Design speaks

Improving patient-centeredness for older people in a digitalizing healthcare context

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Chapter 1

General introduction

This thesis explores the ways in which patient-centeredness for older people can be improved within a digitalizing healthcare context. The first section of this introduction provides background information on the developments of internet usage on computers and mobile smart devices with regard to digitalization in healthcare, and eHealth specifically. It addresses patient portals and mobile health (mHealth) as significant and exponentially evolving eHealth technologies in relation to patient-centeredness. The second section of this introduction provides background information on the aging population and explains why specifically older people are a target group for patient portals and mHealth. The third section describes the challenges regarding eHealth for older patients and addresses the relevancy of this thesis in focusing on those challenges. It explains the need and significance of the studies performed in this thesis within the context of improving patient-centeredness for older people. Then the aims of this thesis are presented, lastly followed by the outline of this thesis. Key terms used in this thesis are explained in Table 1 of this introduction. To indicate that a term can be found in Table 1, the term will be *italicized* when it is first mentioned.

Digitalizing healthcare context in relation to patient-centeredness

In 2017, 84% of households in developed countries had access to the internet [1]. At that time, even 98% of Dutch households had internet access via a broadband connection and 87% of the Dutch population was connected to the internet via mobile (smart) devices, such as smartphones and tablets [2]. From 2012 to 2017, mobile-broadband subscriptions have grown more than 20% annually; up to 4.3 billion globally at the end of 2017 [1]. This proliferation and adoption of internet usage on computers and mobile smart devices have made an impact on society. For instance, information on any given topic is made more accessible. People are further able to shop online, they can participate in politics, journalism or culture and people can form communities to share experiences. The basic functionalities of mobile smart devices, such as high quality imaging, video streaming, location services and internet access, make it possible to do so at any location or time. The possibility to use such internet and mobile smart devices is given a pivotal role in the domain of healthcare as well. These technologies have the potential to improve people's health as well as efficiency and productivity in healthcare and therefore have strengthened the attention to *patient-centeredness*. Patient-centered care aims to tailor care and related decisions to the individual patient's needs and desired health outcomes, in which shared knowledge between the patient and provider is an important aspect [3-4]. In its Health 2020 report, the World Health Organization's regional office for Europe (WHO EU) mentions patient-centeredness as one of their four priority areas for policy action [5]. To do so, the WHO EU advises to make full use of the 21st-century tools and innovations, digital patient records and *eHealth* [5].

The attention for technological changes that can enable new forms of patient-participation and patient-centeredness, is not new. With the internet becoming available to the public in

the 1990s, medical and health topics were among the most searched-for subject matters [6]. To provide patients with ownership and control of their own medical data and as a communication and decision support tool, *patient portals* were first introduced in the United States (US) by a few large healthcare organizations [7-8]. In the following years several vendors and healthcare organizations aimed to place the patient at the center of healthcare data exchange and introduced patient portals or personal health record systems [9]. Coinciding with the rise of daily internet usage on computers and the introduction of mobile smart devices around 2007, patient portals became more widespread [7]. From then onwards and stimulated by government programs such as the Meaningful Use program in the US and the eHealth action plan as well as the Acceleration Program Information Exchange Patient and Professional in The Netherlands [10-11], patient portals are increasingly being developed, implemented and evaluated [7]. Within the continuously evolving field of eHealth from the late 1990s up till now, these portals remain one of the main pillars of eHealth. New developments in the field of eHealth have additionally emerged with the popularity of *mHealth*, which is growing at a fast pace. At the start of this PhD research in November 2014, there were approximately 100,000 mHealth apps available for Android and iOS [12]. At the end of 2017, this number had grown to 325,000 mHealth apps and this growth is ongoing with approximately 25% per year [13]. The features of these mHealth services are vast, ranging from video communication between patients and healthcare institutions to (automatically) monitoring biometrics of patients. Therefore, mHealth is assigned the potential to assist patients to more actively engage in the management of their care [14].

In summary, the digitalizing healthcare context is typified by the vast supply of eHealth innovations, with patient portals and mHealth as two main and rapidly expanding domains of such health information technologies. These technologies are seen as meaningful to the delivery of patient-centered care, since they can provide medical data to patients and support information sharing and patient/provider interaction that is specific to individual patients' needs and preferences or needs of groups of patients [15-16]. Thereby, these technologies can likewise facilitate the sharing of knowledge between patients and their provider(s). This thesis especially focusses on patient portals and mHealth in relation to tailoring these services to patients' needs, in specific for the older patient group.

mHealth, patient portals and the aging population

Our populations are aging [16-17]. In 2016, 39% of the total Dutch population consisted of people aged 50+ [18-19]. There were almost 3.1 million people aged 65+; 18% of the total Dutch population [18], of which more than 25% were living alone [20]. In addition, it is expected that in the next 25 years the older population in Japan, Italy and Spain will cover more than 40% of their total populations [17]. In Australia the older population is expected to cover more than 25% by then [17]. In the US the older population is expected to more than

double in size in the next 25 to 35 years [21]. Due to these aging populations, our societies face various health and socio-economic challenges [16]. More than 60% of people aged 65+ has one or more chronic conditions [22-23]. Examples of common chronic conditions are diabetes mellitus, heart failure or chronic obstructive pulmonary disease (COPD). To give an indication, diabetes is prevalent in 22% to 33% of older people in the US [24], 16% to 20% of people aged 65+ in Europe and more than 88 million Chinese people aged 60+ have diabetes [25-26]. Chronic conditions generally require long-term treatment consisting of multidisciplinary teams, possibly working at multiple healthcare provider organizations, that all need to communicate with patients as part of patient care along the whole continuum of diagnosis, treatment planning and follow-up care. To manage their disease, chronically ill patients have to attend a variety of consults, that are accompanied by administrative tasks, and undertake health-related measures as part of their treatment plan. A challenge that consequently arises is that patients and their relatives need to adapt their lives to the treatment and management of the patient's disease and medical condition [23]. This can include clinical aspects as well as communication aspects; respectively monitoring symptoms, regulating medication intake and maintaining physical exercise as well as overseeing the planning of appointments and interactions with healthcare providers. An additional challenge related to patients with chronic conditions is their high impact on expenditures within healthcare: 70%-80% of costs are spent on chronic conditions [23]. Combined with the aging populations, this creates the pressure to lower the expenditures within healthcare.

The pivotal role that is attributed to eHealth, including mHealth and patient portals, to place patients at the center of care, tailor care to their individual needs and share their medical data with them, is especially relevant within this aging population context. *Older adult* patients are a main target group for mHealth apps, because of the assistance that these apps can provide to these older patients, especially to chronically ill patients. The apps may for example provide medication assistance by prompting alerts or they can be used to monitor physical activity and vital biometrics of older and chronically ill patients to avoid emergency situations [16, 27]. Patient portals can be specifically beneficial for (older) patients with a chronic condition as well, since the type of features offered via portal can support them in monitoring and managing their health [28]. For example, access to personal health information, such as laboratory test results and appointment information, as well as digital opportunities to request medication refills or communicate with their provider can assist these (older) patients in accomplishing health-related and administrative tasks in the management of their disease [28]. In addition to these benefits for patients, healthcare organizations aim to lower hospitalizations and hospital visits by means of patients' usage of mHealth and patient portals, thereby reducing the financial burden on their healthcare facilities [16].

Taken together, eHealth is ascribed the potential to be a facilitator to patient-centered care for the aging population. The examples of mHealth and patient portals described above show the variety of functionalities offered to older patients via these relatively new technologies. These functionalities are continuously evolving within the fast pace of developing these technologies. From the perspective of patient-centered care, tailored to what patients need and prefer, it is evident to assess the aptness of these technological developments in relation to older patients' needs and preferences. More understanding is needed on the balance between these rapid developments of eHealth and older patients' contexts. Such an understanding can be gained via a *user-centered design* (UCD) approach; an approach that aims to place the patient at the center of the design and development process of eHealth [29]. The research reported in this thesis therefore approached patient-centeredness from the perspective of UCD in gaining more insights on how eHealth fits older patients' needs and contexts.

Challenges of eHealth for older patients and relevancy of this thesis

The adoption of digitalization in society can facilitate the willingness of older people to use eHealth. Nevertheless, even though older patients are showing more interest in eHealth, adoption of eHealth by this target group remains low to this date. As is described in previous research, for technologies to be successfully used by older patients, *usability* and *technology acceptance* by these patients is of critical importance [16, 30-31]. However, within the constantly evolving technical landscape of eHealth and its promising functionalities, a UCD approach is often overseen in the development of these technologies. This challenges the fit of these technologies to older patients' capabilities and needs. This challenge becomes apparent in studies on mHealth, stating that especially older people experience usability problems in its use [26, 32]. What is less clear is the nature of these experienced usability problems by older people and the influence of aging characteristics on the user-experience of mHealth technologies. Current studies regarding patient portals further show that despite portals' long existence, they still fail to be appropriately designed for older patients' actual contexts of use [33-35]. To improve patient-centeredness for older patients by means of mHealth and patient portals, it is thus important to respectively design mHealth interfaces that optimally support the user-experience of older patients as well as to adjust the design and functionalities of patient portals to older patients' user-contexts. This thesis therefore makes a contribution to these matters: it presents knowledge on aging barriers that may influence usability of mHealth interfaces and addresses how to use this knowledge in improving mHealth interface designs for older patients. It further reports on older patients' user-contexts of patient portals. This allows for new insights to emerge on how older patients may want to receive medical information, interact and communicate via mHealth and patient portals with their healthcare providers; insights that can progress our knowledge on what patient-centeredness entails for older patients in a digital setting.

Another key challenge regarding eHealth for older people is rooted within the research methodologies used to examine eHealth on effectiveness. Effectiveness of eHealth is of major importance for older adult patients as they are a key user group. UCD approaches have shown that *Human Factor* aspects may positively or negatively influence health information technologies' effectiveness [29, 36]. So far, little attention has been paid to the appropriateness of research methodologies used to examine these Human Factor aspects for older patients with regards to eHealth. It thus remains unclear if these methodologies are suitable to specifically uncover aging characteristics and needs to older patients' eHealth use and how these influence eHealth's effectiveness for older patients. The relevancy of this thesis on these issues is that it provides recommendations to improve research methods used to develop and evaluate eHealth, specifically from the perspective of UCD for the older patients user group. By improving these methods and making them more adaptive to the aging characteristics of older patients, study outcomes on older patients' needs, capacities and contexts regarding eHealth use will be of greater accurateness, which ultimately improves patient-centeredness for older patients on this matter.

Aims of this thesis

The overall aim of this thesis is to improve patient-centeredness for older patients within the development and evaluation of eHealth, with a specific focus on mHealth and patient portals. In particular, the aims are to:

1. Synthesize knowledge on older adults' use of mHealth and patient portals to provide a structured overview of barriers and facilitators identified in scientific literature;
   (chapters 2 and 4)

2. Validate identified barriers and facilitators by means of case studies with (chronically ill) older adults to get sight on actual factors influencing mHealth's and patient portals' development and use
   (chapters 3, 5 and 6)

3. To explore user-centered design methods with older adult patients to enhance eHealth's effectiveness for this patient group;
   (chapters 7 and 8)

4. To provide clear recommendations on how to involve older adult patients in eHealth's development and evaluation.
   (chapters 9 and 10)

Outline of this thesis

Part 1: Current mHealth designs for older adult patients

Part 1 starts with **chapter 2**, which provides the results of a synthesis of the literature on aging barriers and complexities of medical conditions that may hamper user-experience of older adult patients with mHealth. We present the framework 'mHealth for older users', MOLD-US, to visualize these barriers and complexities of medical conditions in a centralized and accessible overview. **Chapter 3** reports on two case studies of mHealth apps for older adult patients. These apps were assessed on usability problems that older patients encountered. We applied MOLD-US as a classification framework to analyze these issues and show the value of MOLD-US in identifying intrinsic aging causes to usability problems.

Part 2: Patient portal use by older adults

Part 2 starts with **chapter 4,** describing a synthesis of the literature on the barriers and facilitators to patient portal use by older adults. By using the Unified Theory of Acceptance and Use of Technology (UTAUT) as a classification model for those factors, we thematically clustered the barriers and facilitators and enable a comparison in time of patient portal usage or with other technologies. **Chapter 5** proceeds with a case study exploring patient experiences with a patient portal implemented at the Amsterdam University Medical Center (Amsterdam UMC, location AMC). We report the scope of the older patient user group for various age clusters. We further report on older adult patients' experiences with the portal, one year after its implementation, to evaluate validity of the identified barriers and facilitators in literature to patient portal use by older adult patients. **Chapter 6** evaluates the validity of these barriers and facilitators as well; this cross-sectional study is performed with chronically ill patients of two large Dutch patient associations. Their perspectives on the use of patient portals in general are analyzed, as they are one of the main target groups of patient portals. We have used a conjoint analysis approach, in order to get sight on which functionalities these patients valued as most important for using a patient portal.

Part 3: Patient-centered eHealth research for older adults

Part 3 starts with **chapter 7**, which reports the results of a literature study on the effectiveness of patient-centered eHealth applications regarding patient outcomes. We applied a UCD approach by using the Systems Engineering Initiative for Patient Safety (SEIPS 2.0) model to examine whether (aging) patient user-context factors were taken into account in the studies assessing effectiveness of these applications. In **chapter 8** we specifically reflect on the challenges of assessing contextual factors influencing evaluation research on eHealth and patient portals including older patients. It provides a comprehensive overview of methodological considerations to advance participation of older patients to patient portal research and development in order to improve these patients' health outcomes. **Chapter 9** subsequently proposes several approaches to tackle those challenges, particularly related

to user-testing of mHealth, eHealth and medical devices for older patients. This thesis ends with **chapter 10**, the discussion and conclusion. It provides an overview of principle findings of this thesis and discusses these within the perspective of improving patient-centeredness for older people in a digitalizing healthcare context. Practical implications and recommendations for future research are given based upon key learnings of the studies in this thesis.

Table 1: *Definitions of key terms used in this thesis, per theme*

Term	Definition
Technologies	
eHealth (electronic health)	eHealth is defined by the European Commission as: "the use of ICT in health products, services and processes combined with organizational change in healthcare systems and new skills, in order to improve health of citizens, efficiency and productivity in healthcare delivery, and the economic and social value of health. eHealth covers the interaction between patients and health-service providers, institution-to-institution transmission of data, or peer-to-peer communication between patients and/or health professionals" [37]
mHealth (mobile health)	This thesis combines the definitions of mHealth given by the World Health Organization and the National Institutes of Health Consensus Group: "mHealth is an area of electronic health (eHealth) and it is the provision as well as usage of health services and information via mobile and wireless technologies to improve health outcomes, healthcare services and health research" [38-39]. This thesis therein focuses on mHealth for patients.
Patient portal	Patient portals are secure online information systems that provide patients and/or their proxy with access to personal health information [15, 40], such as laboratory test results and appointment information, as well as digital messaging between patients and providers. The foremost type of a patient portal is the tethered patient portal. A tethered patient portal is an application build on an Electronic Health Record (EHR) infrastructure of a specific healthcare organization [41]. The tethered patient portal differs from for example a personal health record, in which the patient can collect health data and he/she decides whether to share that data with providers or family members.
Age	
Elderly	People aged 65+. See further explanation at 'older adults'.
Older adults	The age ranges that have been studied in scientific research on older adult people vary, starting from 50+, 60+ or 65+; there is no fixed consensus on the definition of 'older adults'. As risks for a (severe) decline in visual abilities increase from the age of approximately 50 years and onwards [42], which is of importance i.r.t. technology use, and studies on older adults' technology use start from 50+, this thesis defines the term 'older adults' as people aged 50+. The terms used for other age clusters are: 'seniors' or 'elderly' for people aged 65+, 'middle-aged adults' for people aged 40-50 years and 'younger adults' for people aged 18-40 years.
Seniors	People aged 65+. See further explanation at 'older adults'.

Methodological concepts	
Human Factors	'Human factors' (HF) is the scientific discipline that examines the relationship between persons, organizations and the (technological) systems with which they interact by focusing on improving efficiency, creativity, productivity and (user) satisfaction, with the goal of minimizing errors [43-44]. In the HF engineering profession knowledge on human capacities, skills, needs and limitations is used to design products or systems that fit these human abilities and barriers. HF principles and methods are used to uncover hidden needs, assumptions and unexpected interactions, such as usability testing and user-centered design approaches.
Patient-centeredness	Patient-centeredness aims to "deliver care that is respectful, individualized and empowering. It implies the individual participation of the patient and is built on a relationship of mutual trust, sensitivity, empathy and shared knowledge" [3], as is described in the concept analysis review by Castro et.al. on patient-centeredness, patient-participation and patient-empowerment. In patient-centered care, the individual patient's needs and desired health outcomes are of crucial importance in relation to healthcare decisions.
Technology acceptance	Technology acceptance of users is multidisciplinary; psychological factors such as a user's attitude and beliefs towards technology, as well as user characteristics, such as age, influence if a user will accept and use a technology [45]. Technology acceptance (accepting to use a technology and willingness to use a technology) differs from technology adoption, where a user actively engages with the technology over a longer period of time.
Usability	Usability is explained by Nielsen, an authority within the field of usability, as: "a quality attribute that assesses how easy user interfaces are to use. The word "usability" also refers to methods for improving ease-of-use during the design process. Usability is defined by 5 quality components: *Learnability*: How easy is it for users to accomplish basic tasks the first time they encounter the design? *Efficiency:* Once users have learned the design, how quickly can they perform tasks? *Memorability:* When users return to the design after a period of not using it, how easily can they reestablish proficiency? *Errors:* How many errors do users make, how severe are these errors, and how easily can they recover from the errors? *Satisfaction*: How pleasant is it to use the design?" [46].
User-centered design (UCD)	User-centered design (UCD) focusses on the user as the heart of the design approach, instead of placing the technology or the idea at the center of the design process [29, 47]. Design does not focus purely on aesthetics; it is a process in which the user's interaction with the environment or system are made more natural and complete [47]. A UCD process focusses on users throughout the planning, design, development and evaluation of a product or system. According to the ISO 9241-210:2010 standards, the UCD process consists of four main activities: to understand and specify the context of use, to specify the user requirements, to produce design solutions and to evaluate design against requirements [48]. These activities form the basis for designing usable systems that increase the chances of successful system implementation and adoption [49].

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