engagement, personal relevance, active control, trust, and novelty

We included five constructs to explore the theoretical mechanisms through which (tailored) IAs may influence knowledge acquisition and satisfaction. The first is user engagement, as measured through the UES-SF. We obtained permission to translate this validated questionnaire to Dutch (personal communication by H.L. O'Brien, May 18 2018) according to the guidelines for cross-cultural adaptation of self-reported instruments (Beaton et al., 2000; Sousa & Rojjanasrirat, 2011). The instrument contains 12 questions which form one index score (α= .88) and four subscales: focused attention ('I was absorbed in this experience', α= .75), aesthetic appeal ('the website was attractive', α= .87), reward ('using the website was worthwhile', α= .71), and perceived usability ('I felt frustrated while using the website', α= .79) (see Appendix 6A). The other user perceptions of interest included perceived personal relevance (‘the website was relevant to my situation’, two items, α= .83) (Jensen, King, Carcioppolo, & Davis, 2012), perceived active control (‘during the website visit, I could freely decide what I wanted to see’, four items, α= .96) (Voorveld et al., 2011), perceived novelty (‘the website incited my curiosity’, three items, α= .90) (O’Brien & Toms, 2010), and trust (‘the website is sincere and honest’, three items, α= .97) (Yi et al., 2013). All questions were answered on a 5-point Likert scale (1 = ‘strongly disagree’, 5 = ‘strongly agree’).

6.2.4 Statistical methods

We conducted Chi-square and analyses of variance (ANOVA) tests to check whether background characteristics were equally randomized over experimental conditions. To test the main effect of IA, two ANOVA tests were conducted with satisfaction and knowledge gain as dependent variables. Follow-up pairwise t-tests were corrected using the Bonferroni correction. The concept of tailored IAs was explored in a two-way ANOVA with condition and profile as the independent variables.

Second, to construct a conceptual model of how IA influences satisfaction and knowledge acquisition, we used structural equation modelling (SEM). User perceptions of engagement, personal relevance, active control, trust, and novelty (hereafter, mediating variables) were regressed on IA. Satisfaction and knowledge were regressed on IA and the mediating variables. To improve the parsimony and fit of the model we removed non-significant paths and added additional paths based on significant modification indices. Model Chi-square (χ^2), Comparative Fit Index (CFI), the Standardized Root Mean Square Residual (SRMR), and Root Mean Square Error of Approximation (RMSEA) were used to determine model fit. A model was considered to have a good fit when χ^2 / degrees of freedom ≤ 3 with $p < .05$; CFI ≥ 0.95; SRMR ≤ 0.09; and RMSEA ≤ 0.07 (Hooper, Coughlan, & Mullen, 2008; Iacobucci, 2010). All analyses were conducted in R version 3.5.1 (R Core Team, 2016) with α = .05.

6.3 RESULTS

We enrolled 235 participants of which the data of 215 participants were included in the analysis (Figure 6.3). No significant associations were found between background characteristics and experimental condition indicating that participants were successfully randomized over all three conditions. All participant characteristics are reported in Table 6.2. On average, participants were 57 years old (*SD*=7.7), female (72%), attained lower secondary education (44%) and were (self-)employed (55%). They used the Internet daily ($M_{daily\ hours}$=3.2, *SD*=2.1) mainly on PC or laptops (91%) and mobile phones (82%). Participants rated their overall health significantly lower (69 out of 100) than the Dutch average of 81.5 for people aged 50-59 (Essink-Bot, Stouthard, & Bonsel, 1993; Szende & Williams, 2004) and experienced considerable movement-evoked joint pain (*M*=4.9, *SD*=2.3).

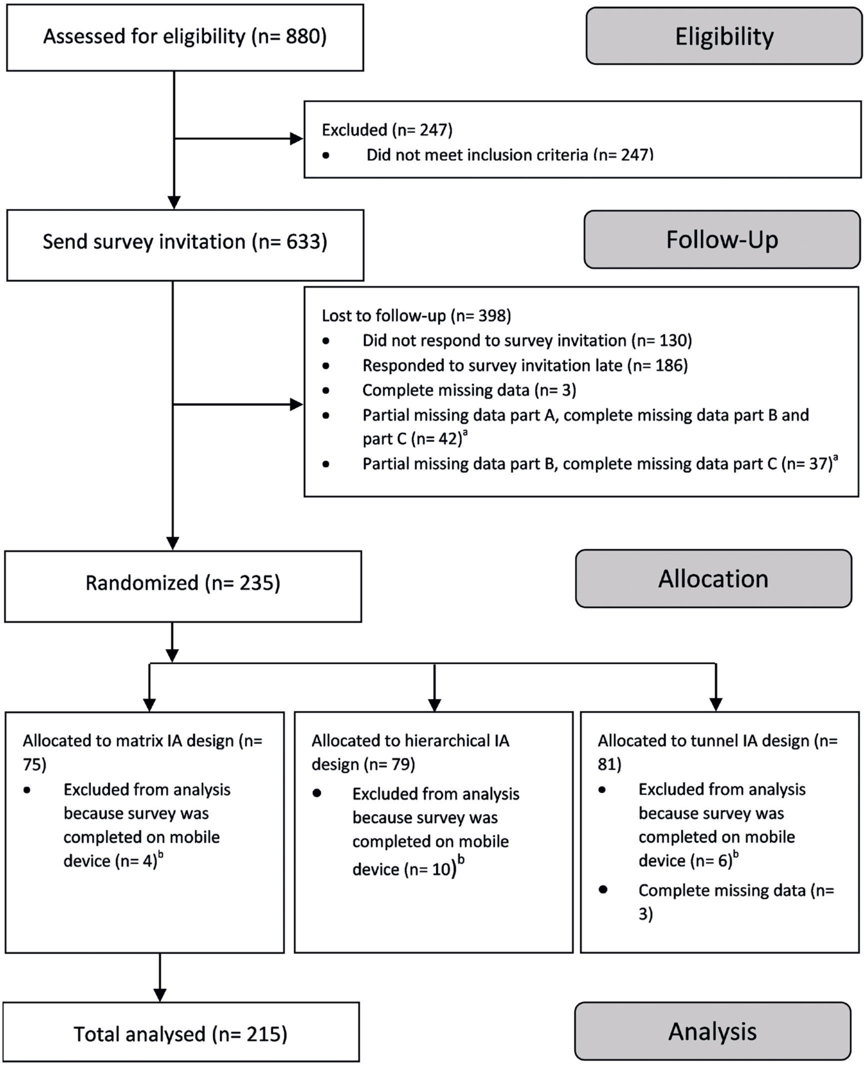

Figure 6.3 Patient recruitment and follow-up diagram

[a] The survey consisted of three parts. Part A included questions to determine the patient profile. Part B comprised website viewing and evaluation. Part C consisted of socio-demographic questions. The survey was set up so that participants first had to complete part A to be able to view part B, and part B to view part C. As randomization occurred only in Part B, loss to follow-up is reported prior to allocation.

[b] 20 participants completed the survey on a mobile device, despite instructions to view the survey and the websites on a laptop or PC. Because the layout and thus the information architecture of the websites may appear distorted on mobile devices, these participants were excluded from analysis. There were no significant differences between the excluded participants compared to included participants on background characteristics with the exception of device usage (*P*<.001). Excluded participants used the PC less (47% vs. 9% non-use) and tablet devices more (89% vs. 41% use).

Table 6.2 Participant characteristics

	Total sample (N = 215)		
	Count	**%**	**NA**
Age in years (mean, SD)	57.18	7.70	1
Sex			
Female	155	72.1	0
Male	60	27.9	0
Education			
Primary education	3	1.4	0
Lower secondary education	95	44.2	0
Higher secondary education	36	16.7	0
Tertiary education	81	37.7	0
Occupation			
Employed	83	38.6	0
Self-employed	35	16.3	0
Retired	37	17.2	0
Beneficiary	29	13.5	0
Other or none	31	14.4	0
Relationship status			
Married or long-term relationship	132	61.4	0
Divorced	41	19.1	0
Never married	35	16.3	0
Widowed	5	2.3	0
Other	2	0.9	0
Social support [a]			
Partner	124	57.7	0
Friend	75	34.9	0
Child	52	24.2	0
Neighbour	36	16.7	0
Family member	34	15.8	0
Colleague	7	3.3	0
Group (church, sports)	4	1.9	0
Other	2	0.9	0
No support	25	11.6	0
Internet usage in hours per day (mean, SD)	3.17	2.14	10
Device usage [a]			
PC or laptop	194	90.7	1
Phone	175	81.8	1
Tablet	88	41.1	1
Self-reported previous knowledge of hip replacement surgery (mean, SD)	1.85	0.92	2
Patient profile			
Optimistic	90	41.9	0
Modest	72	33.5	0
Managing	53	24.7	0

[a] Participants could select multiple answers.

6.3.1 Effects of information architecture on knowledge acquisition and satisfaction

All three websites received predominantly positive feedback; participants appreciated that they were ‘clear and organized’. Appendix 6B summarizes the perceived (dis)advantages for each IA. Table 6.3 reports the overall effects of information architecture. Information architecture did not directly affect knowledge gain, $F(2,212)=1.023$, $p =.361$, $\eta_p^2= .010$ or overall satisfaction, $F(2,212)=2.702$, $p =.069$, $\eta^2=.025$. Information architecture did have a significant effect on satisfaction with emotional support, $F(2,212)=6.376$, $p =.002$, $\eta^2=.057$. Post hoc analyses indicated that participants were significantly less satisfied with the hierarchical IA design ($M=2.86$, $SD=0.60$) compared to the matrix ($M=3.17$, $SD=0.69$) and tunnel ($M=3.22$, $SD=0.67$) architectures. The hierarchical design was perceived the least favourable in general: users devoted less focused attention ($\Delta_{\text{tunnel}}=0.319$, $p =.030$) saw the design as less novel ($\Delta_{\text{tunnel}}=0.332$, $p =.023$, $\Delta_{\text{matrix}}=0.363$, $p =.012$) and less personally relevant ($\Delta_{\text{tunnel}}=0.442$, $p =.006$), and found that it provided the least active control ($\Delta_{\text{matrix}}=0.317$, $p =.019$).

Table 6.3 Knowledge acquisition, satisfaction and user perceptions of patient education website by information architecture

Outcome	Tunnel IA (N=75)		Hierarchical IA (N=69)		Matrix IA (N=71)			
	M	SD	M	SD	M	SD	P	η^2
Website satisfaction	3.69	0.52	3.65	0.52	3.50	0.48	.069	
Attractiveness	3.73	0.61	3.68	0.65	3.61	0.61	.501	
Comprehension	4.24	0.56	4.21	0.59	4.17	0.71	.793	
Emotional support	3.22	0.67	3.17	0.69	2.86	0.60	.002[a]	.057
Knowledge acquisition	51.64	19.55	48.02	19.75	47.3	19.63	.361	
User engagement	3.16	0.75	3.65	0.55	3.48	0.57	.047[b]	.028
Focused attention	3.76	0.68	3.00	0.70	2.85	0.79	.040[c]	.030
Aesthetic appeal	3.81	0.62	3.75	0.68	3.52	0.76	.082	
Reward	3.43	0.75	3.78	0.57	3.58	0.68	.055	
Perceived usability	3.71	0.55	4.05	0.78	3.98	0.78	.674	
Perceived active control	3.84	0.67	3.95	0.65	3.63	0.74	.023[f]	.035
Perceived personal relevance	3.08	0.86	2.73	0.83	2.64	0.86	.005[e]	.050
Perceived trustworthiness	3.94	0.56	3.92	0.57	3.78	0.59	.209	
Perceived novelty	4.08	0.68	3.46	0.73	3.10	0.76	.007[d]	.046
Time spent in seconds	353.16	263.62	318.13	254.98	299.15	248.63	.443	

Note. Subscales are indicated in cursive. All post-hoc analyses concerned pairwise t-tests with Bonferroni correction for multiple comparisons.

[a] Hierarchical IA was significantly different from both tunnel IA ($p =.016$) and matrix IA ($p =.016$).

[b] Hierarchical IA was significantly different from tunnel IA ($p =.050$)

[c] Hierarchical IA was significantly different from tunnel IA ($p =.034$)

[d] Hierarchical IA was significantly different from both tunnel IA ($p =.025$) and matrix IA ($p =.013$).

[e] Tunnel IA was significantly different from both hierarchical IA ($p =.006$) and matrix IA ($p =.038$).

[f] Hierarchical IA was significantly different from matrix IA ($p =.021$).

Table 6.4 Pathways included in mediation models M1 to M4

Outcome	Predictor/mediator	Path estimate	*P* (M1)	M2	M3	M4
User engagement	Tunnel IA	0.190	.015	✓	✓	
	Matrix IA	0.139	.077	✓		
Perceived active control	Tunnel IA	0.142	.070	✓		
	Matrix IA	0.215	.006	✓	✓	✓
Perceived personal relevance	Tunnel IA	0.243	.002	✓	✓	✓
	Matrix IA	0.048	.539			
Trust	Tunnel IA	0.133	.092	✓		
	Matrix IA	0.109	.167			
Perceived novelty	Tunnel IA	0.208	.007	✓		
	Matrix IA	0.225	.004	✓	✓	
Knowledge	User engagement	0.226	.045	✓	✓	✓
	Perceived active control	0.006	.955			
	Perceived personal relevance	0.089	.220			
	Trust	-0.007	.933			
	Perceived novelty	-0.006	.949			
Satisfaction	User engagement	0.382	<.001	✓	✓	✓
	Perceived active control	0.273	<.001	✓	✓	✓
	Perceived personal relevance	0.169	<.001	✓	✓	✓
	Trust	0.227	<.001	✓	✓	✓
	Perceived novelty	0.026	.601			
Knowledge	Tunnel IA design	0.042	.593			
	Matrix IA design	-0.018	.823			
Satisfaction	Tunnel IA design	-0.011	.797			
	Matrix IA design	-0.017	.677			
Knowledge	User engagement * Matrix IA	0.031	.185			
	Perceived novelty * Matrix IA	-0.001	.949			
	Trust * Matrix IA	-0.001	.933			
	Perceived personal relevance * Matrix IA	0.004	.583			
	Perceived active control * Matrix IA	0.001	.955			
	User engagement * Tunnel IA	0.043	.122			
	Perceived novelty * Tunnel IA	-0.001	.949			
	Trust * Tunnel IA	-0.001	.933			
	Perceived personal relevance * Tunnel IA	0.022	.254			
	Perceived active control * Tunnel IA	0.001	.955			
Satisfaction	User engagement * Tunnel IA	0.073	.023	✓	✓	
	Perceived active control * Tunnel IA	0.039	.088	✓		
	Perceived personal relevance * Tunnel IA	0.041	.011	✓	✓	✓
	Trust * Tunnel IA	0.030	.111			
	Perceived novelty * Tunnel IA	0.005	.608			
	User engagement * Matrix IA	0.053	.088	✓		
	Perceived active control * Matrix IA	0.059	.016	✓	✓	✓
	Perceived personal relevance * Matrix IA	0.008	.543			
	Trust * Matrix IA	0.025	.183			
	Perceived novelty * Matrix IA	0.006	.607			

Note. The standardized parameter values of the full mediation model (M1) are provided. Only pathways indicated with a check-mark were included in subsequent model formulations.

Overall, models 2 to 4 all achieved similarly good fit (Table 6.5). Model 4 (Figure 6.4) was selected as the final model as it was the most parsimonious (expressed by highest degrees of freedom[15]). This model explained 74.3% of the variance in satisfaction and 6.8% of the variance in knowledge and achieved excellent fit: $\chi^2(17,215)=14.684$, $p=.618$, RMSEA=0.000 [CI 0.000-0.053], CFI=1.00, SRMR=0.044.

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[15] See Raykov & Marcoulides (1999) for a detailed discussion on parsimony in structural equation model selection.

6.3.2 Model of information architecture effects

The analyses of variance tests demonstrated that the tunnel and matrix designs performed significantly better than the hierarchical IA design. To explain why tunnel and matrix IAs perform better compared to hierarchical IAs, we therefore selected the hierarchical IA as the reference category in the mediation model.

The first mediation model (M1) specified that the effect of IA on knowledge and satisfaction would be mediated by user perceptions of engagement, active control, personal relevance, trust and novelty. Specification of complete mediation results in a fully-saturated regression model with zero degrees of freedom as the number of observations is equal to the number of parameters (T. K. Dijkstra, 1992; Kenny, 2018). Therefore, the first model was interpreted based on the regression paths instead of the fit indices (Table 6.4). All pathways with $P<.10$ were considered in a second model (M2). For model M3 and M4 we continued eliminating pathways with a more stringent cut-off of $P<.05$.

Table 6.5 Fit statistics of mediation models M2 to M4

Model	χ^2	P	df	χ^2/df	CFI	SRMR	RMSEA [CI]
M2	4.694	0.86	9	0.522	1	0.027	0.000 [0.000-0.041]
M3	10.826	0.625	13	0.833	1	0.042	0.000 [0.000-0.057]
M4	14.684	0.618	17	0.864	1	0.044	0.000 [0.000-0.053]

The model explains the effect of IA as follows: compared to hierarchical IAs, health information presented in a tunnel IA is perceived as more personally relevant (β=.11). This subsequently increases user satisfaction (β=.17). Matrix IAs, in comparison to hierarchical IAs, increase the active control users perceive to have over the health information (β=.18) which also increases satisfaction (β=.27). Furthermore, the model shows that next to user perceptions of personal relevance and active control, user engagement and perceived trust in the health information affects users' satisfaction with a patient education website. While we hypothesized that perceived novelty would also be affected by IA and affect satisfaction and knowledge in turn, this was not found to be the case.

Finally, we already established that IA design did not directly affect knowledge acquisition. The model demonstrated that IA also did not indirectly influence knowledge since no of the tested mediation pathways were significant. Knowledge acquisition was influenced by user engagement (β=.26) but user engagement itself was unaffected by IA.

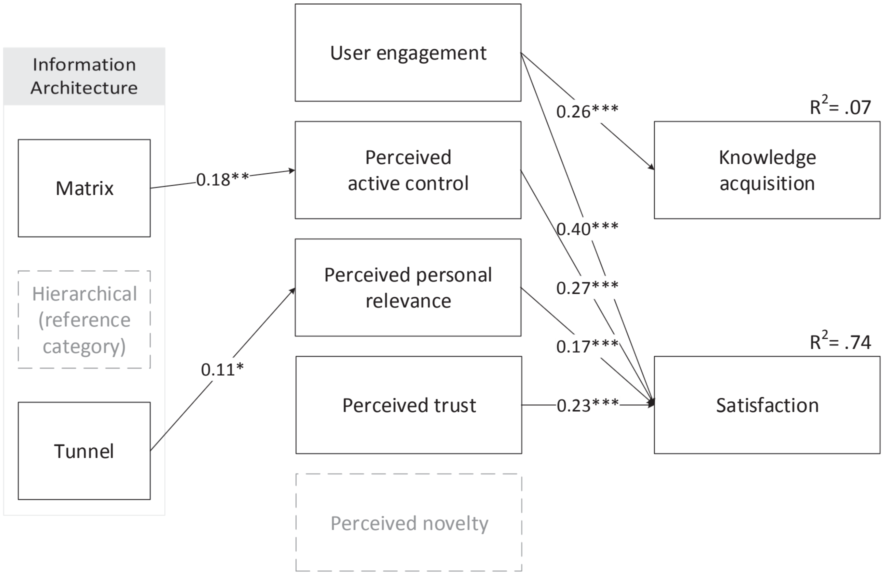

Figure 6.4. Structural equation model of the effects of information architecture

6.3.3 Tailored information architectures: interactions with patient profile

Interaction effects between IA and patient profile indicated that some IA designs were more preferred by users with specific profiles, $F(4,206)=2.646$, $p = .035$, $\eta_p^2 = .049$. In the post hoc analyses a consistent difference was demonstrated between participants of the managing profile and modest profile using a tunnel IA design (Figure 6.5). Managing participants were significantly more satisfied with the tunnel design ($\Delta_{\text{modest}}=0.489$, $p = .044$), perceived it as more attractive ($\Delta_{\text{modest}}=0.673$, $p = .013$) and trustworthy ($\Delta_{\text{modest}}=0.630$, $p = .009$) and found it to provide more active control ($\Delta_{\text{modest}}=0.764$, $p = .009$).

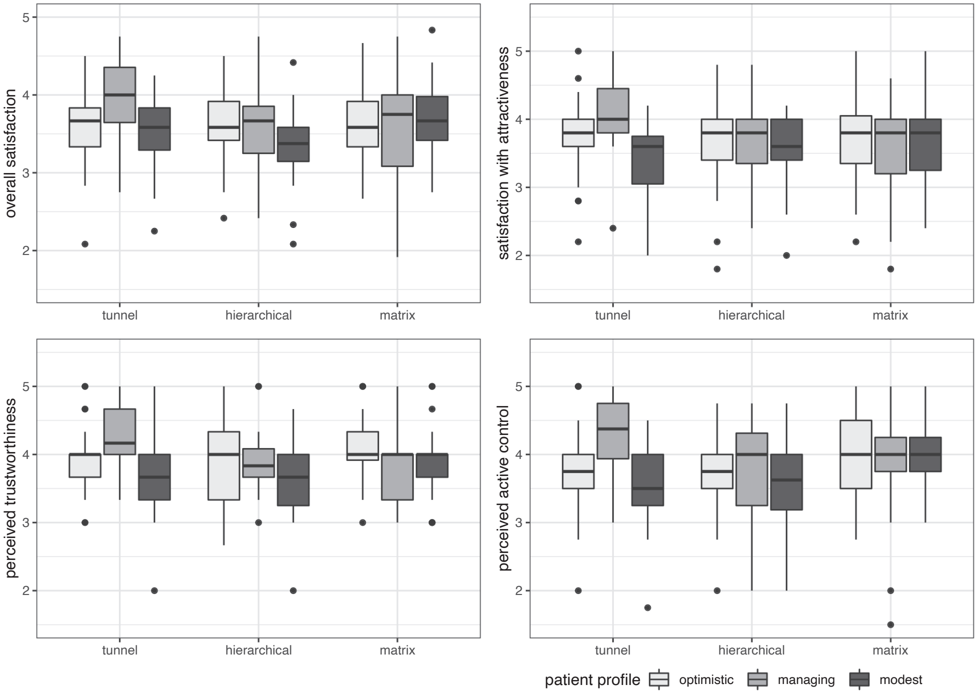

Figure 6.5 Interaction effects between information architecture and patient profile

6.4 DISCUSSION

The aim of this study was to investigate how the organization, display, and structural design of a website, i.e. the information architecture (IA), influences patients' experience with online patient education and their knowledge of the educational content. We wanted to understand if user perceptions of engagement, control, personal relevance, trust, and novelty could explain how IA affects satisfaction and knowledge. Furthermore, we examined whether a user's profile affected which IA design they considered to most effective or enjoyable to explore the potential of tailored IA design. Research on IA in the context of online health education has been sparse (Pugatch et al., 2018) which has limited intervention designers' ability to make informed design choices that enhance patients' experiences with online education.

The current study compared three IA designs; the tunnel, hierarchical, and matrix design. We found that in comparison to hierarchical IAs, tunnel and matrix IAs increase user satisfaction. This effect may be explained through increased user perceptions of personal relevance in the tunnel IA, and increased perceptions of control in the matrix IA. Contrary to our hypotheses and earlier findings (Crutzen et al., 2012) no direct or indirect effects of IA on knowledge acquisition or website usage were found. Finally, our findings indicate IA preferences differ between patients with different user profiles. Specifically, patients with a so-called *managing* profile, who prefer open communication and have high communicative competences, are more satisfied with health education that is presented in a tunnel IA.

Our finding that IA affects satisfaction with emotional support specifically is consistent with research that shows that tunnelled education improved the emotional well-being of patients with type 2 diabetes and chronic low back pain (Weymann, Dirmaier, von Wolff, Kriston, & Härter, 2015). However, we did not replicate previous findings indicating that tunnelling increases usage of online health interventions (Crutzen et al., 2012; McClure et al., 2013). We did perceive a trend in this direction: participants in the tunnel condition used the website longer on average. However, this difference did not reach statistical significance.

Tunnelling has also been previously shown to improve knowledge acquisition (Crutzen et al., 2012). We found no evidence for this effect. Instead, user engagement emerged as the only predictor of knowledge acquisition. The results of IA on user engagement were mixed; the matrix IA achieved the highest subjective (i.e. self-reported) engagement, but the tunnel IA was used the longest (albeit, not significantly longer). There is some debate whether self-report or system usage data best reflect engagement (Short et al., 2018; Yardley et al., 2016). As IA affects both, determining the exact role between IA, engagement, and knowledge acquisition is an important avenue for further research.

A secondary objective of this study was to explore the potential of tailored information architectures. We found that participants with the highest information needs (so-called '*managers*') preferred tunnel IAs. This finding supports the idea that patients' online learning experiences may be improved when IA is tailored to relevant user characteristics. However, we did not envision beforehand that the tunnel IA would actually match the *managing* profile. Rather, we assumed that participants in this group would prefer a matrix IA, as their skills, high self-efficacy, and preferences for openness and participation are in line with the theoretical 'ideal' user of matrix IA websites (Danaher et al., 2005). In practice, translating stated preferences to a tailored design was more complex.

This complexity has two implications for intervention design. First, it may be more beneficial to offer users a choice of IAs rather than dictating one design. Studies that explored the benefit of tailoring the mode of health information (e.g. text, illustrations, audio-visual material) have successfully used '*user-initiated tailoring*' when working with multiple interfaces (M. H. Nguyen, Smets, Bol, Loos, & Van Weert, 2018; M. H. Nguyen et al., 2017). User-initiated tailoring requests users to customize a website's content and graphical user interface directly. Such customizations improved user satisfaction, attention and knowledge recall (M. H. Nguyen et al., 2018, 2017). Possibly, user-initiated tailoring may also be applicable to tailored IA design if users are offered a choice of IA designs when they first visit the website. A second implication may be to design IAs which support many different styles of health information processing. Pang and colleagues' work on a website that was purposely designed to support four (rather than one) distinct health information-seeking behaviours, showed that users were more engaged with more dynamic interfaces (Pang, Chang, Verspoor, & Pearce, 2016). The communality between these studies is that users were not restricted or coerced to use the website in a particular way, but instead were able to customize the online experience to their self-determined preferences and needs at the time of visiting. Still, while this design approach may improve the fit between user and design, it may also introduce new issues (such as motivating people to adjust interfaces, or additional costs associated with developing multiple interfaces) that warrant further research.

6.4.1 Strengths and limitations

This study was conducted among adults who had self-reported joint complaints and may have viewed the online education differently than patients. Still, previous studies have successfully tested health education websites in similar general populations (Crutzen et al., 2012; M. H. Nguyen et al., 2018, 2017) and the high self-reported pain and lower health scores indicate that the study sample did suffer from considerable health concerns. Another limitation of the sample was that participants could determine whether they wanted to join or leave the study. Between invitation for participation and inclusion in the study, we lost 37% of participants to follow-up. Of particular concern is that 6% of the sample dropped out after viewing the allocated website, as they might have done so based on their (negative) response to the website. This could make the study susceptible to type I errors (Gupta, 2011; Wertz, 1995). This problem could not be remedied by intention-to-treat analysis due to the design of the experiment in which dropped-out participants had complete missing outcome data (Gupta, 2011). Therefore, we checked whether drop-out was associated with allocation to a specific website, which was not the case. This made it unlikely that participants stopped because they were discontent with the allocated website. Another issue with self-selection was that participants could have been exceptionally interested in and already knowledgeable about TJR surgery. This would explain why we did not find any effects on knowledge. However, self-reported knowledge of hip replacement was generally low: 81% of participants said to have no or very limited prior knowledge. This is further reflected in the overall low knowledge acquisition scores (47-52%). A final limitation is that we determined satisfaction and knowledge gained from visiting the website once. As such, we cannot draw conclusions about experience with the website over time or knowledge retention after longer periods.

Strengths of this study include the experimental design. While randomized experiments of website features known as 'A/B tests' or online field experiments (Kohavi & Longbotham, 2017) are common in industry, the method is not often used in academic research on online health interventions. Various scholars have advocated moving beyond the 'black box approach' that assesses only intervention efficacy. Testing specific features can help understand by which mechanisms online interventions (do not) improve health outcomes (McClure et al., 2013; Pugatch et al., 2018; Whitton et al., 2015). By experimentally manipulating one feature and assessing both outcomes as well as mediating variables, this study takes a step in that direction. Secondly, the study took a human-centred and interdisciplinary approach to patient education design. The team included interaction designers, clinicians, and psychologists and followed an iterative design process that involved patients early via pilot studies to ensure the usability of all three variants of the website. We believe that this commitment to developing three distinct but comparable, usable, and enjoyable online experiences has made it more likely that the effects on satisfaction can be attributed to differences in IA only.

6.4.2 Future work

The current study focussed on three simple IA designs for experimental clarity. However, Danaher and colleagues (2005) also discuss the potential of hybrid IAs that combine design elements from the different IAs to mitigate disadvantages associated with non-hybrid IAs. This potential warrants further exploration. Since users were most satisfied with matrix and tunnel IAs, hybrid matrix-tunnel designs should be explored further specifically. Hybrid forms could include a matrix landing page depicting broad topics which lead to tunnelled learning modules, or initially tunnelled content which opens up to a matrix after first completion of the tunnel.

Another important venue of future research concerns the exploration of IA designs suitable for health interventions distributed through mobile devices (mHealth). The current study identified that a large proportion of older adults with self-reported joint complaints use mobile phones (82%) and tablet devices (41%). In an updated review on IA for mHealth interventions, Danaher and colleagues (2015) warn that simply porting a personal computer design fails to capture the push and pull features of smartphones. Instead, hybrid eHealth interventions that combine mHealth and web-based components may be more beneficial. The current study shows that the market for such hybrid interventions exists, also in middle-aged and elderly populations.

Finally, the field of IA has been affected considerably by the rise of recommender systems (RSs). These machine-based learning and information retrieval systems can predict and present the most relevant content directly; easing requirements for an adequate IA to help users locate content themselves. Moreover, as only the most relevant content is presented, RSs may also prevent information overload directly (K. L. Cheung, Durusu, Sui, & de Vries, 2019). A lack of personal relevance and information overload were identified as disadvantages of matrix IAs. Combining a matrix IA with RSs for content generation may diminish these drawbacks. Alternatively, recommended topics may be arranged in a tunnel to further enhance perceived personal relevance. Irrespective of the specific implementation, the potential benefits of combining RSs techniques and IA in online health interventions warrant further research.

6.4.3 Conclusion and recommendations for intervention design

Overall, our findings indicate that online health education intervention designers should employ tunnel information architecture (IA) to guide users through sequentially ordered content if they want to improve user satisfaction or if they target a patient population with high information needs. On the other hand, providing users with more control over the way they progress through an online health intervention via a matrix IA design has positive effects on user perceptions of active control, which also contributes to higher satisfaction. Hierarchical IA designs are not recommended, as hierarchical content is perceived as less supportive, engaging, and relevant which may diminish the usage, and in turn the effect of the educational intervention.

Chapter 7

General discussion

Summary

The previous chapters described the development and validation of patient profiles and the implementation of said profiles for the design of tailored orthopaedic healthcare services. This final chapter discusses the findings of these studies and concludes that total joint replacement (TJR) surgery patients can be represented in three patient profiles that reflect distinct ways in which TJR patients may experience their health, cope with major surgery and wish to communicate with their healthcare provider. We provide suggestions for future research and discuss implications of the findings for the medical and creative industry.

Fuelled by societal and technological change the healthcare system is shifting to be more patient-centric. This has led to new ideas regarding the qualities a healthcare system should deliver. The way in which technical care is implemented through interpersonal processes and the patient experience have become critical indicators of safe, efficient, and high-quality healthcare (Anhang Price et al., 2014; Browne et al., 2010; Donabedian, 1988; Doyle et al., 2013). Patients, the group of people who make use of the healthcare system to treat conditions, promote health, prevent disease, and manage chronic illness, have also become more culturally and demographically diverse (Hoving et al., 2010). In order to deliver care that is more than only clinically appropriate, healthcare services should be tailored to the psychological and social needs of these diverse individuals. Such tailored healthcare services are associated with positive patient experiences, higher patient engagement with and adherence to treatment plans, and consequently, better health outcomes (Kiesler & Auerbach, 2006; Street et al., 2012).

Yet, healthcare services need to compromise the values of tailoring (e.g. empathy, integration, individual effectiveness) with the values of standardization (e.g. safety, predictability, (cost-)efficiency). Manufacturing and service industries strike this balance through mass customization, customer segmentation, and user profiling. Central is the design of specific product variants for each customer segment. By integrating these variants under a single product family, mass customization combines tailoring to the customers' needs with the (cost-)efficiency of standardized mass production. This thesis poses that by creating accurate representations of healthcare consumers (i.e. data-driven patient profiles), the mass customization approach could be extended to the healthcare industry. However, to the best of our knowledge, no validated profiles of patients are available yet. Rather, personas (i.e. “hypothetical archetypes of actual users”, Cooper 2004, p. 124) are used to represent patients. However, personas have limited applicability in the healthcare sector due to poor generalizability, credibility, and the risk of imposing stereotypes (Chapman & Milham, 2006; Floyd et al., 2008; Massanari, 2010; Vincent & Blandford, 2014).

Therefore, the primary aim of this thesis was to define and validate a set of data-driven patient profiles that represent the common and distinctive characteristics of orthopaedic patients. We describe how these data-driven patient profiles are embedded in the design process through the patient profiling approach. The secondary aim was to examine the effect of a tailored healthcare service (designed using the patient profiling approach) on patient experience. Both objectives were explored in a case study on total joint replacement surgery (TJR), a high volume elective surgery that has high rates of dissatisfaction which cannot be fully explained by medical or surgical factors (Anakwe et al., 2011; Eftekhary et al., 2019; Hamilton et al., 2013; Jones et al., 2000; Lim et al., 2015). Below, I will briefly summarize the findings in relation to the research aims, elaborate on the implications of the research for medical (orthopaedic) and creative practice, and provide recommendations for future research.

7.1 SUMMARY AND REVIEW OF FINDINGS

7.1.1 Relevant characteristics for patient profiling

The patient profiling approach posits that data-driven patient profiles can be developed through identification of a target population, assessment of relevant characteristics of patients in that population, and stratification of patients into profiles based on the collected data. Relevant characteristics were determined from two perspectives. Chapter 2 examined relevance from the perspective of orthopaedic surgeons. Chapter 3 examined relevance from the perspective of orthopaedic patients' self-reported data, i.e. which characteristics best differentiated patients and which characteristics were predictive of patient experience.

Eighty consultations between orthopaedic surgeons and patients were observed to determine which patient characteristics are relevant for tailoring communication from the surgeons' perspective. Surgeons frequently mentioned patients' abilities in illness management and communication, autonomy, and interpersonal behaviour. Their perceptions of the patient influenced their communicative behaviour during the consultation. For example, when patients were perceived as able to adequately manage their illness, surgeons adapted their communicative behaviour by providing more elaborative information. Three consistent associations between perceived characteristics and adapted communication were identified, describing prototypical *informing*, *counselling*, and *social* consultation variants. These findings suggest that the orthopaedic consultation is already a (intuitively) tailored healthcare service (see Figure 7.1.). Yet, the observations also showed that the participating surgeons relied on their own perception to assess patient characteristics.

The main question is whether the surgeons' perceptions accurately reflected true and meaningful differences between patients and whether their (adapted) communication strategies met patients' actual preferences. To address this question, we used validated questionnaires to retrospectively assess the communicative preferences, psychological coping mechanisms, and health experience of 191 patients who had undergone TJR in the previous year. This study showed that patients were indeed highly diverse on the aspects previously mentioned by the healthcare professionals. Patient characteristics were also found to influence patients' experience with the healthcare service: specifically, their satisfaction with patient-provider communication.

Chapter 4 collected the same data as above in 235 prospective orthopaedic health consumers. This data on health consumers' health experience, psychological coping, and communication preferences and competences was combined with the previously collected retrospective patient dataset. The combined dataset was used to develop a final stratification instrument containing only the most relevant characteristics. The goal was to keep the instrument short, so that both medical and creative professionals could use it to determine the profile of an individual patient. Nine characteristics, including four *health experience* characteristics (preoperative health status, preoperative movement-evoked pain, age, and anxiety), two *psychological coping* characteristics (pain catastrophizing tendencies and coping through active support seeking), and two *communicative* characteristics (preferences for open communication and competences in critical communication) were identified as the most distinctive for patient profiling. These were included in the instrument which determines the most likely profile of an individual patient with around 80% accuracy.

In summary, the findings from Chapter 2, 3, and 4 suggest that health experience, psychological coping mechanisms, and preferences and competences in health communication are essential patient characteristics for patient profiling in the orthopaedic domain. These characteristics are relevant according to physicians, differentiate data from the target population of patients in treatment and potential health consumers, and are predictive of the outcome of interest, patient experience.

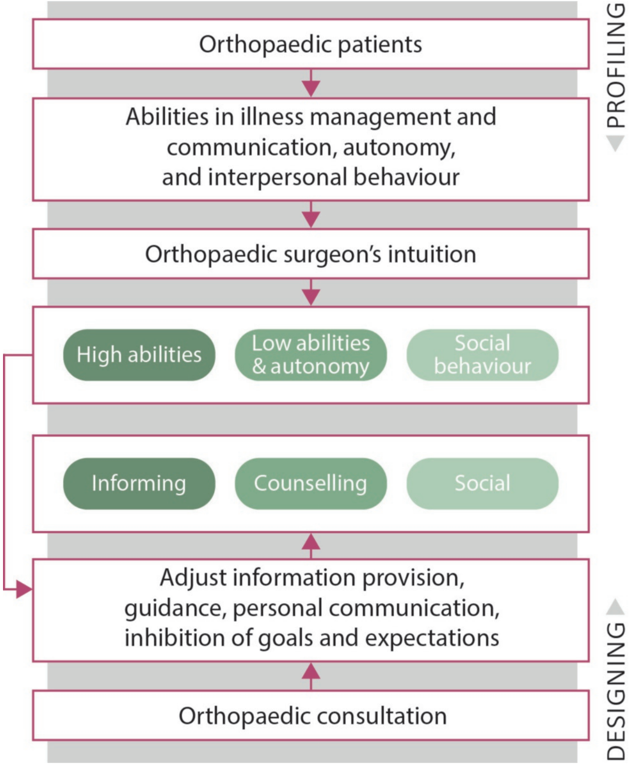

Figure 7.1 The patient profiling approach applied to the orthopaedic consultation

Orthopaedic surgeons' characterized orthopaedic patients based on their perceptions of the patients' abilities, autonomy, and interpersonal behaviour. Based on these perceptions, the surgeons adjusted information and the way through which they guided patients and communicated with them. In contrast to the formal patient profiling approach, surgeons' did not consciously construct patient profiles nor consultation variants. Still, specific perceptions, e.g. the perception that a patient was able to manage their illness and communicate effectively, were associated with specific consultation variants, e.g. *informing* consultations that primarily focussed on elaborate information provision (Dekkers, Melles, Mathijssen, et al., 2018, see also Chapter 2).

7.1.2 Three data-driven patient profiles

After determining and assessing the relevant characteristics the set of patient profiles was developed. First, the retrospective data collected in Chapter 3 was subjected to a cluster analysis. The results showed that the TJR population consists of three patient segments that differ significantly in the way they experience their health, cope with major surgery and wish to communicate with their healthcare provider. In the study presented in Chapter 4 these segments were validated subsequently when three similar clusters emerged from the data of prospective orthopaedics health consumers who were not yet under treatment for their chronic joint complaints. Thus, the final set of data-driven patient profiles included three patient profiles, which were dubbed the *managing, optimistic,* and *modest* profile.

- *The managing patient profile*

44% of treated patients and 24% of untreated health consumers were characterized as exhibiting a *managing* profile. These patients were more likely to demonstrate a diverse range of coping behaviours (including actively seeking emotional and instrumental support from others), preferred to participate and receive open information during medical consultations, had excellent communicative competences, and were less healthy preoperatively. The label *managing* was derived from the amount and diversity of resources these patients involved in managing the surgical process and the high standards they set for patient-provider communication.

- *The optimistic patient profile*

32% of patients and 42% of health consumers were clustered to the so-called *optimistic* profile. These patients were less anxious, reported fewer coping mechanisms, found patient-provider communication a less important aspect of care provision, had good communicative competences, and had better preoperative health. The label *optimistic* was chosen because these patients exhibited low needs even when faced with a potentially stressful event such as TJR surgery. Compared to managing and modest patients, optimistic patients were most satisfied with communication and reported being in better health and less pain three months after surgery.

- *The modest patient profile*

24% of patients and 34% of health consumers were stratified to a *modest* profile. These patients were more anxious, had a great tendency to catastrophize pain, preferred both open information and emotional support, had lower communicative competences, and were in poorer health. The label *modest* was selected because these patients did hold specific preferences for the health care service but were less vocal in expressing them. Patients in the modest profile showed limited postoperative improvements after surgery and were the least satisfied with communication.

As far as we know, these studies were the first to expose the diversity in health experiences, psychological coping mechanisms, and communicative preferences and competences in the orthopaedic patient population. Together, the findings suggest that both treated patients and untreated health consumers can be represented by a set of three data-driven patient profiles. Each profile has unique characteristics that are shared by individuals within that profile (for example, strong preferences for open information in the managing profile, low pain catastrophizing tendencies in the optimistic profile, and high anxiety in the modest profile) which can be used to adjust elements in the healthcare service and develop tailored variants. Finally, the patient study also suggests that some patients (demonstrating characteristics of the optimistic profile) are better serviced by the healthcare service currently provided in TJR surgery than others (modest and managing profiles).

7.1.3 Web-based patient education: a healthcare service suitable for tailoring

The first step in designing a tailored service according to the patient profiling approach is the identification of currently standardized services that are suitable for tailoring. In Chapter 5, we systematically reviewed one standardized service common in orthopaedics: web-based patient education. The combined results of 10 trials reported in 14 studies showed that web-based patient education improves patients' objective knowledge (i.e. test scores), subjective knowledge (i.e. feeling knowledgeable), and satisfaction in comparison to verbal, written, and audio-visual education alone. Health outcomes (e.g. anxiety about the surgery, pain, function) were not affected by web-based patient education. These findings suggest that web-based patient education is a service that affects the patient experience. This is the one reason why we considered it suitable for tailoring.

Most trials on web-based patient education included only considerably younger, higher educated patients who had more internet experience. This suggests a need to design educational online platforms tailored to patients who possess these competences to a lesser extent (e.g. the modest profile). We also found that web-based patient education systems consist of many design elements, ranging from the macro-level embedding of the intervention (e.g. the extent to which healthcare professionals were involved for support) to micro-level intervention design (e.g. program content, interface design, multimedia use)[16]. This offers designers many options to adjust the service to the set of patient profiles, again confirming that web-based patient education is a healthcare service suitable for tailoring.

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[16] A preliminary exploration identified over 20 elements (corresponding to 6 categories) which could be tailored. This exploration is included in Appendix 7A.

7.1.4 Tailored healthcare services and patient experience

The randomized experiment described in Chapter 6 examined the effect of a tailored healthcare service, designed with patient profiles, on patient experience. It specifically explored the patient experience with tailored web-based patient education and the satisfaction and knowledge patients derived from using the service. The organization, display, and structural design (i.e. the information architecture) of existing patient education material was adjusted to the preferences and needs of each patient profile. This resulted in three patient education website variants: a sequential tunnel IA design, a hierarchical IA design, and a matrix IA design. The hypothesized embedding of the variants in the patient profiling approach is depicted in Figure 7.2A.

- *Matrix IA design*

The matrix IA design offered users full control over the selection, order, and duration of displayed information. It was designed to accommodate the strong preferences for open information of the managing profile.

- *Hierarchical IA design*

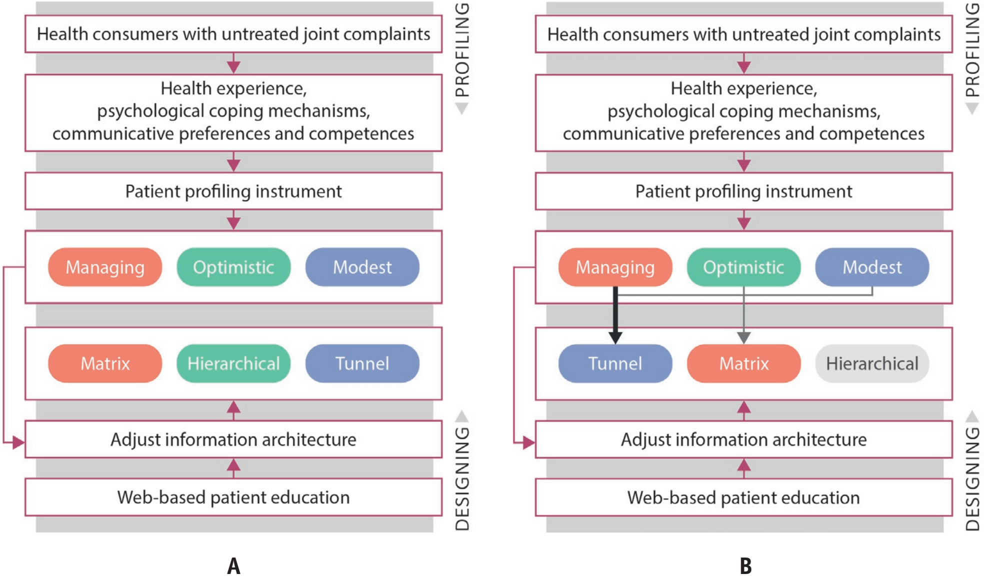
The hierarchical IA design provides a hierarchal overview of topics that users can explore. It is considered a simple and familiar IA design and was designed to meet the ambivalent communication preferences of the optimistic profile.

- *Sequential tunnel IA design*

The sequential tunnel IA design offered users less control over navigation in an attempt to decrease the complexity of the health information. This variant was designed for the modest profile to respond to the lower communicative competences that characterize this profile.

The findings showed that health information relayed via a tunnel or matrix design elicits a more positive online experience compared to hierarchical designs, regardless of the patient's profile. Users favoured these designs because they were experienced as more personally relevant (tunnel) and offered more active control (matrix). The tailored variant only improved the user experience of managing patients. They preferred the tunnel design over all other IA designs. Participants of other profiles (optimistic, modest) did not prefer a particular IA design. Finally, the website's effectiveness (i.e. the knowledge that patients obtained from website use) was not affected by (tailored) IA design. Note that since the experiment lacked a control group that was not exposed to patient education nor a pre-test of participants' TJR knowledge, this finding does not necessarily mean that knowledge was not improved by website use at all.

The proposed match between variant and patient profile did not result in a more positive patient experience. Rather, the findings contradicted our expectations regarding which variant would be most effective for which profile (see Figure 7.2B). Using patient profiles to adjust healthcare services may be more complex than initially anticipated. Still, the findings demonstrate some potential of tailored healthcare services, particularly for the managing profile. We also found new evidence for the hypothesis that people with an optimistic profile do not necessarily require a tailored variant of the current healthcare service. Still, the specific preferences and needs characterizing the modest profile could not be addressed by tailoring the IA of an educational website. Furthermore, tailoring IA did not offer large additional benefits over the standardized educational websites which also improved patient experience (Chapter 5). These findings open up new discussions about the patient profiling approach, specifically concerning how profile information feeds into the design process and how profiles can be allocated to variants. These questions are discussed further in section 7.2.



Figures 7.2 A-B The patient profiling approach applied to web-based patient education

A) Health consumers with untreated joint complaints were profiled based on their health experience, psychological coping mechanisms, and communicative preferences and competences. Health consumers were stratified to a set of three data-driven patient profiles (the managing, optimistic, and modest profile) by using the patient profiling instrument. This set of patient profiles was used to adjusted information architecture (IA) of a patient education website. Managing health consumers were hypothesized to have a better experience with the matrix IA, optimistic health consumers with the hierarchical IA, and modest health consumers with the tunnel IA.

B) In the experimental setting, health consumers were randomly assigned to one of the website variants, rather than only the hypothesized matching variant. This revealed that tunnel IA and matrix IA were preferred over hierarchical IA design, regardless of patient profile. The experience of managing patients was improved when used the tunnel IA, but this match was not hypothesized previously.

7.2 IMPLICATIONS FOR THEORY, CURRENT PRACTICE, AND FUTURE RESEARCH

The initial results on patient profiles are promising. This thesis has shown that orthopaedic health consumers can be represented in three data-driven patient profiles and that patient profiles can be used to design variants that introduce more tailoring to the healthcare service. Several findings do warrant further discussion. Below, I will first discuss the implications of the results in relation to theory. Specifically, I will discuss the relevance of biopsychosocial characteristics in relation to existing biomedical and psychological patient segmentation models. Furthermore, I will discuss stability of the patient profiles. Second, I will discuss the implications for current (design) practice. This section will include the current design guidelines for each profile, recommendations for tailoring educational and informational services, and discuss the critical role of engagement herein. Third, I will reflect on how profiles and variants are united to create a tailored healthcare service. This topic of allocation introduces interesting questions about equity and autonomy which set the agenda for future research.

7.2.1 A biopsychosocial perspective on patient segmentation

In developing the patient profiles, this thesis took a biopsychosocial approach. The biopsychosocial model is a holistic perspective that recognizes the social, psychological, and behavioural dimensions of illness alongside a pure biomedical model (Engel, 1977). Within the context of the thesis, this means that we assume that biomedical characteristics (e.g. pain severity and physical functioning), psychological characteristics (e.g. coping mechanisms and pain catastrophizing), and social characteristics (e.g. communication preferences, competences, and social support) all simultaneously influence the experience of patients and provide relevant information to tailor healthcare services to patients' preferences and needs. Similar 'whole person' perspectives are ubiquitous in Human-Centred Design (HCD). For example, the ISO standard stresses the importance of the whole user experience and the consideration from multidisciplinary perspectives (International Organization for Standardization, 2019) while Giacomin (2014) characterizes HCD by its usage of a wide range of human data sets (e.g. anthropometric, psychological, emotional, sociological, philosophical, etc.). In the orthopaedic medical literature however, research into the social dimensions of healthcare is less obvious.

Previous segmentation models were primarily based on insights from biomedicine or psychology. Biomedical characteristics are considered relevant because they predict health outcomes (Gutacker & Street, 2017; Murphy et al., 2011; Swenson et al., 2016; van der Esch et al., 2015) and recovery trajectories (Dowsey et al., 2015; Porsius et al., 2018) after TJR. In a similar vein, psychological characteristics are considered relevant because they predict poor psychological adjustment after surgery (Cruz-Almeida et al., 2013; Stecz et al., 2017). These studies consistently show that a combination of the following biomedical and psychological characteristics puts patients at risk of poor outcomes: older age, female sex, trait anxiety, and pain catastrophizing (Cruz-Almeida et al., 2013; Dowsey et al., 2015; Porsius et al., 2018; Stecz et al., 2017). For example, Dowsey, Smith, and Choong (2015) found that the odds of worse functioning after total knee replacement (TKR) surgery increase with female sex (3 times more likely compared to males), age (2 times more likely for every 10 years), and pain catastrophizing (0.5 times more likely for every 10 points on the pain catastrophizing scale). Our research on the modest profile supports these previous findings. Female, older patients with higher levels of anxiety and pain catastrophizing clustered together in this profile. A modest profile also predicted worse postoperative health outcomes.

Adding social characteristics in our studies revealed a novel finding. Namely, by looking into communicative competences and satisfaction with patient-provider communication it was found that patients with less favourable biomedical and psychological characteristics also have the poorest communication competences. This puts these patients not only at risk of worse functioning, more pain, and poorer psychological adjustment after surgery, but also reduced satisfaction with communication. It is important to note that since these characteristics are simultaneously present, they possibly aggravate each other. For example, an anxious patient with limited communicative competences may not be attentive to patient education, which in turn may lead to incorrect execution of rehabilitative exercises and more pain. The revelation of this interaction demonstrates the relevance of including social characteristics in patient profiles and draws attention to those patients who are in particular need of tailored care. In the current study, we were only able to assess the influence of social characteristics on short-term outcomes. To better understand their influence on long-term outcomes and closer model the potential interactions with biomedical and psychological characteristics, longitudinal research from the biopsychosocial perspective is needed.

7.2.2 Stability of patient profiles

The abovementioned suggestion of longitudinal research is in line with a question that was often raised during the past few years of working on patient profiles: are profiles stable over time? Do patients' preferences, needs, and competences change throughout the patient journey? Such changes would not be reflected in a static patient profile. The static nature of segmentation is a long standing concern in literature. Calantone and Sawyer (Calantone & Sawyer, 1978) already examined the stability of banking segments over time. After critical examination, they found that on an individual basis, only 29% of customers remained in the same segment between 1972 and 1974. Because individual customers could still access (information about) all banks, it was concluded that here the overall managerial strategy was not affected in itself. This is in contrast to the healthcare system, where individual patients do not have (or need) access to all services. Profile membership could determine which services are made available to a patient and which are not. Since healthcare services affect patients' health and wellbeing, profile stability is therefore a much more pressing concern. In the worst case, misrepresenting a person with changing preferences as a stable profile could mean that patients end up trapped in a tailored healthcare service which is no longer appropriate. Below, I will first discuss the stability of healthcare service preferences. Next, I will suggest future research directions that explore more dynamic forms of segmentation in healthcare.

This thesis found that patients report lower preferences for open information and emotional support *after* TJR surgery compared to health consumers before surgery. These findings are in line with longitudinal research in oncology which demonstrates that communicative needs decline over the course of cancer treatment (Butow, Maclean, Dunn, Tattersall, & Boyer, 1997; Douma, Koning, Zandbelt, De Haes, & Smets, 2012; Vogel, Bengel, & Helmes, 2008). However, the results are contrary to the only longitudinal study on TJR communication preferences that we are aware of, which showed that information needs actually increase after discharge (Billon et al., 2017). This contradiction may be due to the cross-sectional research set-up of the studies presented in Chapters 3 and 4. Because we compared two cohorts but did not examine individual patients' communicative preferences longitudinally, discrepancies in preferences may have been due to baseline differences between the cohorts. For example, the treated patients were significantly older than the untreated health consumers. In comparison to middle-aged people, the communicative preferences of elderly are generally less outspoken, regardless of gender, education, health perception, or care utilization (de Graaf-Ruizendaal, Berendsen, de Boer, & de Bakker, 2013). So, our cross-sectional studies alone cannot conclusively show that communicative preferences change over time and if so, in what direction. In order to examine this more longitudinal studies are needed. Ideally, future studies would examine information preferences of TJR patients (as done in the Billon et al. 2017 study) as well as emotional support preferences since both appear to fluctuate over time.

While the exact nature of the change is unknown, both our and other previous research findings do suggest that preferences likely change over the course of treatment. A theoretical account, the ecological model of patient preferences (Street et al., 2012), proposes that preferences change when patients reside in different social, cultural, media, and economic contexts, interact with medical professionals and evaluate the outcomes of care. The differences in preferences observed in the patient and health consumer populations may be explained by any of these factors. For example, patients were in a different social, media, and economic context than health consumers (e.g. more likely to receive support from family, less likely to use the internet, and less likely to be employed). But more importantly, patients had already interacted extensively with healthcare professionals and were experiencing the (short-term) outcomes of surgery, while health consumers had not. Both patient-provider contact and evaluations of perceived outcomes are situational factors that may affect an individual patient's preferences over the course of their medical treatment. If these preferences are represented as stable (i.e. single assessment of profile throughout treatment), the risk of misalignment between patient and treatment may be substantial.

Thus, a more dynamic representation of the patient may be needed to continuously provide tailored care. A straightforward suggestion to accomplish this is to embed multiple assessments of a patients' profile during the patient journey. According to the ecological model (Street et al., 2012), preferences are likely established prior to any clinical encounters, and change after the medical consultation and post-outcome. These would be suitable moments for (re)assessment of the patient profile. Furthermore, since patient profiles also describe competences and other modifiable factors such as anxiety, the profile should also be (re)assessed after conscious efforts have been made to change these characteristics (for example, after communicative skills training or psychological counselling).

Unfortunately, multiple assessments of a patient's profile may place unintended additional stress on the healthcare system. Two-thirds of healthcare professionals are already concerned with current administrative pressure, including administration, registration, and reporting in the electronic patient record (de Veer, de Groot, Brinkman, & Francke, 2017). Healthcare professionals experience more pressure when administration is not embedded in their daily work, when administration does not provide a clear benefit, and when the electronic record has poor usability. Thus in order to make multiple assessment feasible in practice, these design challenges should first be tackled.

For now, it is important to realize the limitations of the patient profile approach on an individual level. While more longitudinal research is needed, there are multiple reasons why people's preferences, and thus their profile, would change over time. These dynamic individual changes are not reflected in our patient profile approach. Still, on a population level we found that the same set of patient profiles could represent patients and health consumers both before and after surgery. Specifically, the total number of profiles and distinctive characteristics of each profile remained virtually the same[17]. This contradiction may exist because individual fluctuations in patient profile do not necessarily affect the overall patient profiling approach. Since information about the *set* of patient profiles rather than the patient profile of an individual patient is used to inform the design of tailored healthcare service variants, the designed variants remain stable as well. I expect the design process only to be impacted when the distinctive characteristics of profile change or when a specific profile becomes obsolete. Repeated individual assessments as described above could alert health care professionals or designers if this is the case.

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[17] Interestingly, the aforementioned 1970's banking study (Calantone & Sawyer, 1978) also found that the number of segments and the distinctive characteristics of each segment had remained the same despite the changes in profile allocation on the individual level.

7.2.3 Implications for current practice

The main focus of this thesis was on the definition and validation of a set of data-driven profiles. We also examined how patient profiles could be embedded in the design process in one case study on web-based patient education. It was not the intention to provide a detailed specification and validation of design guidelines. Still, to support creative professionals in designing tailored healthcare services I will now shortly discuss the preliminary design guidelines for each profile that are being developed elsewhere in HiPP project (Groeneveld, Melles, Vehmeijer, Mathijssen, & Goossens, 2019; Groeneveld, Melles, et al., 2018) and provide general recommendations for tailoring educational and informational services.

Over the course of multiple interviews and generative design sessions with TJR patients, preliminary design guidelines are being developed for each profile (Groeneveld, Melles, Vehmeijer, Mathijssen, & Goossens, 2019; Groeneveld, Melles, et al., 2018). These guidelines are used in the design of a tailored telemonitoring rehabilitation support system which is currently being tested in orthopaedic practice (Groeneveld et al., 2019). Table 7.1 shows the overarching interaction qualities per profile and provides a first starting point for adjustments the creative industry can make. More research is needed to validate these guidelines. As mentioned in Chapter 6, we recommend experimental research designs to do so. Experiments are particularly useful because they allow researchers to establish whether design are beneficial or disadvantageous for a specific patient profile without making explicit assumptions about variant suitability. A potential research design would manipulate one element of the service according to the design guidelines (for example, design for consistency-reliance) and assess design outcomes (e.g. usability, user experience). To test whether the outcomes change depending on patient profile, the patient's or user's profile could be included as a moderating factor.

Table 7.1 Interaction qualities by patient profile

Managing	Optimistic	Modest
Controllable	Realistic - practical	Simple - accessible
Trustworthy	Positive	Consistent - reliant
Upbeat - friendly	Strict	Empathic - humane
Timely	Reassuring	Guiding
Specific - accurate		

Note. Based on Groeneveld et al. (2018, 2019) and ongoing research of B.S. Groeneveld.

To employ the above mentioned guidelines, creative professionals will have to decide which service (and which elements) to tailor. Throughout this thesis, I have focussed on tailoring communicative and informational services: the orthopaedic consultation and web-based patient education. This may seem a relatively narrow scope[18]. Yet, even within this service alone many elements could be adjusted to meet patients' preferences, needs, and competences. For example, designers could experiment with interface design, initiation and embedment of use of the service, dissemination channels, etc. (see Appendix 7A). Different design elements suited for tailoring web-based communication and information services have been partially described in existing frameworks of tailoring (Hawkins et al., 2008; Noar, Harrington, & Aldrich, 2009) and taxonomies of internet-supported interventions (Barak et al., 2009; Win et al., 2016). However, there are no exhaustive overviews available, nor has the (relative) effectiveness of tailoring specific elements been examined. This is an important issue for future research.

At this point, tailoring content and dissemination channel look promising. Content tailoring has small but consistent effects on patients' ability to achieve a healthier lifestyle (Krebs, Prochaska, & Rossi, 2010; Lustria et al., 2013; Noar, Benac, & Harris, 2007). Adjustments in the dissemination channel (i.e. mode-tailoring) improves adults' satisfaction, attention, and knowledge recall from a preparatory health information website (M. H. Nguyen et al., 2018, 2017). Of course, tailoring these different elements could also have synergistic effects that need to be examined. Future research in this direction would bring about advancements in tailoring theory, as research efforts up to now have primarily focussed on content tailoring alone (Kreuter et al., 1999; Noar et al., 2007).

7.2.4 The critical role of user engagement

The experiment described in Chapter 6 provided interesting results regarding the role of engagement in web-based patient education. The findings showed that only user engagement is a significant predictor of knowledge retention from an online health information website. Furthermore, engagement was the most influential factor in the online patient experience. Patients who found the online interaction engaging were most likely to be satisfied, and engagement was more predictive of satisfaction than perceptions of relevance, active control, or trustworthiness. Designing for engaging online experiences should thus be considered a primary objective for creative professionals in healthcare.

Engagement has been used as an umbrella term, but does not have to be an ambiguous target. More and more studies conceptualize detailed accounts of engagement (O'Brien, 2016; Yardley et al., 2016) and relate these to specific measurement tools (Short et al., 2018; Yardley et al., 2016) that include methodologies many human-centred designers will be familiar with (e.g. in-depth interviews, questionnaires, and logs of system usage and sensor data). The creative industry can use these tools to contribute to the knowledge base on user engagement. In an effort to promote this goal, we have translated and validated one of the more promising questionnaires – the short form of the user engagement scale (O'Brien

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[18] For example, the physical environment (e.g. patient room) or medical service (e.g. surgical tools, implant) are aspects of the healthcare system that fell beyond this scope. These may be interesting avenues for future research on tailored healthcare services.

et al., 2018) – in Dutch and made this instrument available in this thesis (Appendix 6A).

Both this tool and the studies in this thesis focussed on micro-level engagement, i.e. 'the moment-to-moment engagement with the intervention including the extent of use and the user experience' (Short et al., 2018; Yardley et al., 2016). This includes user interface design, such as aesthetic appeal and perceived usability on an interface, and dimensions of the user experience, such as whether attentional focus was achieved and whether the experience was seen as rewarding. The results from the experiment showed that especially the rewarding dimensions of the user experience predict whether participants were able to acquire and recall medical information. Thus, I consider design for rewarding experience a specifically important topic for future design research as it may be used to develop more effective online interventions, especially when interventions are self-paced or used on a voluntary basis.

7.2.5 Future research

At the start of this project, we naively assumed that it was relatively straightforward to align profiles and variants to create a tailored healthcare service[19]. We expected that when patient X was stratified to profile Z, and service Z had been designed with the preferences, needs, and competences of profile Z in mind, service Z would be tailored to the preferences of patient X – and consequently improve patient X's experience. However, over the course of the project we discovered that allocation of variants to profiles is actually a more complex process which presents design choices that we were not aware of at the time. For example, it raises questions of autonomy and power (who decides which variant is appropriate for a patient?) and equity and access (can health care professionals seek out patients with profiles they expect to do well in their standardized service, or should they adapt the service instead)? To acknowledge this complexity, I suggest that allocation should be further explored and could possibly be added to the patient profiling approach in the future as depicted in Figure 7.3. Conceptualizing allocation as a conscious design decision may broaden the theoretical and practical scope of the design of tailored healthcare services. Below, I will discuss two themes in particular: equity and autonomy.

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[19] As is reflected by an earlier publication on the patient profiling approach (Dekkers & Hertroijs, 2018) which does not include allocation as an explicit step.

7.2.5.1 Direction of allocation & equity

Health inequities are avoidable differences among social, economic, demographic, or geographic groups in the access to resources needed to improve and maintain health (World Health Organization, n.d.). Typically, inequities result from a lack of power and are experienced by marginalized groups, including people that are poor, ethnic minorities, and women (World Health Organization, n.d.). Equity is recognized by the WHO as a vital indicator of a well-functioning healthcare system. Yet, novel healthcare services such as eHealth may increase inequity because of the persistent digital divide (Hellberg & Johansson, 2017; Kontos, Blake, Chou, & Prestin, 2014; Mattsson, Olsson, Johansson, & Carlsson, 2017; Morey, 2007).

During the patient profiling project, we found one profile that may potentially suffer from health inequities; the *modest* profile. On average, patients of this profile were more likely to be unemployed, more likely to be female, less likely to use the Internet, and less competent in health communication. They were also the least satisfied with current, standardized healthcare services and experienced the worst health outcomes after surgery. This group may therefore be considered at risk of both a poor experience and poor outcomes.

There are two ways to address risk groups, which both affect equity differently. First, a healthcare service may be adapted to the needs and competences of a particular risk group to improve their access to and experience with the service. In this case, the direction of tailoring runs from patient to a tailored variant. This is the approach taken in this thesis. However, there are also examples from the creative and medical industry that instead flip the direction of allocation by selecting specific patients for a standardized service. This direction of allocation may limit access of risk groups to services. For example, the research company InboudMD (Smith, 2017) uses negative patient personas: patients that orthopedic surgeons and chiropractors are advised not attract to their practice. Not surprisingly, the negative persona is described as poorer, older, and less healthy. In the orthopedic literature, surgeons are advised to select patients based on gender and mental health (Husain & Lee, 2015; Van Onsem et al., 2016). My concern with such stringent patient selection is that it limits the access of people who do not thrive under the *standardized* service, but may be helped with a *tailored* service. Yet, the person is asked to change instead, or otherwise denied[20] access. Mannion and Exworthy (2017) strikingly described this phenomenon as 'remaking the procrustean bed'. In this ancient Greek myth, Procrustes offered a bed that would magically adjust to fit any traveler. Yet instead of the bed changing size, Procrustes would actually cut off limbs or stretch travelers to achieve the desired fit. With current practices that promote avoidance of at-risk patients and promotes targeting at-benefit groups (Swenson et al., 2016) we may wonder if this metaphor is becoming reality.

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[20] Denial can also manifest as underutilization of the service by patients who do not consider themselves appropriate candidates. See for example (J. P. Clark et al., 2004; Frankel et al., 2012).

Overall, the potential influence of tailored healthcare services on health equity is a topic that deserves further attention. By specifying the direction of allocation (product to user, or user to product) creative professionals can consider equity in their designs. This should also help designers discuss potential issues of inequity with clients early in the design process.

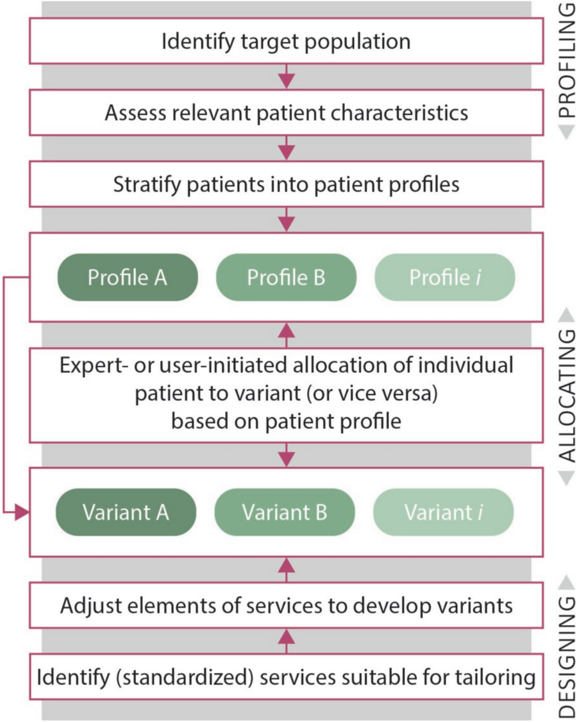

Figure 7.3 Proposed amendment of patient profiling approach with allocation as a separate step

Inclusion of allocation in the patient profiling approach draws attention to the direction of allocation_(i.e. whether a patient is matched to a tailored variant, or is a standardized service matched to a specifically selected patient) and the allocating agent (i.e. who determines which variant is allocated to a patient).

7.2.5.2 The allocating agent & autonomy

This thesis has described allocation of profiles to variants by healthcare professionals (Figure 7.1, Chapter 2) and by the design and research team (Figure 7.2, Chapter 6). In these cases, the same party (healthcare professionals and design and research team, respectively) developed the tailored service and disseminated the service to individuals of the profile they were targeting. For clarification, I now refer to these approaches as expert-initiated tailoring. This term is meant to describe that an expert (whether healthcare professional, creative professional, marketer, behavioural scientist, or a different expertise) decides which design variant is appropriate for the user and is disseminated as the tailored service. Expert-initiated tailoring closely resembles the traditional process of market segmentation

(Gunter & Furnham, 2015). However, it also puts patients in a position in which they are dependent on experts to determine which variant matches their preferences, needs, and competences.

Sometimes, the experts intuitive decisions' herein are quite sound, as was shown in Chapter 2. Orthopaedic surgeons shared the perception that well-managing patients would have a slight preference for informational or non-tailored consultations, an intuition that was later confirmed by the findings regarding the optimistic profile. At the same time, the scientific basis for experts to make such decisions is limited. For example, in Chapter 6 we found that *managing* health consumers preferred tunnel information architecture designs, despite the fact that matrix information architecture designs were considered more appropriate for highly educated users with preferences for open information in the literature (Danaher et al., 2005; Lynch & Horton, 2016). This discrepancy raises the question whether it is justified for experts to make decisions about allocation, possibly at the expense of the patient's autonomy and overall experience with the service. Below, I discuss an alternative user-initiated approach to allocation and provide an overall suggestion for the design of tailored healthcare services based in libertarian paternalism.

User-initiated tailoring is an approach to tailoring in which users determine which design elements, such as content, information architecture, or modality (M. H. Nguyen, 2019), they consider appropriate or preferable. This provides users with greater influence on the production and assembly process of the tailored healthcare service (Minvielle et al., 2014). The role of the expert in user-initiated tailoring is to facilitate customization through user-friendly interface design. International oriented websites (for example, Wikipedia.org) are an example of such an interface, as they allow users to simply toggle between two or more languages. The major benefit of the user-initiated approach is that it alleviates the need for an external expert to make (informed) decisions about the appropriateness of different design variants for different users.

While not yet extensively researched, user-initiated tailoring shows promising results in the healthcare setting. In an experiment of Nguyen and colleagues (2018), user-initiated tailoring was found to increase participants' perceived active control, which resulted in a better online experience, deeper processing of the health information, and ultimately, higher recall of the website content. These results are in line with our findings on the matrix IA, in which users were able to determine their own topics of interest. Again, users perceived to have more active control over the information, which resulted in higher satisfaction with the website. Given additional research, user-initiated tailoring may thus be a way to improve patients' interactions with online health information.

Yet, user-initiated tailoring may also be cognitively taxing for patients, especially when there are many options to choose from. In their user-research, the Nielsen Norman Group found that users generally reported feeling lost and *less* in control on customization websites (Nielsen, 2009). Furthermore, users felt unmotivated to navigate complex customization and simply wanted to get "things done on a website, rather than spending time fiddling with preference settings". Another issue pertains to whether people actually know what they want and or need from a healthcare service. When discussing modality or architecture of health information websites, an argument can be made that most people are aware of their preferences through experiences that they had on other (not health-related) websites. However, people are rarely aware of their specific healthcare preferences as these are constructed through care experiences and discussions with healthcare professionals (Street et al., 2012).

To find a compromise between expert-initiated and user-initiated approaches to allocation, the paradigm of libertarian paternalism may be suitable for the design of tailored healthcare services. Libertarian paternalism is a 'soft' paternalism in which people's decisions are steered (or 'nudged') in the direction that a choice planner (the expert, the system) deems most beneficial, while maintaining freedom for individuals to choose otherwise (Sunstein & Thaler, 2003; Thaler & Sunstein, 2008). In particular, I suggest that future researchers explores the use of no-action defaults, in which the absence of user action promotes the choice planner's choice but allows alternative user choices (Dinner, Johnson, Goldstein, & Liu, 2011; Thaler & Sunstein, 2008). No-action defaults reduce cognitive effort (Aljukhadar, Senecal, & Daoust, 2012) and facilitate preference formation because it constructs the other options as gains or losses (Dinner et al., 2011). These benefits may negate the weaknesses of user-initiated tailoring described earlier. Plus, the availability of alternative choices puts less stress on the expert to precisely allocate tailored variants to patients (see 7.2.2) since patients are able to correct the default as they see fit. All in all, no-action defaults may be suitable for tailored healthcare design and warrant further exploration.

7.3 STRENGTHS AND LIMITATIONS OF THE RESEARCH

We consider the extent to which the profiles were validated a major strength of the presented studies. Most studies use cluster analysis to explore potential groups in a population, but rarely validate their findings (Clatworthy et al., 2005). This study has taken an important step of not only validating the profiles, but doing so in two populations. By doing so, we have also described a suitable validation method for other researchers that employ clustering and machine learning in user segmentation. Since replicability is a great concern in social science generally (Pashler & Wagenmakers, 2012), and cluster analysis specifically (Clatworthy et al., 2005), this is an essential contribution to the field.

Another strength of the study is the mixed methodology employed. This thesis combined qualitative methods (Chapter 2) for exploration with quantitative computer science methods (Chapters 3 and 4) and experimental design (Chapter 6) for validation. The main advantage of the machine learning methods employed is that a large number of multidimensional data was taken into account in defining the patient profiles. This results in a more holistic biopsychosocial view of the orthopaedic health consumer. This holistic perspective may make the profiles accessible to a broad audience of both medical and creative professionals. As noted earlier, medical segmentation models typically provide only a biomedical or psychological perspective on patients, while (human-centred) design values a 'whole person' perspective (Giacomin, 2014; International Organization for Standardization, 2019). Because the profiles include both perspectives, they may bridge the different vocabularies and focal points[21] of medical and creative professionals.

The use of large, quantitative datasets in this design research project has also had the added benefit that decision rules to predict an individual's patient profile could be developed directly from the data. This extends persona-based methods, which to our knowledge do not include methods to allocate individuals users to a persona. Finally, the patient profiling approach described in this thesis proposes a method to systemically embed profiles in the design of tailored services. Possibly, the patient profiling approach could therefore also be used to embed segmentation models of users outside the medical domain, such as e-commerce or tourism. Doing so would be of specific interest to the design community.

In summary, the research shows unique strengths related to the extent to which the profiles were validated and the mixed methodology employed in the different studies. Still, the presented research also has two important limitations that should be taken into consideration when interpreting and applying the findings.

The first limitation relates to the generalizability of the identified profiles. In all studies, we examined health consumers, patients, and healthcare professionals in the Dutch context of orthopaedic elective surgery. The studies presented in chapters 2 and 3 were also conducted in a single hospital. As such, the identified patient profiles may not accurately represent patients outside the Dutch healthcare system or patients with acute or chronic illnesses. The Dutch healthcare system is in transition and traditional reliance on government-centred care is slowly shifting towards self-reliance and family-centred care (van de Berg et al., 2016). However, this change takes time and Dutch citizens still show less patient activation compared to U.S. health consumers (Nijman, Hendriks, Brabers, De Jong, & Rademakers, 2014). Furthermore, Dutch citizens report a better health status than other European citizens even though life expectancy and mortality are around the European average (van de Berg et al., 2016). Finally, mental disorders such as anxiety and depression are prevalent in the Netherlands (van de Berg et al., 2016). As such, patients with an optimistic profile (higher self-reported health) and modest profile (higher anxiety and less participation) might be less common outside the Dutch healthcare context.

Furthermore, it should be restated that TJR surgery is an elective treatment. A major difference between elective care and acute or chronic care is that it can be planned in

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[21] See Groeneveld, Dekkers, Boon, & D'Olivo (2018) for a detailed discussion on differences between medical and creative practice and the difficulties this presents for successful collaboration.

advance. This not only offers more possibilities to plan specific tailored services, but also provides patients with more time to identify and clarify their preferences. Managing patients who hold strong and clear preferences for communication may therefore be much more common elective compared to emergency or acute care settings. On the other hand, elective care may hold lower stakes for patients, since it does not concern life-or-death decisions or invasive long-term care. Therefore, the way in which care is delivered – and whether care aligns with patient preferences – may be considered less important in elective settings as well. All in all, comparisons of patient profiles between elective (this thesis) and acute and chronic care settings are needed to determine to what extent orthopaedic patient profiles can be used to tailor healthcare services in other settings.

A second limitation of this research pertains to the fact that we employed cross-sectional and retrospective data collection. As discussed in the discussion sections of chapters 2, 3, and 4, recall biases may have influenced the assessment of preferences that underlie the patient profiles. Furthermore, the study set-up does not allow us to make conclusive statements on whether patients change profiles over the course of treatment, and if so, which elements of (tailored) healthcare services elicit such changes. As discussed previously, these aspects are however interesting avenues for future research.

7.4 FINAL CONCLUSION

By developing a set of data-driven patient profiles, this work demonstrates how the preferences, needs, and characteristics of patients who undergo a total joint replacement (TJR) surgery can be represented, and how these representations can be implemented in the design of tailored healthcare services. We do not wish to claim that all individual patients who share the same profile are identical or will experience a major surgery the exact same way. Still, three consistent patterns describe how different people tend to experience their own health, cope with pain and stress, and wish to communicate with their healthcare professionals. In turn, these aspects influence how satisfied patients are with the standardized healthcare service that is currently offered to them. Yet, more importantly, patient profiles provide medical and creative professionals with actionable insights into a very diverse group of consumers who at times seem to require very different healthcare services. Hopefully, this thesis has inspired readers to consider the possibility that healthcare can be both standardized as well as tailored – taking into account both our unique and universal characteristics.

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APPENDICES

Appendix 3A	Results of missing data imputation
Appendix 4A	Comparison health consumer and patients by profile
Appendix 4B	Patient Profile Allocation Instrument (paper version)
Appendix 5A	Search strategies for the identification of studies assessing the effects of web-based patient education interventions for the adult orthopaedic population
Appendix 6A	Dutch translation of the User Engagement Scale Short Form (UES-SF-Dutch): Validity, questionnaire items and instructions for scoring
Appendix 6B	Perceived advantages and disadvantages of tunnel, hierarchical, and matrix information architecture designs (translated from Dutch)
Appendix 7A	Options for tailoring design elements of web-based patient education

Appendix 3A Sociodemographic characteristics per cluster

	Cluster 1 (N = 83)		Cluster 2 (N = 62)		Cluster 3 (N = 46)	
	Count	**%**	**Count**	**%**	**Count**	**%**
Age in years (mean, SD)	68.58	8.17	69.40	8.64	75.86	7.91
Sex						
Female	56	67.5	26	41.9	33	75.0
Male	27	32.5	36	58.1	11	25.0
Education						
Primary education	6	7.2	9	14.8	13	30.2
Lower secondary education	25	30.1	17	27.9	20	46.5
Higher secondary education	24	28.9	15	24.6	7	16.7
Tertiary education	28	33.7	20	32.8	3	7.0
Occupation						
Retired	47	56.6	31	50.0	35	79.5
Employed	11	13.3	13	21.0	1	2.3
Self-employed	12	14.5	7	11.3	1	2.3
Beneficiary	5	6.0	4	6.5	1	2.3
Other	8	9.6	7	11.3	6	13.6
Relationship status						
Married	54	65.1	45	72.6	30	68.2
Widowed	18	21.7	8	12.9	9	20.5
Divorced	7	8.4	6	9.7	3	6.8
Never married	4	4.8	2	3.2	2	4.5
Other	0	0.0	1	1.6	0	0.0
Type of surgery						
Hip	47	56.6	36	58.1	23	50.0
Knee	36	43.4	26	41.9	23	50.0
Social support [a]						
Partner	49	59.0	45	72.6	28	63.6
Child	28	33.7	15	24.2	17	38.6
Friend	25	30.1	4	6.5	1	2.3
Neighbor	12	14.5	3	4.8	2	4.5
No support	4	4.8	8	12.9	3	6.8
Family member	5	6.0	3	4.8	3	6.8
Group (church, sports)	1	1.2	2	3.2	1	2.3
Colleague	1	1.2	0	0.0	0	0.0
Other	2	2.4	0	0.0	5	11.4
Internet usage						
Daily	54	65.1	39	65.0	16	41.0
Never	13	15.7	8	13.3	10	25.6
Multiple times a week	12	14.5	10	16.7	7	17.9
Once a week	3	3.6	3	5.0	3	7.7
Monthly	1	1.2	0	0.0	3	7.7

Note. Sociodemographic data was missing for two participants.

[a] Patients could indicate multiple sources of social support.

Appendix 4A

Appendix 4A Comparison health consumers and patients by profile

	Optimistic profile					Managing profile					Modest profile				
	Health consumers (N=100)		Patients (N=62)			Health consumers (N=56)		Patients (N=83)			Health consumers (N=79)		Patients (N=46)		
	M	SD	M	SD	Δ	M	SD	M	SD	Δ	M	SD	M	SD	Δ
Experience of health															
Self-reported health	77.39	12.62	76	15.7		65.61	20.69	65.32	17.73		60.08	16.22	70.74	12.1	-10.67**
Pain in rest	2.23	2.06	3.83	2.39	-1.61**	4.64	2.53	5.4	2.41		4.95	2.27	4.97	2.79	
Movement-evoked pain	3.84	2.26	6.6	2.07		5.52	2.32	7.59	1.61		5.63	1.56	7.56	1.7	
Anxiety	36.52	24.88	13.56	13.24	+22.96***	44.54	27.24	34.51	21.95		72.2	20.87	39.32	23.3	+32.88***
Coping behaviour															
Pain catastrophizing	7.93	5.25	8.78	5.6		17.79	9.55	17.38	8.44		18.99	8.7	19.38	10.02	
Active support seeking	1.67	0.47	0.75	0.51	+0.92***	2.06	0.42	1.73	0.46	+0.33***	1.28	0.39	1.1	0.39	
Maladaptive coping	0.6	0.38	0.22	0.24		0.85	0.43	0.67	0.51		0.89	0.42	0.67	0.38	
Positivity	1.74	0.45	1.33	0.63	+0.41***	2.05	0.48	1.86	0.51		1.3	0.44	1.28	0.42	
Religious coping	0.34	0.58	0.31	0.68		1.18	1.08	0.66	0.88	+0.52**	0.52	0.75	0.81	0.96	
Venting	1.02	0.56	0.26	0.38	+0.76***	1.36	0.67	1.02	0.55	+0.34**	1.18	0.55	0.83	0.54	+0.35*
Substance use	0.3	0.51	0.07	0.25		0.47	0.63	0.46	0.71		0.71	0.86	0.18	0.36	+ 0.52***
Self-distraction	1.77	0.66	0.92	0.77	+0.86**	2.28	0.52	1.93	0.72	+0.35*	1.55	0.62	1.43	0.76	
Preferences and competences in health communication															
Preference open information	74.7	11.2	63.5	14.47	+11.20***	88.08	12.05	80.06	12.11	+8.01**	74.27	13.15	57.83	13.01	+16.44***
Preference emotionally supportive communication	46.42	14.36	38.73	15.43	+7.69*	66.44	18.21	54.01	16.81	+12.43***	48	16.2	48.67	15.82	
Critical communication competences	3.46	0.62	3.36	0.64		4.12	0.66	3.79	0.57		3.21	0.66	2.78	0.59	
Personal communication competences	2.6	0.96	3.03	0.97	-0.44*	3.26	0.92	3.16	0.94		2.45	1	2.13	0.68	
Self-efficacy for health information	3.87	0.55	3.51	0.53	+0.36***	3.62	0.58	3.63	0.55		3.43	0.57	3.05	0.43	+0.385**

Note. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. All p-values are corrected for multiple comparisons (Holm correction). Non-significant differences are not reported.

Appendix 4B

Reinier de Graaf

Research
ORTHOPEDIE DELFT

Vragenlijst

Patiëntervaring op maat

Deze vragenlijst is ontwikkeld door Research Orthopedie Delft in samenwerking met de vakgroep 'Tailored Healthcare' ('Gezondheidszorg op Maat') van Technische Universiteit Delft, faculteit Industrieel Ontwerpen.

Gebaseerd op het basisontwerp meetinstrumenten ontwikkeld door het Nivel.

ID (*in te vullen door de onderzoekers)*:

INTRODUCTIE

Geachte heer/mevrouw,

Hartelijk dank voor uw deelname aan het onderzoek 'Patiëntervaring op maat'.

U zult in dit onderzoek aangeven welke voorkeuren u heeft over de communicatie met uw arts. Tevens stellen wij u enkele persoonlijke vragen, bijvoorbeeld over hoe u omgaat met pijn en stress.

Deze vragenlijst bevat drie delen:

Deel 1	Gesprekken met uw arts
Deel 2	Wat is uw ervaring?
Deel 3	Persoonsgegevens

Elk nieuwe onderdeel zal apart geïntroduceerd en uitgelegd worden.

U bent ongeveer 15 tot 20 minuten bezig met het invullen van de vragenlijst.

LET OP, DE VRAGENLIJST IS DUBBELZIJDIG. WILT U ALSTUBLIEFT CONTROLEREN OF U BEIDE ZIJDEN HEEFT INGEVULD?

Heeft u vragen, dan kunt u contact opnemen met Tessa Dekkers, onderzoeker TU Delft/Research Orthopedie Delft, via het telefoonnummer 015 – 2784640 of per e-mail via t.dekkers@rdgg.nl.

UW DEELNAME

Wanneer u deelneemt aan dit onderzoek stemt u in met de volgende punten:

- De informatie over deelname aan het onderzoek is schriftelijk of mondeling met mij doorgenomen. Ook kon ik vragen stellen. Mijn vragen zijn voldoende beantwoord. Ik had genoeg tijd om te beslissen of ik deel neem aan het onderzoek.
- Ik weet dat deelname vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen of te stoppen met het onderzoek. Daarvoor hoef ik geen reden te geven.
- Ik geef toestemming voor het verzamelen en gebruiken van mijn gegevens. Deze worden anoniem opgeslagen en verwerkt. Ik geef toestemming om mijn gegevens tot 5 jaar na dit onderzoek te bewaren.
- Ik doe vrijwillig mee aan deze vragenlijst en ontvang hiervoor geen vergoeding.

☐ Ja, ik stem toe met de hierboven genoemde punten.

☐ Nee, ik stem niet toe met de hierboven genoemde punten en zie af van deelname. In dit geval willen wij u vragen om alleen deze bladzijde terug te sturen in de antwoordenvelop.

DEEL 1: GESPREKKEN MET UW ARTS

In de hierna volgende lijst staan 10 beschrijvingen van zorgverleners(s). Wij zouden graag van u willen weten wat u persoonlijk belangrijk vindt bij een gesprek met uw arts en welk gedrag van een arts u goed of minder goed vindt. Het gaat daarbij om uw persoonlijke mening. U wordt in deze vragenlijst dus gevraagd om te beoordelen hoe belangrijk u verschillende gedragingen van uw arts vindt en niet of uw arts deze gedragingen vertoont. Baseer uw antwoorden op uw gesprekken met de zorgverlener(s) die u het meest recent heeft gezien, bijvoorbeeld uw huisarts of orthopeed.

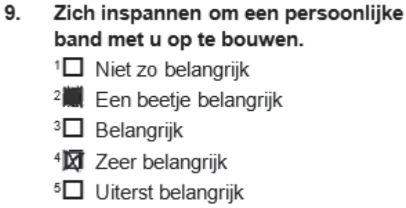
Het is mogelijk dat u sommige vragen van de vragenlijst erg op elkaar vindt lijken. Wij willen u toch dringend verzoeken alle vragen te beantwoorden.

<u>INVULINSTRUCTIE</u>

Bedenk bij elke stelling hoe belangrijk u het beschreven gedrag vindt. U vult in hoe belangrijk u het gedrag vindt door de optie te kiezen die uw mening het best weergeeft. Kruis bij elke vraag aan hoe belangrijk u de beschreven gedraging van de arts vindt (van '**niet zo belangrijk**' tot '**uiterst belangrijk**').

Als u **correcties** wilt aanbrengen (bv. omdat u het kruisje op een verkeerde plaats heeft gezet), vragen wij u – zoals in de volgende voorbeeldvraag aangegeven – het 'verkeerde' vakje helemaal in te kleuren en het 'juiste' vakje normaal aan te kruisen.

Voorbeeldvraag:



9. Zich inspannen om een persoonlijke band met u op te bouwen.
^{1}☐ Niet zo belangrijk
^{2}■ Een beetje belangrijk
^{3}☐ Belangrijk
^{4}☒ Zeer belangrijk
^{5}☐ Uiterst belangrijk

Uw arts moet…

1. Goed naar u luisteren als u iets wilt zeggen.
^{1}☐ Niet zo belangrijk
^{2}☐ Een beetje belangrijk
^{3}☐ Belangrijk
^{4}☐ Zeer belangrijk
^{5}☐ Uiterst belangrijk

2. U aan het eind van de behandeling vertellen hoe de behandeling van uw ziekte wordt voortgezet.
^{1}☐ Niet zo belangrijk
^{2}☐ Een beetje belangrijk
^{3}☐ Belangrijk
^{4}☐ Zeer belangrijk
^{5}☐ Uiterst belangrijk

3. U met betrekking tot uw ziekte open en direct informeren over dingen die een belasting voor u kunnen vormen (bv. bijwerkingen van een behandeling).
^{1}☐ Niet zo belangrijk
^{2}☐ Een beetje belangrijk
^{3}☐ Belangrijk
^{4}☐ Zeer belangrijk
^{5}☐ Uiterst belangrijk

4. U aan het begin van de behandeling vragen uw klachten uitvoerig te beschrijven.
^{1}☐ Niet zo belangrijk
^{2}☐ Een beetje belangrijk
^{3}☐ Belangrijk
^{4}☐ Zeer belangrijk
^{5}☐ Uiterst belangrijk

5. Informeren naar al uw klachten.
^{1}☐ Niet zo belangrijk
^{2}☐ Een beetje belangrijk
^{3}☐ Belangrijk
^{4}☐ Zeer belangrijk
^{5}☐ Uiterst belangrijk

6. **U altijd alles over uw ziekte vertellen, ook als dat onaangename dingen zijn.**
   1☐ Niet zo belangrijk
   2☐ Een beetje belangrijk
   3☐ Belangrijk
   4☐ Zeer belangrijk
   5☐ Uiterst belangrijk

7. **U vragen wat u over uw behandeling wilt weten.**
   1☐ Niet zo belangrijk
   2☐ Een beetje belangrijk
   3☐ Belangrijk
   4☐ Zeer belangrijk
   5☐ Uiterst belangrijk

8. **Bij u navragen of u tijdens de therapieën/behandelingen klachten heeft.**
   1☐ Niet zo belangrijk
   2☐ Een beetje belangrijk
   3☐ Belangrijk
   4☐ Zeer belangrijk
   5☐ Uiterst belangrijk

9. **U de mogelijkheid bieden vragen te stellen.**
   1☐ Niet zo belangrijk
   2☐ Een beetje belangrijk
   3☐ Belangrijk
   4☐ Zeer belangrijk
   5☐ Uiterst belangrijk

10. **U uitleggen wat uw diagnose precies inhoudt.**
   1☐ Niet zo belangrijk
   2☐ Een beetje belangrijk
   3☐ Belangrijk
   4☐ Zeer belangrijk
   5☐ Uiterst belangrijk

Nu volgen 9 verschillende manieren van hoe mensen zich kunnen gedragen in een gesprek met een arts. Wij willen graag van u weten hoe u zich opstelt in gesprekken met uw arts. Het gaat daarbij om *uw eigen waarneming en inschatting* van uw houding. U geeft aan in hoeverre u het eens bent met elke stelling. Er zijn geen goede of foute antwoorden.

Lees iedere uitspraak en geef voor elke uitspraak aan, in hoeverre deze van toepassing is op u (van '**helemaal niet**' tot '**helemaal wel**'). Doe dit door het antwoord aan te kruizen dat het meest op uw persoonlijke situatie van toepassing is.

1. **Als ik van mening verschil met mijn arts, maak ik mijn mening duidelijk.**
   1☐ Helemaal niet
   2☐ Niet
   3☐ Eerder niet
   4☐ Eerder wel
   5☐ Wel
   6☐ Helemaal wel

2. **Ik uit in een gesprek met mijn arts wel eens kritiek.**
   1☐ Helemaal niet
   2☐ Niet
   3☐ Eerder niet
   4☐ Eerder wel
   5☐ Wel
   6☐ Helemaal wel

3. **Ik stel wel eens kritische vragen over de behandeling.**
   1☐ Helemaal niet
   2☐ Niet
   3☐ Eerder niet
   4☐ Eerder wel
   5☐ Wel
   6☐ Helemaal wel

4. Ik geef mijn eigen mening over voorstellen van mijn arts.

1☐ Helemaal niet
2☐ Niet
3☐ Eerder niet
4☐ Eerder wel
5☐ Wel
6☐ Helemaal wel

5. Als ik het niet eens ben met mijn arts, geef ik dat duidelijk aan.

1☐ Helemaal niet
2☐ Niet
3☐ Eerder niet
4☐ Eerder wel
5☐ Wel
6☐ Helemaal wel

6. Ik maak mijn arts duidelijk wat ik van de behandeling vind.

1☐ Helemaal niet
2☐ Niet
3☐ Eerder niet
4☐ Eerder wel
5☐ Wel
6☐ Helemaal wel

7. Ik stel tijdens het gesprek met mijn arts op een passend moment vragen.

1☐ Helemaal niet
2☐ Niet
3☐ Eerder niet
4☐ Eerder wel
5☐ Wel
6☐ Helemaal wel

8. Als ik over iets twijfel, vertel ik dat aan mijn arts.

1☐ Helemaal niet
2☐ Niet
3☐ Eerder niet
4☐ Eerder wel
5☐ Wel
6☐ Helemaal wel

9. Ik stel mij zelfbewust op.

1☐ Helemaal niet
2☐ Niet
3☐ Eerder niet
4☐ Eerder wel
5☐ Wel
6☐ Helemaal wel

Nu volgen twee algemene vragen over beslissingen maken. Geef aan welk antwoord het best overeenkomt met uw mening.

1. In het algemeen, zou u altijd volledig geïnformeerd willen zijn over alle voor- en nadelen van een medische behandeling?

1☐ Ja, altijd
2☐ In sommige gevallen
3☐ Nee, nooit

Nadat men geïnformeerd is over de behandelingsmogelijkheden laten sommige mensen liever de uiteindelijke beslissing voor de behandeling over aan de arts, terwijl anderen dit liever zelf beslissen.

2. Kiest u alstublieft de stelling die het beste beschrijft wat u wilt.

1☐ De arts moet de beslissing maken door gebruik te maken van alle informatie die er bekend is over verschillende behandelingsmogelijkheden.
2☐ De arts moet de beslissing maken, maar mijn mening zeker overwegen.
3☐ De arts en ik moeten gezamenlijk een beslissing maken.
4☐ Ik moet de beslissing maken, maar de mening van de arts zeker over overwegen.
5☐ Ik moet de beslissing maken door gebruik te maken van alle informatie die ik heb of leer over verschillende behandelingsmogelijkheden.

DEEL 2: WAT IS UW ERVARING?

Hartelijk bedankt voor het invullen van de vragenlijst tot nu toe.

Nu volgen een aantal vragenlijsten over uzelf. Wij willen graag weten hoe u pijn ervaart, hoe u omgaat met stress, en hoe u zoekt naar gezondheidsinformatie. Wij willen benadrukken dat alles wat u invult anoniem wordt opgeslagen en verwerkt.

Als u **correcties** wilt aanbrengen (bv. omdat u het kruisje op een verkeerde plaats heeft gezet), vragen wij u het 'verkeerde' vakje helemaal in te kleuren en het 'juiste' vakje normaal aan te kruisen.

GEZONDHEID & PIJN

Hieronder volgen een aantal vragen over uw gezondheid en pijn.

PIJN
Eerst willen wij u vragen om aan te geven hoeveel pijn u (gemiddeld) had gedurende de afgelopen week (7 dagen).

Op de meetschaal hiernaast betekent '10' de ergste pijn die u zich kunt voorstellen, en '0' de minste pijn die u zich kunt voorstellen.

Zet een kruis op het punt op de meetschaal dat volgens u het best de ernst van uw pijn weergeeft. Daarna schrijft u het cijfer in het vak.

GEZONDHEID
Nu willen we u vragen om op de meetschaal hiernaast aan te geven hoe goed of hoe slecht volgens u uw eigen gezondheidstoestand vandaag is.

Op de meetschaal hiernaast betekent “10” de beste gezondheidstoestand die u zich kunt voorstellen, en “0” de slechtste gezondheidstoestand die u zich kunt voorstellen.

Trek een lijn van het hokje hieronder naar het punt op de meetschaal dat volgens u aangeeft hoe goed of hoe slecht uw gezondheidstoestand vandaag is. Daarna schrijft u het cijfer in het vak.

1. **Uw pijn in de afgelopen week:**

10 - Ergst denkbare pijn
9
8
7
6
5
4
3
2
1
0 – Geen pijn

MIJN CIJFER: ☐

2. **Uw gezondheidstoestand vandaag:**

10 – Best voorstelbare gezondheidstoestand
9
8
7
6
5
4
3
2
1
0 – Slechtst voorstelbare gezondheidstoestand

MIJN CIJFER: ☐

OMGAAN MET PIJN

Iedereen ervaart wel eens pijn in zijn leven zoals hoofdpijn, tandpijn, gewrichts- of spierpijn.

Mensen komen ook vaak in situaties terecht die pijn veroorzaken zoals een behandeling bij de tandarts of, in uw geval, een chirurgische ingreep. Wij zijn geïnteresseerd in de soort gedachten en gevoelens die u ervaart als u pijn hebt.

In de hierna volgende lijst staan dertien beweringen die verschillende gedachten en gevoelens beschrijven die mogelijk met pijn te maken hebben. Probeer aan te geven in welke mate deze gedachten en gevoelens ook voor u van toepassing zijn. Kruis bij elke vraag aan in hoeverre de bewering voor u van toepassing is (van '**helemaal niet**' tot '**altijd**').

Als ik pijn heb…

1. **Vraag ik mij voortdurend af of de pijn wel zal ophouden.**
   1☐ Helemaal niet
   2☐ In lichte mate
   3☐ In zekere mate
   4☐ In grote mate
   5☐ Altijd

2. **Voel ik dat ik zo niet verder kan.**
   1☐ Helemaal niet
   2☐ In lichte mate
   3☐ In zekere mate
   4☐ In grote mate
   5☐ Altijd

3. **Is dat verschrikkelijk en denk ik dat het nooit beter zal worden.**
   1☐ Helemaal niet
   2☐ In lichte mate
   3☐ In zekere mate
   4☐ In grote mate
   5☐ Altijd

4. **Is dat afschuwelijk en voel ik dat de pijn mij overweldigt.**
   1☐ Helemaal niet
   2☐ In lichte mate
   3☐ In zekere mate
   4☐ In grote mate
   5☐ Altijd

5. **Voel ik dat ik het niet meer uithoud.**
   1☐ Helemaal niet
   2☐ In lichte mate
   3☐ In zekere mate
   4☐ In grote mate
   5☐ Altijd

6. **Word ik bang dat de pijn erger zal worden.**
   1☐ Helemaal niet
   2☐ In lichte mate
   3☐ In zekere mate
   4☐ In grote mate
   5☐ Altijd

7. **Blijf ik denken aan andere pijnlijke gebeurtenissen.**
   1☐ Helemaal niet
   2☐ In lichte mate
   3☐ In zekere mate
   4☐ In grote mate
   5☐ Altijd

8. **Verlang ik hevig dat de pijn weggaat.**
   1☐ Helemaal niet
   2☐ In lichte mate
   3☐ In zekere mate
   4☐ In grote mate
   5☐ Altijd

9. **Kan ik de pijn niet uit mijn gedachten zetten.**
   1☐ Helemaal niet
   2☐ In lichte mate
   3☐ In zekere mate
   4☐ In grote mate
   5☐ Altijd

Als ik pijn heb…

10. Blijf ik eraan denken hoeveel pijn het wel doet.
1☐ Helemaal niet
2☐ In lichte mate
3☐ In zekere mate
4☐ In grote mate
5☐ Altijd

11. Blijf ik denken hoe graag ik zou willen dat de pijn ophoudt.
1☐ Helemaal niet
2☐ In lichte mate
3☐ In zekere mate
4☐ In grote mate
5☐ Altijd

12. Is er niets dat ik kan doen om de intensiteit van de pijn te verminderen.
1☐ Helemaal niet
2☐ In lichte mate
3☐ In zekere mate
4☐ In grote mate
5☐ Altijd

13. Vraag ik mij af of er iets ernstigs kan gebeuren.
1☐ Helemaal niet
2☐ In lichte mate
3☐ In zekere mate
4☐ In grote mate
5☐ Altijd

EMOTIES

Het is bekend dat emoties bij de meeste ziektes een belangrijke rol kunnen spelen. De volgende vragen dienen als hulpmiddel om te weten te komen hoe u zich voelt.

Lees iedere uitspraak en geef voor elke uitspraak aan hoe vaak u zich zo voelt (van 'bijna nooit’ tot 'bijna altijd'). Doe dit door het antwoord aan te kruizen dat het meest op uw persoonlijke situatie van toepassing is.

1. Ik voel me nerveus en onrustig.
1☐ Bijna nooit
2☐ Soms
3☐ Vaak
4☐ Bijna altijd

2. Ik voel me rustig en beheerst.
1☐ Bijna nooit
2☐ Soms
3☐ Vaak
4☐ Bijna altijd

3. Ik voel dat de moeilijkheden zich opstapelen zodat ik er niet meer tegenop kan.
1☐ Bijna nooit
2☐ Soms
3☐ Vaak
4☐ Bijna altijd

4. Ik pieker teveel over dingen die niet zo belangrijk zijn.
1☐ Bijna nooit
2☐ Soms
3☐ Vaak
4☐ Bijna altijd

5. Ik word geplaagd door storende gedachten.
1☐ Bijna nooit
2☐ Soms
3☐ Vaak
4☐ Bijna altijd

6. Ik voel me veilig.
1☐ Bijna nooit
2☐ Soms
3☐ Vaak
4☐ Bijna altijd

7. Ik voel me op mijn gemak.
1☐ Bijna nooit
2☐ Soms
3☐ Vaak
4☐ Bijna altijd

8. Ik ben gelijkmatig van stemming.

1☐ Bijna nooit
2☐ Soms
3☐ Vaak
4☐ Bijna altijd

9. Er zijn gedachten die ik heel moeilijk los kan laten.

1☐ Bijna nooit
2☐ Soms
3☐ Vaak
4☐ Bijna altijd

10. Ik raak helemaal gespannen en in beroering als ik denk aan mijn zorgen van de laatste tijd.

1☐ Bijna nooit
2☐ Soms
3☐ Vaak
4☐ Bijna altijd

OMGAAN MET STRESS

De volgende vragen gaan over de manieren waarop u met de stress in uw leven bent omgegaan sinds u erachter kwam dat u een gewrichtsvervangende operatie nodig had.

Er zijn vele manieren om om te gaan met stress. Deze vragen gaan over wat u hebt gedaan om om te gaan met de stress rond de operatie. Natuurlijk gaan verschillende mensen op verschillende manieren met dingen om, maar wij willen graag weten hoe u ermee om bent gegaan.

Elke stelling beschrijft een specifieke manier om met stress om te gaan. Wij willen weten in hoeverre u datgene heeft gedaan wat de stelling beschrijft. Beantwoord de vraag niet op basis van in hoeverre het heeft gewerkt – alleen of u het wel of niet heeft gedaan. Probeer elke stelling los van de andere stellingen te beoordelen.

U doet dit door het antwoord te kiezen dat het meest op uw persoonlijke situatie van toepassing is. *We willen dus weten wat u zélf vindt en niet wat u denkt dat de dokter of onderzoeker wil horen.*

Lees iedere stelling en kruis bij elke vraag aan hoe vaak u datgene heeft gedaan wat de stelling beschrijft (van '**nooit**' tot '**vaak**').

Ik heb…

1. Me ingespannen om iets te doen aan de situatie waarin ik zat.

1☐ Nooit
2☐ Soms
3☐ Regelmatig
4☐ Vaak

2. Actie ondernomen om de situatie te verbeteren.

1☐ Nooit
2☐ Soms
3☐ Regelmatig
4☐ Vaak

3. Geprobeerd een strategie te verzinnen over wat ik moest doen.

1☐ Nooit
2☐ Soms
3☐ Regelmatig
4☐ Vaak

4. Goed nagedacht over welke stappen ik zelf kon ondernemen.

1☐ Nooit
2☐ Soms
3☐ Regelmatig
4☐ Vaak

5. Emotionele support gekregen van anderen.

1☐ Nooit
2☐ Soms
3☐ Regelmatig
4☐ Vaak

6. Troost en begrip gekregen van iemand.

1☐ Nooit
2☐ Soms
3☐ Regelmatig
4☐ Vaak

Ik heb…

7. **Hulp en advies van andere mensen gekregen.**
   - 1☐ Nooit
   - 2☐ Soms
   - 3☐ Regelmatig
   - 4☐ Vaak

8. **Geprobeerd om advies of hulp te krijgen van andere mensen.**
   - 1☐ Nooit
   - 2☐ Soms
   - 3☐ Regelmatig
   - 4☐ Vaak

9. **Tegen mezelf gezegd ‘dit is niet echt.’**
   - 1☐ Nooit
   - 2☐ Soms
   - 3☐ Regelmatig
   - 4☐ Vaak

10. **Geweigerd te geloven dat er iets aan de hand was.**
    - 1☐ Nooit
    - 2☐ Soms
    - 3☐ Regelmatig
    - 4☐ Vaak

11. **Het opgegeven om met de stress om te gaan.**
    - 1☐ Nooit
    - 2☐ Soms
    - 3☐ Regelmatig
    - 4☐ Vaak

12. **Het opgegeven om stress het hoofd te bieden.**
    - 1☐ Nooit
    - 2☐ Soms
    - 3☐ Regelmatig
    - 4☐ Vaak

13. **Mezelf bekritiseerd.**
    - 1☐ Nooit
    - 2☐ Soms
    - 3☐ Regelmatig
    - 4☐ Vaak

14. **Mezelf de schuld gegeven over hoe de dingen zijn verlopen.**
    - 1☐ Nooit
    - 2☐ Soms
    - 3☐ Regelmatig
    - 4☐ Vaak

DEEL 3: PERSOONSGEGEVENS

Hartelijk bedankt voor het invullen van de vragenlijst tot nu toe.

U bent bijna klaar met het invullen van de vragenlijst. Wij willen als laatste enkele persoonsgegevens van u weten.

---

1. **Wat is uw geboortedatum?**

   ☐

   (a.u.b. in blokletters)

2. **Wat is uw geslacht?**
   - 1☐ Man
   - 2☐ Vrouw

3. **Wat is uw hoogst genoten opleiding?**
   Staat de juiste optie er niet bij? Kies dan het antwoord wat het meest overeenkomt met uw hoogst genoten opleiding.
   - 1☐ Geen / lager- of basisonderwijs
   - 2☐ VMBO, MAVO, LBO, MBO, MTS, MEAO, of vergelijkbaar
   - 3☐ HAVO, VWO, HBS, MMS, of vergelijkbaar
   - 4☐ HBO, WO, HTS, HEAO, of vergelijkbaar

4. **Welke optie beschrijft uw huidige arbeidssituatie het best?**
   - 1☐ In loondienst
   - 2☐ Zelfstandig
   - 3☐ Uitkeringsgerechtigd
   - 4☐ Gepensioneerd
   - 5☐ Studerend
   - 6☐ Geen arbeidssituatie

5. Wat is op dit moment uw burgerlijke staat?

1☐ Gehuwd, geregistreerd partnerschap, langdurige relatie, of vergelijkbaar
2☐ Voor de wet gescheiden
3☐ Weduwnaar of weduwe
4☐ Nooit gehuwd geweest
5☐ Anders of zeg ik liever niet

6. Heeft iemand uit uw sociale omgeving u geholpen na de operatie?

1☐ Ja
2☐ Nee ➔ ***Indien nee, ga naar vraag 8.***

7. Wat was uw relatie tot deze persoon of personen?

Er zijn meerdere antwoorden mogelijk. Vink alle antwoorden aan die van toepassing zijn.

1☐ Partner
2☐ (Schoon)zoon of (schoon)dochter
3☐ Andere familie (bijvoorbeeld een neef of nicht)
4☐ Vriend of vriendin
5☐ Collega
6☐ Iemand uit de buurt (bijvoorbeeld een buurman of buurvrouw)
7☐ Iemand uit een vereniging (bijvoorbeeld kerkelijke gemeenschap, sportvereniging)
8☐ Iemand anders, namelijk:

(a.u.b. in blokletters)

8. Hoe vaak gebruikt u het internet?

Staat de juiste optie er niet bij? Kies dan het antwoord wat het meest overeenkomt met uw internetgebruik.

1☐ Dagelijks
2☐ Wekelijks
3☐ Maandelijks
4☐ Bijna nooit➔ ***Indien u antwoord (bijna) nooit is, bent u klaar met de vragenlijst.***

9. Op welke apparaten gebruikt u het internet?

Er zijn meerdere antwoorden mogelijk. Vink alle antwoorden aan die van toepassing zijn.

1☐ Computer of laptop
2☐ Tablet of Ipad
3☐ Mobiele telefoon of smartphone
4☐ Anders, namelijk:

(a.u.b. in blokletters)

EINDE

Dit waren de laatste vragen van het onderzoek. Hartelijk bedankt voor het invullen van de vragenlijst.

Stuurt u de ingevulde vragenlijst a.u.b. terug in de bijgevoegde enveloppe.

Een postzegel is niet nodig.

Wanneer u nog vragen heeft over het onderzoek of uw deelname wilt intrekken kunt u contact opnemen via 015 27 84 640 of t.dekkers@rdgg.nl.

Appendix 5A

Search strategies for the identification of studies assessing the effects of web-based patient education interventions for the adult orthopaedic population

Table 1 Overall strategy for the identification of studies assessing the effects of web-based patient education interventions for the adult orthopaedic population.

	Aspects: combine with **AND**				
Synonyms: combine with **OR**	Aspect 1: internet	Aspect 2: patient education	Aspect 3: orthopaedic	Aspect 4: adult	Aspect 5: effectiveness
	"World Wide Web"	"Medical Education"	orthopedic	adult	effect
	online	"Health Education"	orthopedics	aged	efficacy
	web-based	"Patient Education As A Topic"	orthopaedics		performance
	"Computer Assisted"	"Health Knowledge, Attitudes, Practice"	"joint replacement"		result
	E-Health	"Consumer Health Information"	"arthroplasty"		outcome
	network		hip		
	"Web Services"		knee		

Table 2 Specific strategies for the identification of studies assessing the effects of web-based patient education interventions for the adult orthopaedic population.

Database	**Search string**
Cochrane Central Register of Controlled Trials	("internet" or "world wide web" or "online" or "web-based" or "E-health") and ("patient education" or "health education" or "consumer health information") and (arthroplasty or orthopeadic or orthopedic or "joint replacement" or "hip replacement" or "knee replacement") *with Bone, Joint and Muscle Trauma Group, Consumers and Communication Group or Musculoskeletal Group in Review Groups*
CINAHL	((MH "Arthroplasty, Replacement, Hip") OR (MH "Arthroplasty, Replacement, Knee") OR (MH "Arthroplasty, Replacement, Shoulder") OR (MH "Arthroplasty, Replacement, Ankle") OR (MH "Arthroplasty, Replacement") OR (MH "Arthroplasty, Replacement, Elbow") OR (MH "Arthroplasty, Knee, Unicompartmental") OR (MH "Arthroplasty, Reverse Total, Shoulder")) AND (((MH "Education, Health Information Management") OR (MH "Health Education") OR (MH "Patient Education")) AND (internet OR (MH "World Wide Web") OR (MH "World Wide Web Applications"))
EMBASE	(!effectiveness OR effect OR 'efficacy'/exp OR efficacy OR 'performance'/exp OR performance OR result OR 'outcome'/exp OR outcome) AND ((orthopaedic OR orthopedic OR orthopedics OR orthopaedics OR joint) AND replacement OR arthroplasty OR hip OR knee) AND ([adult]/lim OR [middle aged]/lim OR [aged]/lim OR [very elderly]/lim) AND ('patient education' OR 'medical education' OR 'health education' OR 'patient education as a topic' OR 'health knowledge, attitudes, practice' OR 'consumer health information') AND (internet OR 'world wide web' OR online OR 'web based' OR 'computer assisted' OR 'e health' OR network OR 'web services')

MEDLINE	((((TOPIC:(((((“world wide web”) OR online) OR web-based) OR “computer-assisted”) OR E-health) OR “web services”)AND TOPIC: ((((“medical education”) OR “health education”) OR “Patient education”) OR “Health knowledge, attitudes, practice”) OR “consumer health information”)) AND TOPIC:(((((orthopedic*) OR orthopeadic*) OR “joint replacement”) OR “arthroplasty”) OR hip) OR knee)) AND AGE GROUP: ((((“Adult”) OR “Middle Aged”) OR “Aged”) OR “Aged”) OR “Aged, 80 and over”)) AND TOPIC:((((effect) OR efficacy) OR performance) OR result) OR outcome))
PsycINFO	(Effectiveness or Effect or efficacy or performance or result or outcome).mp. [mp=title, abstract, full text, caption text] AND (adult or aged).mp. [mp=title, abstract, full text, caption text] AND (orthopaedic or orthopedic or orthopedics or orthopaedics or joint replacement or arthroplasty or hip or knee).mp. [mp=title, abstract, full text, caption text] AND (“patient education” or “medical education” or “health education” or “patient education as a topic” or “health knowledge, attitudes, practice” or “consumer health information”).ab. AND (internet or “world wide web” or online or web-based or “computer assisted” or e-health or network or “web services”).ab.
PubMed	(internet OR “world wide web” OR online OR web-based OR “computer assisted” OR e-health OR network OR “web services”) AND (“patient education” OR “patient education as topic” [MeSH Terms] OR “consumer health informati*” OR “medical education” OR “health education” OR “health knowledge, attitudes, practice”[MeSH Terms]) AND (orthopedic* OR orthopaedic* OR “joint replacement” or “arthroplasty” OR “hip” OR “knee”) AND (Adult OR Aged) AND (Effect OR efficacy OR performance OR result OR outcome)
Science direct	(“internet” OR “world wide web” OR “online” OR “web-based” OR “E-health”) AND (“patient education” OR “consumer health information”) AND (arthroplasty OR orthopeadic OR orthopedic OR “joint replacement” OR “hip replacement” OR “knee replacement”)
Scopus	((TITLE-ABS-KEY (“Effectiveness”) OR TITLE-ABS-KEY (“Effect”) OR TITLE-ABS-KEY (efficacy) OR TITLE-ABS-KEY (performance) OR TITLE-ABS-KEY (“result”) OR TITLE-ABS-KEY (“outcome”))) AND ((TITLE-ABS-KEY (“patient education”) OR TITLE-ABS-KEY (“medical education”) OR TITLE-ABS-KEY (“Health Education”) OR TITLE-ABS-KEY (“Patient Education As A Topic”) OR TITLE-ABS-KEY (“Health Knowledge, Attitudes, Practice”) OR TITLE-ABS-KEY (“Consumer Health Information”))) AND ((TITLE-ABS-KEY (“adult”) OR TITLE-ABS-KEY (“aged”))) AND ((TITLE-ABS-KEY (“World Wide Web”) OR TITLE-ABS-KEY (“Online”) OR TITLE-ABS-KEY (“Web-Based”) OR TITLE-ABS-KEY (“Computer Assisted”) OR TITLE-ABS-KEY (e-health) OR TITLE-ABS-KEY (network) OR TITLE-ABS-KEY (“Web Services”) OR TITLE-ABS-KEY (internet))) AND ((TITLE-ABS-KEY (“orthopedic”) OR TITLE-ABS-KEY (“orthopedics”) OR TITLE-ABS-KEY (“orthopaedics”) OR TITLE-ABS-KEY (“joint replacement”) OR TITLE-ABS-KEY (“arthroplasty”) OR TITLE-ABS-KEY (hip) OR TITLE-ABS-KEY (knee) OR TITLE-ABS-KEY (orthopaedic)))
Web of Science	TS=(“world wide web” OR online OR web-based OR “computer-assisted” OR e-health) AND TS=(((((“medical education”) OR “health education”) OR “Patient education”) OR “Health knowledge, attitudes, practice”) OR “consumer health information”) AND TS=(orthopedic* OR orthopeadic* OR “joint replacement” OR “arthroplasty” OR hip OR knee) AND TS=(“Adult” OR “Middle Aged” OR “Aged” OR “Aged, 80 and over”) AND TS=(((((effect) OR efficacy) OR performance) OR result) OR outcome)

Appendix 6A

Dutch translation of the User Engagement Scale Short Form (UES-SF-Dutch): Validity, questionnaire items and instructions for scoring

0. Inhoud

a. Algemene gegevens
b. Auteur
c. Soort & vorm van het meetinstrument
d. Methodologische kwaliteit
e. User Engagement Short Form Dutch & instructies
f. Referenties

1. Algemene gegevens

De User Engagement Scale Short Form (UES-SF) is een verkort instrument om gebruikersbetrokkenheid [user engagement] te meten. Gebruikersbetrokkenheid wordt hierbij gezien als een eigenschap van de gebruikerservaring [user experience, UX] die wordt gekenmerkt door de mate waarin iemand geïnvesteerd is tijdens diens interactie met een digitaal systeem [1].

2. Auteur

- o Oorspronkelijke versie: Heather O'Brien, Paul Cairns, Mark Hall [2]
- o Nederlandse versie: Tessa Dekkers, Marijke Melles [3]

Toestemming voor deze vertaling is verstrekt door Heather O'Brien aan Tessa Dekkers op 18 mei 2018.

3. Soort/vorm van het meetinstrument

o Opbouw:	12 vragen met 5 antwoordmogelijkheden
o Invulinstructie:	Gesloten vragen, (online) in te vullen door de deelnemer
o Meetniveau:	Vier dimensie scores (1-5); meetniveau ordinaal Een totaalscore (1-5); meetniveau ordinaal

4. Methodologische kwaliteit

De originele UES is uitgebreid gevalideerd in onder andere [1,4]. De Engelstalige UES-SF is gevalideerd in [2].

De data uit een studie naar het gebruik van online patiënt educatie door middelbare en oudere gebruikers (40-80 jaar) met zelf-gerapporteerde gewrichtsklachten (N=215) is gebruikt om de validiteit van de Nederlandse vertaling van de UES-SF te onderzoeken. Daarbij is methode van O'Brien aangehouden. Dat wil zeggen:

- Explorative 1-factor analyse om te toetsen of alle items een unidimensionaal construct (gebruikersbetrokkenheid) beschrijven.
- Bevestigende bifactor analyse om te toetsen of alle items zowel het unidimensionale construct gebruikersbetrokkenheid als de vier onderliggende dimensies beschrijven. (Gerichte Aandacht [Focused Attention; FA], Waargenomen Gebruiksvriendelijkheid [Perceived Usability; PU], Esthetische Aantrekkingskracht [Aesthetic Appeal; AE] , Beloning [Reward; RW]).
- Toetsing van de interne consistentie uitgedrukt in ω-coëfficiënt & 95% betrouwbaarheidsintervallen en α-coëfficiënt.

1 Factor ladingen

Sub schaal	Exploratief 1-factor	Bevestigend bifactor + 4 subschalen				
	General	General	FA	PU	AE	RW
FA-S.1	0.620	0.501	0.677			
FA-S.2	0.658	0.551	0.341			
FA-S.3	0.676	0.559	0.515			
PU-S.1	- 0.639	-0.479		0.647		
PU-S.2	- 0.640	-0.468		0.730		
PU-S.3	- 0.418	-0.319		0.647		
AE-S.1	0.872	0.720			0.663	
AE-S.2	0.803	0.648			0.505	
AE-S.3	0.899	0.726			0.422	
RW-S.1	0.866	0.704				0.557
RW-S.2	0.718	0.549				0.357
RW-S.3	0.673	0.526				0.214

2 Interne consistentie

Sub schaal	ω	95% CI van ω	α
FA-S	0.77	(0.69, 0.82)	0.75
PU-S	0.79	(0.72, 0.85)	0.79
AE-S	0.87	(0.83, 0.91)	0.87
RW-S	0.72	(0.63, 0.79)	0.71
Totaal	0.72	(0.63, 0.79)	0.88

3 Interpretatie

De items van de UES-SF Dutch laden naar verwachting zowel op het unidimensioneel construct gebruikersbetrokkenheid als op de onderliggende dimensies. De gevonden ω- en α-coëfficiënten tonen aan dat zowel algehele gebruikersbetrokkenheid als de onderliggende dimensies betrouwbaar gemeten kunnen worden met het instrument. Deze resultaten zijn vergelijkbaar met die van de Engelstalige versie van de vragenlijst. Slechts het item RW-S.3 laadt onvoldoende op de 'Beloning' dimensie. Vanwege voldoende betrouwbaarheid van de sub schaal als geheel is toch gekozen om dit item te behouden, maar toekomstige studies dienen extra aandacht hieraan te besteden bijvoorbeeld door het berekenen van de betrouwbaarheid op basis van de eigen verzamelde data.

5 User Engagement Short Form Dutch

Instructies voor beheerders:
Wanneer u de UES-SF afneemt dienen alle stellingen gerandomiseerd te worden. Tevens mogen dimensie aanduidingen (zoals "Focused Attention of FA") niet zichtbaar zijn voor deelnemers. Hieronder staan algemene instructies voor deelnemers die kunnen worden aangepast naar de context van het onderzoek. De vijfpuntschaal moet worden gebruikt om vergelijkingen tussen studies en onderzoekspopulaties mogelijk te maken. De formulering van de vragen kan worden aangepast aan uw gebruikscontext. Bijvoorbeeld, item PU.1 "Ik voelde me gefrustreerd tijdens het gebruik van de Applicatie X" kan worden geformuleerd als "Ik voelde me gefrustreerd tijdens het gebruik van de zoekmachine."

Instructies voor deelnemers:
Hieronder volgen 12 stellingen over uw ervaring met Applicatie X (of "deze studie"). Lees iedere stelling en geef voor elke stelling aan in hoeverre u ermee oneens of eens bent (van 'zeer mee oneens' tot 'zeer mee eens'). Doe dit door het antwoord aan te klikken (of "aan te kruisen") dat het best uw mening reflecteert.

Items:

zeer mee oneens	oneens	neutraal	mee eens	zeer mee eens
1	2	3	4	5

FA-S.1	Ik vergat de wereld om me heen tijdens het gebruik van Applicatie X.
FA-S.2	De tijd vloog voorbij tijdens het gebruik van Applicatie X.
FA-S.3	Ik ging helemaal op in deze beleving.
PU-S.1	Ik voelde me gefrustreerd tijdens het gebruik van Applicatie X.
PU-S.2	Ik vond Applicatie X verwarrend in gebruik.
PU-S.3	Het gebruik van Applicatie X was veeleisend.
AE-S.1	Applicatie X was aantrekkelijk.
AE-S.2	Applicatie X sprak mij aan.
AE-S.3	Applicatie X zag er uitnodigend uit.
RW-S.1	Het gebruik van Applicatie X was de moeite waard.
RW-S.2	Mijn ervaring met Applicatie X was lonend.
RW-S.3	Ik was geïnteresseerd in deze beleving.

Scoring

- U moet de volgende stellingen spiegelen (omcoderen): PU-S.1, PU-S.2, PU-S.3
- Wanneer deelnemers de UES-SF-Dutch meerdere keren hebben ingevuld gedurende hetzelfde experiment dient u afzonderlijke scores voor elke iteratie te berekenen. Dit zorgt ervoor dat de onderzoeker betrokkenheid zowel kan vergelijken tussen deelnemers als wel tussen taken/iteraties.
- U berekent de scores voor elk van de vier dimensies (sub schalen) door de scores van de antwoorden op de drie stellingen binnen een dimensie op te tellen en door drie te delen. Bijvoorbeeld, “Aesthetic Appeal” wordt berekend door AE-S.1, AE-S.2, en AE-S.3 bij elkaar op tellen en deze score door drie te delen.
- Een totale betrokkenheid score kan worden berekend door de scores van alle stellingen bij elkaar op te tellen en deze score door twaalf te delen.

6 Referenties

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3 Dekkers T, Melles M, Vehmeijer SBW, de Ridder H. The effect of information architecture on the effectiveness and user experience of web-based patient education: A randomized experiment with middle-aged and older adults. *Under review.*

4 O’Brien HL, Toms EG. The development and evaluation of a survey to measure user engagement in e-commerce environments. J Am Soc Inf Sci Technol 2010;61:50–69. doi:10.1002/asi.21229.1

Appendix 6B

Perceived advantages and disadvantages of tunnel, hierarchical, and matrix information architecture designs (translated from Dutch)

IA	Advantages	Disadvantages
Tunnel	**Step-by-step approach is clear, legible, and provides a 'checklist'** o "I found it very clear, step-by-step in chronological order" o "the website was very nice and comprehensible and understandable for everyone. It is explained step by step what will happen, this is very clear!!" o "The step-by-step checking of how the process will go from start to finish when you have received a new hip" o "The information was clear and well-organized. No big pieces of text. The check marks on the left side of the page tell you which topics you can find information about."	**Not being able to choose what you want to read** o "I could not start with a specific part of information about the process myself." o "I could not jump from one subject to the other; I did not try it extensively. But that is my impression now. You always had to click the arrows or next and could not click on a tab to read more."
	Clear and simple navigation o "clear path, overview on the left" o "clear language and easy navigation" o "Easy to finish and very clear"	**High (initial) amount of information** o "A lot of information" o "It seemed like a lot of information at the beginning; but later on it was not so bad."
	Ability to revisit a previous topic o "Clear and structured, I can go back to each part if I want to" o "The most pleasant was the clear language and the ease with which you could return to the previous pages."	**Repetitive** o "I sometimes found the website somewhat monotonous"
	Transparency o "The clear explanation and the way it is kind of explained step by step, it is very transparent, from beginning to end."	
Hierarchical	**Concise, no unnecessary information** o "Clear, short and concise" o "clear language, short and concise, well-organized" o "Very clear, large font for those who need it. Clear language. no unnecessary information" o "An understandable Dutch website. With no unnecessary information. Clear for when you are in such a situation."	**Difficult to navigate to main menu when accessing deeply-nested information** o "That "back to main menu" is below the text and therefore sometimes not visible. I prefer to have this [button] at the top." o "The only thing that I found that, with the PC, that if you want to exit the menu, it was not clearly indicated to me."
	Phases logically relate to the treatment itself o "Clearly arranged and divided into the different phases of treatment" o "I was able to view each phase in the treatment and healing process, grouped by subject at my own pace. There was a logical navigation and practical information was everywhere." o "The choice menu, which shows stages that can be viewed, depending on the treatment, the complaints of the person afterwards. It answered all questions from shortly after and longer after the treatment.	**Fragmented information** o "Some topics still contain relatively long text. I would find it much more pleasant if certain instructions are mentioned in a row, so that it is clearer sooner what you should do or should not do."
	Knowing where you are and where you are going on the website o "The clarity of what you can read and the clarity that you know where you are on the website" o "where I could find everything" o "Clarity, you knew exactly where you were"	**Not knowing where you are going on the website** o "that I did not always know where I was going."

Matrix	**Clear, minimalistic overview** o “Clear overview per theme” o “What you selected was very clear. You immediately got the relevant information.” o “I found that the boxes provided clarity and overview.” o “The clarity of the searchable information, on the first screen with all the topics together.” o “That you had clear buttons for all the different information. You just click the button and you get specific information. That better than an A4 with a lot of text in a row” o “Minimalistic, information is clearly clustered to boxes”	**Messy and chaotic** o “It was messy; sometimes it was not clear where I ended und thus I was unnecessarily clicking back and forth” o “Although everything was discussed, the website also has something chaotic by ‘clicking’ the topics without any obligation. This would allow you to overlook something. I prefer to see a ‘fixed’ order such as day of surgery, discharge, home, physiotherapy, checks, etc. and what you have to do or can expect during these occasions.”
	Rapid availability of specific information o “You can get the information quickly and easily just by pressing the buttons” o “The headings where clear so you know very quickly where to go if you want to know more about a specific topic.”	**Effortful and tiring** o “I did not want to read all those headings…” o “I found the way to get information a bit cumbersome and messy with all those boxes. I think if you do not do a lot of computer work this will be tiring”
	Knowing where you are and where you are going on the website o “I knew exactly where I was and I could easily return if I wanted to read something again.” o “I always knew where I went” o “I liked the ability to click through, clear choice of topics so that you do not get lost when you want to read something again.”	**Boring** o “The website looks a little boring. It is nice and minimalistic and clear, but rather boring.”
	Being able to choose what you want to read o “I liked that you could choose where and when you wanted to see information about something.” o “You can choose what you want to read and when. There is no determined order. It is clear.”	

Appendix 7A

Options for tailoring design elements of web-based patient education

Information architecture			**Interface design choices**				**Initiation and embedment of use**				**Communication methods**	
Structure & ordering	**Navigation**	**Detailing**	**Interpretability**	**Credibility**	**Safety**	**Appearance**	**Scheduled use**	**Initiation of use**	**Reminder of use**	**(Technical) support**	**Medium**	**(Implied) source**
How the information is structured, determines which information is shown when	*How the user navigates through the information*	*How much information the user sees at once, amount of clicks required from general to detailed*	*How easily the information can be interpreted*	*How trustworthy and credible information is perceived to be*	*How safe information is perceived to be*	*Interface aesthetics, look & feel note: each category has low-high dimensions)*	*How use of the site is scheduled*	*How (by whom) start of site usage is determined, the trigger*	*How (by whom) continued usage of site usage is determined, the continued trigger*	*How (by whom) technical support is provided*	*Through which medium information is conveyed*	*By whom information is (implied to be) conveyed*
no/limited ordering (book)	Linear (infinite scroll)	High (all at once)	low (medical jargon, long length/ amount of total information)	low (none)	low (none)	colour (mono-tonous-colourful)	not or random	product initiated (reminders, prompts)	no reminders (or dependent on people)	none	textual	healthcare professional
conceptual ordering (content)	Tunnel (step-by-step)	medium (content blocks assessable with single click)	medium (glossary of medical terms, medium length/ amount)	high (recent date of content update, accreditation by health organization, patients' right displayed on homepage, endorsement by patients and/or hcp in ratings & testimonials)	high (adherence & reference to quality guidelines, personal info is secured, must login/ password to see personal information)	(screen) size (small-large)	scheduled to care process (e.g. each consultation)	patient initiated	prompts on website	delayed (e-mail, contact details, forum)	textual w/ auditory (screen reader, audio files, transcripts)	patient/ peer (e.g. vignettes, testimonials, stories, experiences)
chronological ordering (timeline)	Hierarchical (menu & submenus)	low (superficial information first, as in f.a.q., detail pages after click-through, short time spent per topic)	high (no medical jargon, short length/amount)			colour contrast-readability (poor-good)	reflective (after surgery, looking back)	health professional initiated	e-mail reminders	direct (live chat)	visual-factual (scientific figures, graphs, fact-lists)	system (gamification, avatars)
contextual ordering (based on current place, context, activities)	Associated (recommend reading, suggestions, sliders)					text/picture balance (low-high)	preventive (before surgery, looking forward)	other person initiated (peer, family, friend, informal caregiver)	push-notifications (phone, app)	collaborative (shared screens, collaborative assignments)	visual-playful (animations, info-graphics)	self (feedback)
automated ordering (based on user input)	Matrix (grid-like buttons, hyperlinks)						individual dependent (based on user input e.g. low scores, inactivity)				video	
individual ordering (self-selection of topics, add-button)	Hybrid (combi-nation)											

Self-monitoring							**Peer support & contact**
User input	**Feedback**	**Tailoring of feedback**	**Feedback agent**	**Timing of feedback**	**Type of comparison**	**Referential group**	
How and to what extent users are able to provide input	*Whether feedback is provided on user input*	*If feedback is given, on which user input?*	*If feedback is given, by whom?*	*If feedback is given, when?*	*If user input is compared, how?*	*If user input is compared, to whom?*	*Whether and how peers can be contacted*
not	no (just input)	overt/fake (feedback claims to be about user input, but is not)	system (knowledge tests, quizzes)	immediate (feedback on short-term user input)	descriptive (no comparison, just report back input)	self (earlier inputs)	none
limited (closed questions, pre-set questions)	yes	targeted (feedback on averages in user group group)	person (hcp, family, peer)	collecting (feedback on short-term embedded in long-term)	comparative (compare user input to other users)	comparative patients (users in same profile or trajectory)	outsourced (links to social media networks, share buttons)
detailed (open questions, free text, dairy)		personalized (feedback on individual user input but limited, e.g. name)		long term only (e.g. at end of collecting period)	evaluative /both (interpret or give judgement about all user input)	all patients (users in same and different profiles)	moderated (moderated forum, facilitated shared sessions)
user generated (users generate questions, topics, blogs)		tailored (feedback on individual user input)			evaluative /positive (interpret or give only positive judgement about 'correct' user input, e.g. "good job")		unmoderated (unmoderated chat room, forum, etc.)
					evaluative /negative (interpret or give only negative judgement about 'incorrect' user input, e.g. alarms)		

SUMMARY

Data-driven Patient Profiles

Definition, validation, and implementation for tailored orthopaedic healthcare services

In order to provide patients with the highest possible quality of care, healthcare institutions often standardize the way they provide healthcare. Yet, there are also more and more calls for tailored healthcare services that are intended for one specific person and based on characteristics that are unique to that person. This dissertation investigates tailored healthcare services and does so specifically in the orthopaedic context. Orthopaedic patients, in particular patients who have undergone joint replacement surgery of the hip or knee joint, are relatively dissatisfied with the current healthcare service provided to them. Specifically, the communication with total joint replacement patients (including the way in which patients are informed about the surgery, its risks and the treatment plan, but also the emotional support they receive from healthcare providers) often leaves something to be desired.

In examining tailored healthcare as a potential solution to dissatisfaction with patient-provider communication, this dissertation focuses on the definition, validation and implementation of so-called patient profiles. Patient profiles represent the common characteristics of a specific subgroup of patients that are unique compared to the overall patient population. The patient profiling approach is derived from the principles of mass customization and assumes that representations of the common and unique preferences, needs, and competences of different groups of patients can be used to design tailored healthcare services. These tailored healthcare services can then be offered to individual patients based on their profile. It is expected that tailored healthcare services will lead to improvements in patient experience.

This dissertation examines patient profiles and the effect of the patient profiling approach on patient experience following four questions: (1) what are relevant patient characteristics for patient profiling?, (2) which data driven patient profiles can be distinguished?, (3) which orthopaedic healthcare services are suitable for tailoring?, and (4) what is the effect of tailored healthcare services on patient experience? These questions are approached using the biopsychosocial model. The biopsychosocial model assumes that biomedical factors (such as pain and physical functioning) as well as psychological and social factors (such as coping mechanisms and communication preferences and competences) influence how someone experiences their illness, and therefore, what type of healthcare service would suit them. A combination of research methods including observations, interviews, questionnaires, machine learning, systematic literature reviews and experiments were used to answer the specific research questions.

Which patient characteristics are relevant for patient profiling?

Observations and interviews with 7 orthopaedic surgeons (Chapter 2) and questionnaire research among 191 patients (Chapter 3) showed that communication preferences, psychological coping mechanisms, and the patient's own experience of health are relevant characteristics for differentiating orthopaedic patients. Orthopaedic surgeons already use these features informally to adjust one of the healthcare services they provide: the orthopaedic consultation. The same characteristics also clearly distinguish the diversity in the patient population from a patient and data perspective. In addition, the score of a patient on these characteristics appears to be predictive of his or her satisfaction with (standardized) patient-provider communication. In a later validation study among 235 health consumers with untreated joint complaints (Chapter 4), both treated and untreated patients were again well differentiated by these characteristics.

Nine patient characteristics proved to be the most relevant and these form the basis of the patient profile: health experience (measured as self-reported health status, movement-evoked pain, age, and trait anxiety), psychological coping mechanisms (measured as tendency towards pain catastrophizing and coping through active support seeking), and communication preferences and competences (measured as a preference for open communication and competence in critical communication). These characteristics are included in the patient profiling instrument which predicts the most likely profile of a patient with 80% certainty.

Which data driven patient profiles can be distinguished?

Based on the patient characteristics described above, three patient profiles were defined (Chapter 3) and validated (Chapter 4) through cluster analysis and machine learning. The patient profiles represent three unique ways in which (future) orthopaedic patients experience their own health, deal with the prospect and aftermath of major surgery, and wish to communicate with their healthcare providers. An interesting finding was that patients with a certain profile thrive better with standardized care than others.

The first profile (44% of treated patients and 24% of untreated patients) uses a diverse set of coping mechanisms, including actively seeking emotional and instrumental support from others. These patients want to participate in patient-provider communication and expect open information provision. On average, they have higher communication competences, but they see themselves as less healthy. This profile was called the *managing* profile, given the quantity and diversity of sources that these patients use to manage the care process and the high standard they set for patient-provider communication.

The second profile (32% of treated patients and 42% of untreated patients) is characterized by better health, lower trait anxiety, and limited use of coping mechanisms. They have well-developed communication competences but consider patient-provider communication a less important part of the healthcare service. This profile was called the *optimistic* profile because these patients appear to have fewer additional care needs even faced with a potentially stressful event such as joint replacement surgery. Patients with an optimistic profile were the most satisfied with (standardized) patient-provider communication and experienced the best clinical outcomes after the surgery.

The third profile (24% of treated patients and 34% of untreated patients) experiences their health to be worse and has a greater tendency towards anxiety and pain catastrophizing. These patients have poorer communication competences while both open communication and emotional support are important aspects of patient-provider communication to them. This profile was called the *modest* profile because these patients have specific needs but are less likely to express them. Patients with a modest profile achieve poorer clinical results after surgery and are the least satisfied with (standardized) patient-provider communication.

Which standardized healthcare services are suitable for tailoring?

Instead of an exhaustive review of all different orthopaedic care services that may be suitable for tailoring, the thesis examined the suitability of a specific service: web-based patient education interventions. Ten different web-based patient education interventions were compared with each other and with regular patient education interventions on clinical health outcomes and patient experience (Chapter 5).

Web-based patient education was found to be a service of which many different aspects can be tailored, both at the micro-level (for example interface design) and macro-level (for example to what extent caregivers are involved for extra support). Unfortunately, the current (standardized) educational programs are primarily suitable for a limited group of patients; those who are younger, higher-educated, and with better-developed online skills. Nevertheless, web-based patient education interventions still improved patient experience compared to regular patient education programs.

Overall, orthopaedic web-based patient education is adaptable and improves patient experience, but does not yet reach the entire patient population. This makes web-based patient education an orthopaedic healthcare service that is suitable for tailoring. Adaptability, impact, and current inclusiveness are criteria which can be taken into account to evaluate other healthcare services on their suitability for tailoring.

What is the effect of tailored healthcare services on patient experience?

Building on the results of the systematic review from Chapter 5, a randomized online experiment was conducted. The experiment examined the effect of tailored web-based patient education on patient experience (Chapter 6). Existing patient education material was tailored by adapting the structural layout and organization of the information on the website (e.g., the information architecture) to the preferences, needs, and competences of the three patient profiles. The results showed that patients generally preferred matrix or tunnel information architectures and that patients with a managing profile preferred a tunnel architecture specifically. This points to a potential positive effect of tailoring web-based patient education to patients with the managing profile. However, the match between *managing* patients and tunnel architecture was not hypothesized, and the online patient education program only slightly improved the patient experience in comparison to standardized patient education.

Implications of the findings

This dissertation shows that three patient profiles can be used to represent the orthopaedic patient and to design healthcare services that better fit the preferences, needs and competences of different patients. Tailored healthcare services care seem particularly prudent for patients with a *modest* profile. These patients were both less satisfied with patient-provider communication and experienced (possibly as a result) poorer physical and psychological outcomes after surgery. This relation has not been shown explicitly in orthopaedic practice before and demonstrates how the biopsychosocial patient profiles complement existing biomedical segmentation models.

Each patient profile represents a group of patients with their own characteristics and challenges. Because the profiles are data-driven, they offer an empirical alternative to personas for healthcare designers. Designers can get started with tailoring by adapting existing services to the preferences and needs of the three patient profiles. The results of the experiment from Chapter 6 are of particular interest to designers of online healthcare services, i.e. eHealth. This experiment showed that it is crucial to design eHealth services that are engaging, as user engagement is the strongest predictor of both a positive online experience as well as educational effectiveness. eHealth designers are therefore advised to primarily focus on designing interactions that maximize user engagement to increase the impact of their solutions.

Future research

There are unanswered questions regarding the extent to which patient profiles are stable over time. Findings from this dissertation show that although three profiles adequately represent the orthopaedic population both before and after surgery, it is unknown whether individual patients change profiles during the healthcare process, and if so, why and when this happens. This question requires more (longitudinal) research. The finding that tailored care does not unequivocally improve the patient experience but does assign an individual to a profile also raises questions regarding equity and autonomy. For example, is it acceptable to only treat patients of a certain profile when a healthcare service shows the best results in that group? And should the assignment of a patient to a profile - and thus to a certain healthcare service - always be done by an expert, or is it also possible to provide patients say in the tailoring process?

The discussion of this dissertation provides two recommendations on these topics. First of all, it is recommended to recognize allocation (of a patient to profile, and therefore to a product or service) as an explicit step in the patient profiling process. By allocating individual patients, creative and medical specialists make important choices that may influence equity. Secondly, the paradigm of libertarian paternalism may offer a solution to provide patients with more autonomy in tailored care without overwhelming patients with many choice options. Yet, future research is needed to determine to what extent this paradigm is actually useful in the design of tailored healthcare services.

Conclusion

Three unique and consistent patterns represent how different orthopaedic patients experience their own health, deal with the pain and stress of major surgery, and wish to communicate with their healthcare providers. Insight into these profiles is relevant for both orthopaedic healthcare provides who wish to tailor their care closer to the needs of individual patients and designers who want to design healthcare services that better match the preferences, needs, and competences of a diverse group of patients.

SAMENVATTING

Datagedreven patiëntprofielen

Definitie, validatie en implementatie voor orthopedische gezondheidszorg op maat

Zorginstellingen bieden veelal gestandaardiseerde zorg aan. Dit wordt gedaan om de veiligheid en kwaliteit van zorg te waarborgen. Tegenwoordig is er echter ook veel vraag naar zorg op maat; een manier van zorg verlenen waarbij juist rekening wordt gehouden met de voorkeuren, behoeften, en vaardigheden van elke unieke patiënt. Dit proefschrift onderzoekt het fenomeen zorg op maat in de context van orthopedie. In het bijzonder is gekeken naar patiënten die een gewrichtsvervangende operatie van het heup- of kniegewricht hebben ondergaan, omdat deze patiëntengroep relatief ontevreden is over de huidige – gestandaardiseerde – manier waarop zij zorg ontvangen. Specifiek de communicatie tussen arts en patiënt (o.a. de manier waarop patiënten worden geïnformeerd over de operatie, de risico's en het behandelplan, maar ook de emotionele support die zij krijgen van zorgverleners) laat nogal eens te wensen over. Er wordt verwacht dat het aanbieden van zorg op maat deze patiëntervaring kan verbeteren.

Als handvat om zorgverleners, ontwerpers, en patiënten samen over zorg op maat te laten nadenken richt dit proefschrift zich specifiek op het definiëren, valideren, en implementeren van zogeheten *patiëntprofielen*. Patiëntprofielen beschrijven de gemeenschappelijke kenmerken van een unieke subgroep patiënten. Het werken met subgroepen (de patiëntprofileringsaanpak) is afgeleid van *mass customization*, een ontwerpaanpak die veronderstelt dat men diensten op maat kan ontwerpen door inzicht te krijgen in de unieke en gemeenschappelijke voorkeuren, behoeften, en vaardigheden van verschillende groepen mensen. De nieuwe diensten die uit dit ontwerpproces voortvloeien kunnen vervolgens weer aan individuele patiënten met een overeenkomend profiel worden aangeboden, waardoor zorg op maat ontstaat.

Dit proefschrift onderzoekt patiëntprofielen en het effect van de patiëntprofileringsaanpak op patiëntervaring aan de hand van vier vragen: (1) wat zijn relevante patiëntkenmerken om patiëntprofielen op te definiëren?, (2) welke patiëntgroepen kunnen met behulp van data onderscheiden worden?, (3) welke orthopedische diensten zijn geschikt om op maat te worden ontworpen, en (4) wat is het effect van zorg op maat op de patiëntervaring?

Deze vragen worden overkoepelend behandeld vanuit het biopsychosociaal model. Dit model gaat er van uit dat zowel biomedische factoren (zoals pijn en fysiek functioneren) als psychologische factoren (zoals de manier waarop iemand met pijn en stress omgaat) als sociale factoren (zoals communicatievoorkeuren en -vaardigheden) beïnvloeden hoe iemand een ziekte ervaart en dus wat voor zorg bij hem of haar past. Een combinatie van onderzoeksmethoden waaronder observaties, interviews, vragenlijsten, *machine learning,* systematische literatuur reviews en experimenten zijn vervolgens toegepast om de specifieke onderzoeksvragen te beantwoorden.

Wat zijn relevante patiëntkenmerken om patiëntprofielen op te definiëren?

Uit observaties van en interviews met 7 orthopedisch chirurgen (Hoofdstuk 2) en vragenlijstonderzoek onder 191 patiënten (Hoofdstuk 3) bleek dat de communicatievoorkeuren, psychologische copingmechanismen, en eigen ervaring van gezondheid van orthopedisch patiënten onderling sterk verschillen. De relevantie van deze kenmerken werd bevestigd door vier bevindingen: orthopedisch chirurgen gebruiken deze kenmerken reeds informeel in de praktijk om het orthopedisch consult aan te passen aan verschillende patiënten, patiënten gaven zelf aan op deze dimensies te verschillen, de data wees uit dat op deze dimensies de grootste verschillen bestonden, en de score van een patiënt op deze kenmerken was voorspellend voor diens tevredenheid over (gestandaardiseerde) arts-patiënt communicatie. In een later validerend onderzoek onder 235 gezondheidsconsumenten met onbehandelde gewrichtsklachten (Hoofdstuk 4) werd hetzelfde gevonden.

Uiteindelijk bleken 9 patiëntkenmerken het meest relevant en deze vormen de basis van het patiëntprofiel: eigen ervaring van gezondheid (gemeten als zelf-gerapporteerde gezondheidsstatus, ervaren pijn bij beweging, leeftijd, en neiging tot angst), psychologische copingmechanismen (gemeten als neiging tot het catastroferen van pijn en het actief zoeken van support bij pijn en ziekte), en communicatievoorkeuren en -vaardigheden (gemeten als de voorkeur voor open communicatie en de vaardigheid in kritische communicatie richting arts). Deze kenmerken zijn opgenomen in een instrument dat het meest waarschijnlijke profiel van een patiënt met 80% zekerheid kan voorspellen.

Welke patiëntgroepen kunnen met behulp van data onderscheiden worden?

Op basis van de hierboven beschreven patiëntkenmerken zijn drie patiëntprofielen gedefinieerd (Hoofdstuk 3) en gevalideerd (Hoofdstuk 4) door middel van clusteranalyse en *machine learning*. De patiëntprofielen vertegenwoordigen drie unieke manieren waarop (toekomstig) orthopedische patiënten hun eigen gezondheid ervaren, omgaan met het vooruitzicht en de nasleep van een grote operatie, en hoe zij hierover willen communiceren met hun zorgverleners.

Het eerste profiel (44% van de behandelde patiënten en 24% van de toekomstige patiënten) gebruikt een diverse set aan copingmechanismen, waaronder het actief zoeken van emotionele en instrumentele support bij anderen. Deze patiënten willen actief participeren in de arts-patiënt communicatie en verwachten open informatievoorzieningen. Gemiddeld hebben zij hogere communicatievaardigheden, maar zien ze zichzelf als minder gezond. Dit profiel is het *managing* profiel genoemd, gelet op de hoeveelheid en diversiteit van bronnen die deze patiënten aanboren om het zorgproces zelf te managen en de hoge standaard die zij zetten voor arts-patiënt communicatie.

Het tweede profiel (32% van de behandelde patiënten en 42% van de toekomstige patiënten) wordt gekenmerkt door een hogere ervaren gezondheid, lagere neiging tot angst en beperkt gebruik van copingmechanismen. Zij bezitten goed ontwikkelde communicatievaardigheden maar vinden arts-patiënt communicatie een minder belangrijk onderdeel van de zorg. Dit profiel is het *optimistisch* profiel genoemd omdat deze patiënten weinig extra zorgbehoeften lijken te hebben zelfs wanneer zij een potentieel stressvolle gebeurtenis als een operatie ondergaan. Deze patiënten zijn het meest tevreden met huidige (gestandaardiseerde) arts-patiënt communicatie en ervaren de beste gezondheidsuitkomsten na de operatie.

Het derde profiel (24% van de behandelde patiënten en 34% van de toekomstige patiënten) schat zijn of haar gezondheid lager in en heeft een grotere neiging tot angst en tot het catastroferen van pijn. Deze patiënten hebben slechtere communicatievaardigheden maar vinden zowel open communicatie als emotionele support belangrijke aspecten van arts-patiënt communicatie. Dit profiel is het *bescheiden* profiel genoemd, omdat deze patiënten wel specifieke behoeften hebben maar deze minder gemakkelijk uitdrukken. Deze patiënten behalen minder goede resultaten na de operatie en zijn het minst tevreden over huidige (gestandaardiseerde) arts-patiënt communicatie.

Welke orthopedische diensten zijn geschikt om op maat te worden ontworpen?

In plaats van een uitputtende review naar alle verschillende orthopedische zorgdiensten die mogelijk geschikt zouden zijn voor zorg op maat gaat deze thesis in op de geschiktheid van een specifieke dienst: patiënteducatie programma's die via het internet aangeboden worden. Tien verschillende online patiënteducatie programma's werden vergeleken met elkaar en met reguliere patiënteducatie programma's op behaalde gezondheidsuitkomsten en patiëntervaring (Hoofdstuk 5).

Online patiënteducatie bleek een dienst te zijn waarvan veel verschillende aspecten kunnen worden aangepast op zowel microniveau (bijvoorbeeld interfaceontwerp) als macroniveau (bijvoorbeeld in hoeverre zorgverleners worden betrokken). Helaas zijn de huidige (gestandaardiseerde) programma's voornamelijk geschikt voor een beperkte groep patiënten: zij die jonger en hoger opgeleid zijn en goed ontwikkelde online vaardigheden hebben. Desondanks verbeteren online patiënteducatie programma's alsnog de patiëntervaring in vergelijking met reguliere patiënteducatie.

Patiënteducatie programma's die via het internet aangeboden worden zijn dus aanpasbaar en verbeteren de patiëntervaring, maar bereiken nog niet de volledige patiëntpopulatie. Dit maakt online patiënteducatie binnen orthopedie geschikt voor zorg op maat. De criteria aanpasbaarheid, impact, en huidige inclusiviteit kunnen worden meegenomen om andere diensten op hun geschiktheid voor zorg op maat te evalueren.

Wat is het effect van zorg op maat op patiëntervaring?

Voortbouwend op de resultaten van de systematische review uit Hoofdstuk 5 is een gerandomiseerd experiment uitgevoerd naar het effect van een op maat gemaakt online patiënteducatie programma op patiëntervaring (Hoofdstuk 6). Specifiek is de structurele indeling en organisatie van de informatie op de website (oftewel, de informatie-architectuur) aangepast om aan de voorkeuren, behoeften, en vaardigheden van de drie profielen te voldoen. De resultaten lieten zien dat patiënten over het algemeen een voorkeur hadden voor een matrix- of tunnel-indeling, maar dat patiënten met een *managend* profiel meer tevreden waren over de tunnel-indeling dan alle andere patiënten.

Deze match tussen *managende* patiënten en de tunnel-indeling was echter niet op voorhand voorzien. Daarnaast leverde het online patiënteducatie programma slechts een kleine verbetering in patiëntervaring op ten opzichte van gestandaardiseerde patiënteducatie programma's. Dit wijst erop dat zorg op maat potentieel een positief effect heeft op de patiëntervaring, maar dat het ontwerpen van zorg op maat niet eenvoudig is.

Implicaties van de bevindingen

Dit proefschrift laat zien dat drie patiëntprofielen gebruikt kunnen worden om de orthopedische patiënt te vertegenwoordigen en zorgdiensten te ontwikkelen die beter passen bij de voorkeuren, behoeften en vaardigheden van verschillende patiënten. Elk patiëntprofiel representeert een groep patiënten met hun eigen kenmerken en uitdagingen.

Doordat de profielen met behulp van data zijn ontwikkeld bieden zij een empirisch alternatief voor persona's aan ontwerpers in de gezondheidszorg. Ontwerpers kunnen aan de slag met zorg op maat door bestaande diensten aan te passen aan de kenmerken en behoeften van de drie patiëntprofielen. Zorg op maat lijkt in het bijzonder nodig voor de groep patiënten met een *bescheiden* profiel. Deze patiënten zijn zowel minder tevreden over communicatie en ervaren (mogelijk daardoor) slechtere fysieke en psychologische uitkomsten na de operatie. Deze relatie is nog niet eerder expliciet aangetoond binnen orthopedie en laat zien hoe de biopsyschosociale patiënt profielen een aanvulling vormen op bestaande biomedische segmentatie modellen.

Vervolgonderzoek

Een nog onbeantwoorde vraag is in hoeverre patiëntprofielen stabiel zijn over tijd. Bevindingen uit dit proefschrift laten zien dat drie profielen weliswaar de populatie zowel voor als na de operatie adequaat vertegenwoordigen, maar het is onbekend of individuele patiënten gedurende het zorgtraject wisselen van profiel, en zo ja, waardoor en wanneer dit gebeurt. Hiervoor is meer (longitudinaal) onderzoek nodig.

Daarnaast werd gevonden dat zorg op maat niet eenduidig zorgt voor een verbeterde patiëntervaring. Dit dient verder onderzocht te worden. In het bijzonder moet worden afgevraagd of de effectiviteit van zorg op maat in verhouding staat tot mogelijke beperkingen in kansengelijkheid en autonomie. Bijvoorbeeld, is het geoorloofd om alleen patiënten van een bepaald profiel te behandelen wanneer een gezondheidsdienst de beste resultaten toont in die groep? En moet het toewijzen van een patiënt aan een profiel – en hiermee aan een bepaalde manier van zorg verlenen – altijd gebeuren door een expert of een systeem, of is het ook mogelijk om patiënten hier inspraak in te geven?

De discussie van dit proefschrift geeft hierover twee adviezen. Allereerst wordt aangeraden om toewijzing (van patiënt aan profiel, en daarmee aan product of dienst) te erkennen als een expliciete stap in het patiëntprofilering proces. Door het toewijzen van individuele patiënten maken ontwerpers en medisch specialisten namelijk belangrijke keuzes die kansengelijkheid mogelijk beïnvloeden. Ten tweede biedt het paradigma van libertair paternalisme mogelijk een uitkomst om patiënten meer inspraak te geven over wat zorg op maat voor hen inhoudt, zonder ze te overweldigen met vele keuzemogelijkheden. Vervolgonderzoek is nodig om aan te wijzen in hoeverre dit paradigma werkelijk bruikbaar is in het ontwerpen van zorg op maat.

Conclusie

Drie unieke en consistente patronen beschrijven hoe verschillende orthopedische patiënten hun eigen gezondheid ervaren, omgaan met pijn en stress rond een operatie, en willen communiceren met hun zorgverleners. Inzicht in deze profielen is relevant voor zowel orthopedische zorgverleners die hun zorg meer op maat willen aanbieden als ontwerpers die gezondheidszorgdiensten willen ontwerpen die beter aansluiten op de voorkeuren, behoeften, en vaardigheden van een diverse groep patiënten.

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ABOUT THE AUTHOR

Tessa Dekkers was born on the 6th of October 1991 in Utrecht, the Netherlands. She attended high school (Gymnasium Bernrode) from 2003 to 2009. In 2009, she moved to Nijmegen to study Psychology at the Radboud University Nijmegen. During that time she also attended the Radboud Honours Academy, where her interest in interdisciplinary research emerged as she learned of mathematics in music and politics in the Divine Comedy. In 2015, she completed a Research Master in Social and Health Psychology at Utrecht University, with a thesis focussed on self-control (and the need to redesign dessert menus). Now fully drawn towards the cross-section between psychology and design, she started her PhD at the Industrial Design Engineering faculty of Delft University of Technology in 2015. Here she worked within the project Tailored Healthcare through Customer Profiling, an interdisciplinary effort to provide patients with a design-based, personalized approach to joint replacement surgery.

Tessa has presented her work on patient experience and healthcare design in various journals and international conferences. In 2018, her work was rewarded with an outstanding poster award at the 32nd conference of the European Health Psychology Society. She has also put effort in teaching engineers interested in psychology and health, from Massive Open Online Courses on patient journey mapping to an introductory course on health psychology for designers at Delft University of Technology. Currently, she is a lecturer at the department of Psychology, Health and Technology at the University of Twente.

LIST OF PUBLICATIONS

Journal articles

Dekkers, T., & Hertroijs, D. F. L. (2018). Tailored healthcare: Two perspectives on the development and use of patient profiles. *Advances in Therapy*, 35(9), 1453–1459. doi: 10.1007/s12325-018-0765-2

Dekkers, T., Melles, M., Groeneveld, B. S., & de Ridder, H. (2018). Web-based patient education in orthopaedics: A systematic review. *Journal of Medical Internet Research*. doi: 10.2196/jmir.9013

Dekkers, T., Melles, M., Mathijssen, N. M. C., Vehmeijer, S. B. W., & Ridder, H. de. (2018). Tailoring the orthopaedic consultation: How perceived patient characteristics influence surgeons' communication. *Patient Education and Counseling*, 101(3), 428–438. doi: 10.1016/j.pec.2017.08.018

Groeneveld, B. S., Dekkers, T., Boon, B., & D'Olivo, P. (2019). Challenges for design researchers in healthcare. *Design for Health*, 1–22. doi:10.1080/24735132.2018.1541699

Groeneveld, B., Melles, M., Vehmeijer, S., Mathijssen, N., Dekkers, T., & Goossens, R. (2019). Developing digital applications for tailored communication in orthopaedics using a Research through Design approach. *Digital Health*, 5, 1-14. doi:10.1177/2055207618824919

Kwasnicka, D., Inauen, J., Nieuwenboom, W., Nurmi, J., Schneider, A., Short, C. E., Dekkers, T., Williams, A. J., Bierbauer, W., Haukkala, A., Picariello, F., & Naughton, F. (2019). Challenges and solutions for N-of-1 design studies in health psychology. *Health Psychology Review*, 1–36. doi:10.1080/17437199.2018.1564627

de Ridder, E., Dekkers, T., Porsius, J. T., Kraan, G., & Melles, M. (2018). The perioperative patient experience of hand and wrist surgical patients: An exploratory study using patient journey mapping. *Patient Experience Journal*, 5(3), 97–107. https://pxjournal.org/journal/vol5/iss3/13

van Smoorenburg, A., Hertroijs, D., Dekkers, T., Elissen, A., & Melles, M. (2019). Patients' perspective on self-management: Type 2 diabetes in daily life. *BMC Health Services Research*, 19:605. doi: 10.1186/s12913-019-4384-7

Conference presentations (abstracts)

Dekkers, T., Groeneveld, B., Melles, M., Mathijssen, N., Vehmeijer, S., & de Ridder, H. (2018). Communication, coping, and clinical status: A holistic perspective on TJA patients to improve satisfaction. Presented at the 13th congress of the *European Hip Society*, The Hague, NL.

Dekkers, T., Melles, M., Groeneveld, B., Mathijssen, N., Vehmeijer, S., & de Ridder, H. (2018). From empirical data to tailored design: Role-based patient representations. Presented at the 20th congress of the *International Ergonomics Association*, Florence, IT.

Dekkers, T., Melles, M., Groeneveld, B., Porsius, J., Mathijssen, N., Vehmeijer, S., & de Ridder, H. (2018). Classification of patients by clinical, psychological, and communication characteristics: Patient profiles for personalized care. Presented at the 32nd annual conference of the *European Health Psychology Society*, Galway, IR.

Dekkers, T., Melles M., Mathijssen, N.M.C., Vehmeijer, S.B.W., & de Ridder, H. (2017). Intuitive tailoring in medical consultations: How perceived patient characteristics influence physicians' communication. Presented at the 31st annual conference of the *European Health Psychology Society*, Padova, IT.

Dekkers, T., Melles, M., Vehmeijer, S. B. W., & de Ridder, H. (2019). Information Architecture: A design feature to improve patients' satisfaction with online health education interventions. Presented at the 33rd annual conference of the *European Health Psychology Society*, Dubrovnik, KR.

Dekkers, T., de Ridder, H., Mathijssen, N.M.C., & Melles, M. (2016). Do physicians tailor their communication during medical consultations? Presented at the 5th conference of *Health Ergonomics and Patient Safety*, Toulouse, FR.