From dialogue to decision

Using technology to facilitate shared decision-making in a fall prevention context

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CHAPTER 1

General introduction

General Introduction

This dissertation investigates the role that technology can play in providing personalized treatment advice and facilitating shared decision-making (SDM) in doctor-patient conversations. Both artificial intelligence (AI) and other forms of technology hold considerable potential to improve the quality of healthcare by enhancing safety, efficiency, and effectiveness (Shekelle et al., 2006). This is crucial given the imminent shortage of healthcare professionals and the ever-increasing demand. In addition, technology can facilitate and enhance communication processes, such as SDM (Davis et al., 2017; Jones et al., 2011). SDM is a communication process during which healthcare professionals and patients make health-related decisions together, reflecting medical evidence, treatment options, and personal goals and priorities as experienced by the patient (Elwyn et al., 2017; Légaré et al., 2014). One context in which technology and SDM are expected to be particularly valuable is the prevention of medication-related falls in older patients in a primary care setting. In the context of preventing medication-related falls, technology can be used to assist general practitioners (GPs) and older patients with medication management and applying SDM. The aim of this dissertation is to describe the development and evaluation of an intervention that uses technology to facilitate SDM in the context of medication-related fall prevention in primary care. This chapter illustrates the importance of fall prevention as a context, the role of SDM, and the potential of technology to facilitate SDM in this context.

Falls in Older Adults

To understand the potential value of AI-based SDM in the context of fall prevention, it is important to illustrate the magnitude of falls as a health problem. In 2022, every 4 minutes, a person aged 65 years or older was admitted to the emergency room in the Netherlands due to a fall, and 87,000 older people faced serious injury (e.g., fracture or brain damage) because of a fall (VeiligheidNL, 2022). These falls largely impact older people's independence and quality of life, and can even result in death (Soriano et al., 2007). Each day, 16 people in the Netherlands aged 65 and over die because of a fall (VeiligheidNL, 2022). The number of emergency room visits, injuries, and deaths caused by falls is rising rapidly, mainly due to the aging population: the number of people aged 65 and older is increasing, and the proportion of frail older people is rising as well (VeiligheidNL, 2022; Xu et al., 2022). Meanwhile, the pressure on nursing homes, primary care, and hospitals remains unrelentingly high.

To safeguard older persons' independence and quality of life, and ease the burden on the healthcare system, it is essential to develop effective fall prevention strategies. We know from previous research that medication forms an important risk factor for falls (Ham et al., 2014; Michalcova et al., 2020). The aging population often experiences multiple chronic conditions, typically resulting in an increased number of medications (Bokhof & Junius-Walker, 2016). Additionally, older people are more prone to experiencing side effects of the medication they take, thereby also increasing their fall risk (Lavan & Gallagher, 2016). Older patients often take multiple kinds of medication simultaneously (i.e. polypharmacy; Bokhof & Junius-Walker, 2016; Masnoon et al., 2017). These medications are often prescribed by several different specialists and their indication is not always monitored sufficiently (Zwietering et al., 2019). This can cause patients to experience unnecessary side effects and could lead to unnecessarily prolonged usage of certain medications (Vaismoradi et al., 2021). In the context of fall prevention, it means that different types of medication often interact, causing side effects such as dizziness and, consequently, increasing a patient's fall risk.

Medication use is a major contributor to a person's fall risk, but it also forms a modifiable risk factor (Ham et al., 2014; Michalcova et al., 2020). Therefore, regular evaluation of older patients' medication use by the GP and patient together is imperative (Ming et al., 2021). GPs currently lack adequate tools to estimate personalized risks and encounter difficulties in medication management related to fall prevention, because knowledge on this topic is largely fragmented and has not been aggregated to support GPs. Older patients, on the other hand, often do not feel empowered to actively engage in the decision-making process surrounding their medication-related fall risk.

Shared Decision-Making

Over the past decades, there has been a growing focus on the role of patients in medical decision-making. Traditionally, clinicians took a paternalistic approach, making decisions for the patient based on the belief that they knew best due to their medical expertise (Emanuel & Emanuel, 1992). However, there has been a shift towards more patient-centered care, where patients are actively involved in the decision-making process (Tinetti, Esterson, et al., 2016). SDM has increasingly become the norm, especially since the Dutch Medical Treatment Contracts Act (WGBO) obliges healthcare professionals to decide which care fits best together with the patient (Ubbink, 2021), and more than one medically reasonable treatment option is often available (Stiggelbout et al., 2015). However, even though it is known to be beneficial and is increasingly becoming the norm, its implementation in practice is not easy and shows a lot of room for improvement (Légaré et al., 2018; Stiggelbout et al., 2015). Therefore, the intervention described in this dissertation aims to facilitate SDM, making it an important outcome measure.

When discussing an older patient's medication use in relation to their fall risk, applying SDM is essential. Altering a person's medication always comes with benefits and drawbacks, and a patient's personal goals and priorities play an important role when deciding whether or not to alter their medication. It also often involves medications that a patient has been taking for a long time, which can cause some patients to be reluctant towards medication changes, for instance, because of concerns about possible destabilization of established therapeutic effects (Petty et al., 2003). Properly applying SDM during a medication review can help to elicit the patient's goals, priorities, and concerns, and together make a decision that aligns best with the individual patient's needs (Mathijssen et al., 2020).

Several theoretical models have been introduced to illustrate the process of SDM. One of the most prominent models is the three-talk model (Elwyn et al., 2017). This model describes the process of SDM as a collaborative approach that consists of three conversational stages that occur between the patient and the healthcare professional. The first stage is *team talk*, during which the patient and healthcare professional work together as a team, choices are described, and the patient's goals are explored. The second stage is *option talk*, where possible options are compared and discussed, while also eliciting the patient's personal preferences. Lastly, during the *decision talk* phase, preference-based decisions are made together. Throughout the entire process, active listening (i.e., carefully observing and responding accurately) and deliberation (i.e., thinking carefully about the available options) are continuously applied (Elwyn et al., 2017). The three-talk model is renowned and very valuable. However, this does not suffice for older patients, who often require complex care. The three-talk model was later combined with the three-goal model, resulting in the goal-based three-talk model, specifically focused on patients with complex, chronic conditions (Elwyn & Vermunt, 2020). In this model, goals prioritized by the patient guide the presented options and the decision-making. A model tailored even more specifically to an older patient population is the dynamic model for shared decision-making in frail older patients, which was developed specifically to dive deeper into the SDM process with older patients as the target group (van de Pol et al., 2016). SDM in the context of older patients and their medication-related fall risk is particularly challenging, as managing the medication is difficult, and this patient population is often not fully equipped to engage in SDM about their medication and fall risk. This could partly be caused by a lack of knowledge; approximately 85% of older patients with polypharmacy are unaware of the reasons why their medication was prescribed (Bosch-Lenders et al., 2016). Therefore, in this dissertation, the dynamic model for shared decision-making in frail older patients forms the basis for describing and analyzing SDM.

The dynamic model consists of six factors (van de Pol et al., 2016). *Preparation* entails looking into the patient's history and making an assessment to prepare for the conversation. During *goal talk*, the patient's goals of care and values are identified. *Choice talk* aims to identify the available options, and to elicit the patient's treatment aims. Personalized treatment options are discussed during *option talk*. The goal of *decision talk* is to inquire whether the patient is ready to make a decision and, subsequently, to make the decision together while focusing on the patient's preferences. Lastly, *evaluation talk* is meant to evaluate the decision-making process and to examine if everyone is satisfied with the decision. These are all important steps that should also be applied in consultations about older patients' medication-related fall risk. However, even though SDM has been proven beneficial, for instance resulting in better understanding and less decisional conflict, it is often not applied (well) in practice (Jansen et al., 2016; Van Weert et al., 2016). Therefore, innovative, evidence-based interventions should be developed to facilitate SDM in this context.

Technology in Healthcare

Technology and, more specifically, AI are on the rise in healthcare (Bohr & Memarzadeh, 2020). The rapid advancement of technology and AI has led to promising prospects regarding the use of aggregated health data to create models that have the potential to, for instance, offer tailored treatment advice and assist in diagnosis (Panch et al., 2019). The technology used in this dissertation consists of three components. First, a prediction model predicts the chance of a fall in the next 12 months (Dormosh, Schut, et al., 2022). It was learned from routinely collected data in the GP's electronic medical record. Clinical prediction models utilize AI and big data to screen individuals for (asymptomatic) diseases, assist in diagnosis, predict future events (such as falls), and assist in medical decision-making (Lee et al., 2016). In this dissertation, AI systems are defined as systems that use knowledge-based, statistical, or certain other data-driven approaches to generate predictions, recommendations, or decisions (EUR-Lex, 2021). In the intervention presented in this dissertation, the prediction model is used to screen older patients and identify those with a high fall risk. Second, the intervention includes a clinical decision support system (CDSS) that presents a patient's fall risk and corresponding personalized advice for altering their medication. A CDSS connects patient health data with medical knowledge (e.g. computer-interpretable guidelines) to support the clinical decision-making process (Hayward, 2004). The prediction model is integrated within the CDSS, and the CDSS is connected to the electronic medical record. In this way, the CDSS can autonomously use the patient's health data extracted from the electronic medical record to run the prediction model and to provide tailored advice on possibilities to alter medication based on a knowledge base of if-then rules. Lastly, the intervention includes a patient portal that contains information about falling and fall prevention, and that helps the patient prepare for the consultation with their GP.

From a theoretical perspective, no theory specifically focusing on CDSS usage and acceptance currently exists. However, several general models of technology acceptance have been developed throughout the years, such as the technology acceptance model (TAM; Davis, 1989), the unified theory of acceptance and use of technology (UTAUT; Venkatesh et al., 2003), and the human, organization and technology-fit model (HOT-fit; Yusof et al., 2008). The TAM and UTAUT were developed for technology-use in general, but can also be used to measure acceptance of CDSSs and patient portals. Compared to the TAM and UTAUT, the HOT-fit model has been developed specifically for health information systems. Additionally, whereas the TAM and UTAUT mostly focus on behavioral determinants of the user, the HOT-fit model states that a fit between human, organizational, and technological factors is essential for a health information system to be successful in terms of acceptance and effectiveness (Yusof et al., 2008; Figure 1). The model is, therefore, not merely focused on the system itself, but also on the support and organization surrounding it (Yusof et al., 2008). In practice, even though the benefits of CDSSs on patient safety and healthcare quality have been shown, the acceptance of these systems remains relatively low (Nanji et al., 2018; Van Der Sijs et al., 2006). Regarding CDSS usage, barriers and facilitators of acceptance among clinicians (human), technical problems with the software (technology), and the extent to which the system can be integrated into the organizational environment (organization) are all identified as potential causes of the low CDSS usage estimates (Trivedi et al., 2002).

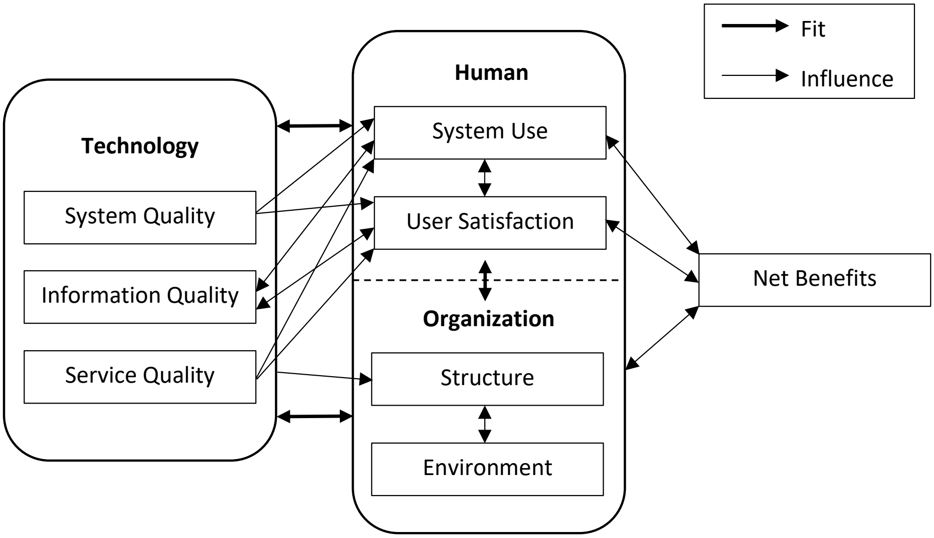

Figure 1. The HOT-fit framework (Yusof et al., 2008)

The first HOT-fit component is technology; consisting of system quality (i.e. user interface), information quality (i.e. information provided by the system) and service quality (i.e. overall support from system provider). Research has shown that system quality is an important predictor of CDSS usage by clinicians (Erlirianto et al., 2015; M. P. Johnson et al., 2014). System characteristics such as excessive reminders can lower system quality and in turn hinder CDSS usage (Varonen et al., 2008). Furthermore, the literature indicates that the quality of the content and information presented within the CDSS is an important prerequisite for CDSS uptake as well (Erlirianto et al., 2015; Varonen et al., 2008). The human factor in HOT-fit consists of two parts; system use and user satisfaction (Yusof et al., 2008). These are crucial factors in the use of CDSSs, as the system is only useful if the clinician actually uses, reads, and considers the provided recommendations (Moxey et al., 2010), and user satisfaction is an important predictor of health information system use (Erlirianto et al., 2015). The level of CDSS usage by clinicians is rather low and should increase in order for such systems to improve healthcare quality and patient outcomes (Kilsdonk et al., 2017; Nanji et al., 2018). Organization is divided into two components; structure (of the organization) and environment (Yusof et al., 2008). Especially the clinical workflow is expected to be important for evaluating CDSS usage, as the fit of the CDSS into the clinical workflow is an important factor for CDSS usage (Arts et al., 2017; Moxey et al., 2010). The last variable in the HOT-fit model is net benefits, which capture the balance of positive and negative impacts of the system on the user (Yusof et al., 2008). The model forms a useful instrument for the categorization of barriers and facilitators for the uptake of these systems, which afterward provides useful guidance in the process of intervention development.

Developing and Evaluating the SNOWDROP Intervention

The research presented in this dissertation was part of the SNOWDROP[1] project. SNOWDROP is an interdisciplinary project combining medical-, data-, and communication sciences. The project has two main objectives: 1) to develop and validate a prediction model for falls among older patients that can be used to estimate their individualized fall risk (data science), and 2) to employ this prediction model to provide smart decision support for SDM between GPs and older patients, through a CDSS and a patient portal (communication science). This dissertation is focused on the second objective of the SNOWDROP project, but does use and implement the prediction model created for the first objective (Dormosh, 2023).

For the development and evaluation of the intervention, we followed the Medical Research Council (MRC) guideline for complex interventions (Skivington et al., 2021). The guideline comprises four fundamental phases: development, feasibility, evaluation, and implementation (see Figure 2). The guideline emphasizes the value of incorporating both existing theoretical and empirical evidence, complemented by additional primary research where needed. While following the MRC guideline, a mix of methodologies is applied to develop and evaluate a solid, evidence-based intervention. A user-centered design (UCD) methodology is applied when developing the intervention. This means that end users of the systems (i.e. GPs and older patients) are closely involved in all stages of the development process. Research has shown that acceptance rates of technological systems, and more specifically CDSSs and patient portals, in healthcare, are often suboptimal (Van Der Sijs, 2015; Wildenbos et al., 2017). Applying a UCD approach will contribute to both the initial adoption and continued use of the CDSS and patient portal (Brunner et al., 2017; Nazi et al., 2018).

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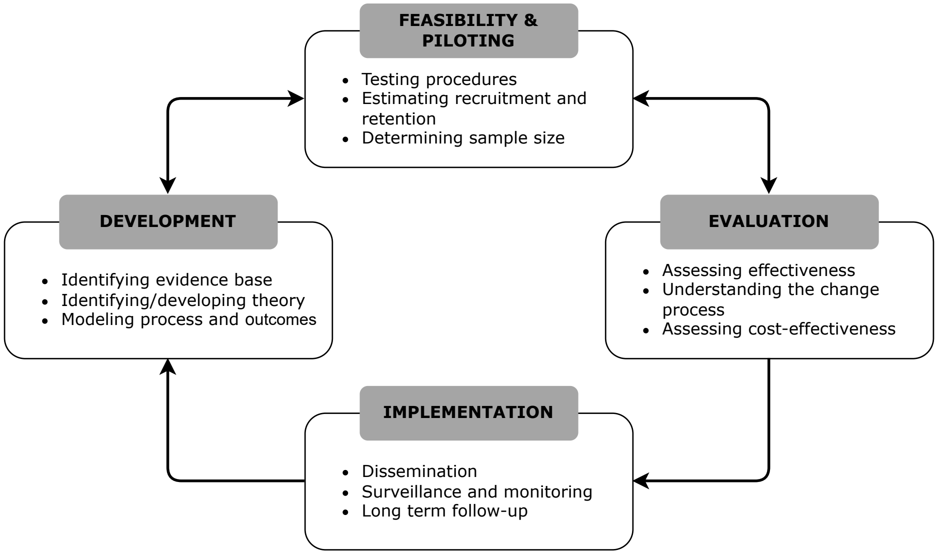

Figure 2. MRC guideline for complex interventions

Dissertation Outline

The main aim of this dissertation is to describe the systematic development and evaluation of a technological intervention that can provide personalized decision support to GPs and older patients to facilitate SDM for medication optimization in the context of fall prevention. This aim will be achieved through answering the following research questions:

RQ1. Which barriers and facilitators for using a medication-based CDSS have been indicated by clinicians in existing literature? (Chapter 3)
RQ2. What are general practitioners' needs and wishes for a CDSS as part of an intervention targeting the medication-related fall risk? (Chapter 4)
RQ3. What are older patients' needs and wishes for a patient portal as part of an intervention targeting their medication-related fall risk? (Chapter 5)
RQ4. How can the SNOWDROP intervention be systematically developed and feasibility-tested? (Chapter 5)
RQ5. What are the effects of the SNOWDROP intervention on patient-provider communication, patient-reported outcomes, and medication changes? (Chapter 6)

Chapters 2 to 6 present a general overview of the SNOWDROP project, a systematic review, focus groups, interviews, usability testing, and a randomized controlled trial (RCT). It is important to realize that all chapters were written as self-contained articles, which inherently leads to some overlap in introductions and inevitable stylistic differences. Each chapter was written as a separate research paper and can be read individually. However, the chapters do represent the different phases of the MRC guideline for complex interventions. They build upon each other to form a coherent narrative leading from the development to the evaluation of the intervention, together contributing to the main aim of this dissertation. The studies covered in chapters 2, 3, and 4 have been accepted for publication. Chapters 5 and 6 have been or will be submitted to peer-reviewed journals. Figure 3 presents a visual overview of the outline of this dissertation.

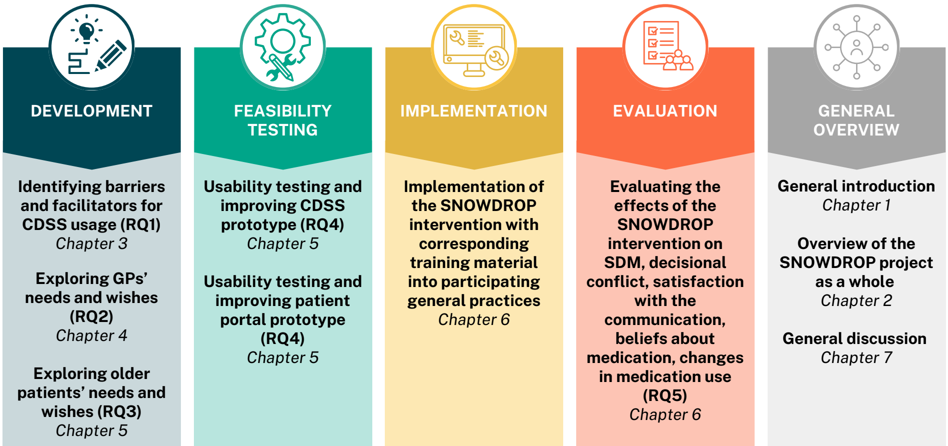

Figure 3. Overview of the research outlined in this dissertation.

Chapter 2 To provide sufficient context about the SNOWDROP project as a whole and to fully grasp its content, interdisciplinarity, and research aims, chapter 2 provides a full overview of the SNOWDROP project and the research that is conducted within this project. This chapter provides insight into the data science objective as well as the communication science objective.

Chapter 3 Before gathering new empirical evidence, we wanted to establish the current state of knowledge regarding the acceptance of medication-related CDSSs. To do so, I conduct a systematic review in chapter 3. The systematic review reveals barriers and facilitators that clinicians perceive when using a medication-based CDSS. This results in a better understanding of factors to take into account when developing the CDSS for the SNOWDROP project.

Chapter 4 The state of the art identified in chapter 3, is complemented by new empirical evidence in chapter 4. In chapter 4, I conduct a focus group study to assess GPs' needs and wishes for a CDSS in the context of the SNOWDROP intervention. The chapter reveals an overview of important considerations to take into account during the development process, relevant for this project, but also relevant for the development of CDSSs in different health contexts.

Chapter 5 In the fifth chapter, I describe the process of developing and feasibility testing the intervention. To this end, multiple studies are conducted, continuously involving GPs and older patients. The development of the intervention is based on a focus group study with GPs and an interview study with older patients. After creating prototypes based on the results of phase one, elaborate usability testing as part of the feasibility phase is conducted. A think-aloud method is applied in the testing of the CDSS with GPs, and the patient portal with older patients. These studies together result in a ready-to-implement CDSS and patient portal.

Chapter 6 The systematic development and feasibility testing described in the previous chapters result in a ready-to-implement intervention that needs a thorough evaluation. Hence, chapter 6 describes the implementation and evaluation of the intervention through a randomized controlled trial (RCT) that was conducted to evaluate its effectiveness. With this RCT, the effects of the intervention on SDM, decisional conflict, beliefs about medication, and actual medication changes are assessed.

Chapter 7 In the final chapter of this dissertation, I reflect upon the previous chapters and integrate their findings. By doing so, I attempt to answer the research questions by integrating all findings. I also propose avenues for future work and reflect on the future of using technology and AI in healthcare.