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Enhancing patient participation among older and migrant cancer patients through eHealth

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CHAPTER 1

Introduction and dissertation outline

INTRODUCTION

Cancer is currently one of the leading causes of death worldwide (WHO, 2018), and is expected to become even more prevalent and to cause more deaths in the future (WCRF, 2018). In the Netherlands as well as in many other Western countries, the number of older and (older) migrant cancer patients is expected to rise due to an aging population (de Magalhaes, 2013; Dutch Cancer Society, 2006; Finkel et al., 2007; Siegel et al., 2020; Stirbu et al., 2006). Both an older age and a migration background pose patients at higher risk of suboptimal participation in their healthcare process, while patient participation is considered one of the cornerstones of high quality oncological healthcare, associated with positive health outcomes (Courtot et al., 2019; Dillon, 2012; Kremer et al., 2007; Noordman et al., 2017; Richard et al., 2017; Vahdat et al., 2014; Wiering et al., 2016). As the ‘Participation Ladder’ depicts, patient participation can occur at different levels, varying from no participation at all to the patient being completely in control (Abma & Broerse, 2010; Arnstein, 1969). In the literature, patient participation is defined in several ways. A widely accepted definition is: *“the extent to which patients produce verbal responses that have the potential to significantly influence the content and structure of the interaction as well as the healthcare professional’s beliefs and behaviors”* (Street & Millay, 2001, p. 62). This definition does not specify the topic of the interaction. As for the topic of the interaction, one conceptualization of patient participation refers to the concept as a *“process that involves the ways in which patients are given opportunities to contribute to the discussion about what their health problem is and what should be done about it”* (Peräkylä et al., 2007, p. 122). Hence, the more opportunities patients are given to contribute to the discussion, and the more verbal responses are produced by patients to influence the interaction with the healthcare professional, the more active patient participation is deemed to be.

One barrier to patient participation experienced by older patients is the age-related decline they face in information processing capacity (Gaissmaier & Gigerenzer, 2008; Peters, Dieckmann, et al., 2007; Reyna, 2008). This decline poses problems for the comprehension of information provided by healthcare professionals and the use of this information for important decisions. Older migrant patients often also experience a language barrier that affects their understanding of information and ability to participate actively during medical encounters (Hawley & Morris, 2017). The barriers faced by older and migrant patients, in turn, can reduce the influence that these patients have on their interaction with healthcare professionals, as well as their contribution to patient participation and decision-making. In order to support these more vulnerable patient groups and to stimulate their participation, eHealth interventions – such as online decision support tools that structure information and multilingual eHealth tools – seem to be promising approaches (Cushing & Steele, 2010). eHealth interventions aim to support patient participation by tackling language barriers and by enhancing information processing, in particular

when alternative presentation formats are used. More specifically, providing information in eHealth tools in audiovisual modality, a narrative narration style, and in patients' mother tongue might enhance understanding of information and subsequent information processing. However, relatively little attention has been devoted to the question of how to develop or optimize eHealth tools for the more vulnerable patient groups such as older and older migrant cancer patients with low language proficiency in a country's dominant language. Therefore, this dissertation entails two aims:

1. To optimize online decision support tools for older cancer patients, by assessing the effect of audiovisual and narrative presentation formats on older cancer patients' information processing.
2. To develop and evaluate an oncological multilingual eHealth module that could diminish the language barrier to participation among older migrant cancer patients, taking into account patients' and healthcare professionals' preferences and needs.

This introduction will first outline the demographics in the Netherlands with regard to cancer in the older and (older) migrant population. Next, the concept of patient participation, barriers experienced by older and (older) migrant cancer patients to patient participation, and eHealth interventions that possibly could support patients in participation will be described. The *Introduction* will conclude with the research questions and an outline of the dissertation.

Cancer incidence in the Netherlands

In 2018, Dutch statistics showed that cancer incidence (i.e. the number of newly diagnosed cancer patients per year) was 114,863 and cancer mortality was 45,513 in the Netherlands (NKR/IKNL, 2020). These numbers are expected to rise, and one of the main reasons is that the Dutch population is ageing (StatLine, 2019). While the number of Dutch older people (i.e. ≥ 65 years old) was approximately 1.7 million in 2000 (10.4% of the total population), this number increased to 2.5 million in 2019 (14.6% of the total population) (StatLine, 2019). It is known that cancer is mainly a disease of older age (Bray et al., 2018; de Magalhaes, 2013; GBD, 2016; Nolen et al., 2017). In the Netherlands, cancer incidences are highest in adults aged 60 to 74 years old (NKR/IKNL, 2020). Along with the continuing ageing of the population, both cancer incidence and mortality rates are expected to increase further in the coming decades (de Magalhaes, 2013).

In the Netherlands, cancer incidence is also increasing among migrant populations (Anand et al., 2008; Dutch Cancer Society, 2006; Smith et al., 2009). Turks and Moroccans settled in the country after the 1960s and now make up the major part of the migrant groups in the Netherlands, with 409,877 Turkish-Dutch (first generation: 193,698; second generation: 216,179) and 402,492 Moroccan-Dutch people (first generation: 170,357; second generation: 232,135) (StatLine, 2019). Although cancer rates have been lower among Turkish-Dutch and

Moroccan-Dutch migrants compared to the native Dutch population (Dutch Cancer Society, 2006), these rates tend to converge to the rates in the host country, and it is expected that the cancer incidence among Turkish-Dutch and Moroccan-Dutch migrants will increase (Stirbu et al., 2006). Between 2005 and 2030, the share of non-Western migrant cancer patients in the total number of new cancer diagnoses is expected to triple from 1.8% to 6.5% (Dutch Cancer Society, 2006). Altogether, it can be concluded that oncological care for both older patients and migrant patients, including older migrant patients, will expand.

Patient participation in healthcare

Patient participation in healthcare is one of the pillars of Western healthcare systems (Damman et al., 2020; Jani et al., 2018; Porter & Lee, 2016). During medical encounters, patient participation requires that several gaps between healthcare professionals and patients in information and competences are being bridged (Thompson, 2007). This means, on the one hand, that patients need to be willing to and to be able to ask questions, express concerns, and give responses assertively (Bomhof-Roordink et al., 2019; Fisher et al., 2018; Street & Millay, 2001). On the other hand, healthcare professionals need to involve patients actively. Depending on patients' willingness and ability, and healthcare professionals' attitude and behavior, different levels of patient participation can occur (Thompson, 2007). While a patient can completely refrain from participation (see *Figure 1*; 'no participation'), a patient can also participate passively. According to the 'Participation Ladder', no patient participation occurs when healthcare professionals only aim to treat or to educate patients (Abma & Broerse, 2010; Arnstein, 1969). Passive participation, or 'tokenism', entails a form of participation in which aforementioned characteristics are almost lacking, the patient only seeks or gives information, and leaves decisions to the healthcare professional (Abma & Broerse, 2010; Arnstein, 1969; Thompson, 2007). Autonomous participation can be seen as a form of participation in which the mentioned characteristics are fully present, and the patient makes all decisions on his/her own (Castro et al., 2016; Palmer et al., 2013; Thompson, 2007). In between no/passive participation and autonomous participation, different forms of active patient participation exist. One is shared decision-making (SDM), which has gained ground as a model to make evidence-based decisions in active collaboration with patients (Coulter, 2012; Hawley & Jagsi, 2015; Portielje & Stiggelbout, 2018; Stiggelbout et al., 2015; Thompson, 2007). SDM can only take place if there is a partnership between the healthcare professional and the patient (Abma & Broerse, 2010; Arnstein, 1969). SDM often occurs in decisions that involve treatment choices or provider (e.g. hospital) choices, and can be seen as a process in which healthcare professionals support patients in making healthcare choices by sharing knowledge, values, and preferences (Elwyn et al., 2012; Godolphin, 2009; van de Pol et al., 2016). SDM is characterized by active participation of patients driven by patients' own initiatives and/or elicited by healthcare professionals, ultimately aimed at reaching mutual agreement between the patient and the healthcare professional regarding the (treatment) option that

will both benefit the patient and matters most to the patient (Elwyn et al., 2012; Holland et al., 2016; Stiggebout et al., 2015; van de Pol et al., 2016).

More active patient participation among cancer patients, such as SDM, is highly encouraged in health policy, e.g. in developments towards value-based healthcare, for several reasons. One reason is that more active participation is associated with better decision quality and patient outcomes, such as enhanced recall of the information discussed during the medical encounter (Dillon, 2012; Richard et al., 2017), better information comprehension (Courtot et al., 2019), and lower decisional conflict (Kremer et al., 2007; Stacey et al., 2017). Moreover, active participation is (directly and indirectly) associated with beneficial outcomes such as higher patient satisfaction (Noordman et al., 2017; Vahdat et al., 2014), and diminished stress, disbelief and the feeling of loss of control over one's life among patients (Wiering et al., 2016). However, although more active patient participation, and in particular SDM, is increasingly embraced, older and migrant cancer patients remain at risk of suboptimal patient participation (Ekdahl et al., 2011; Hawley & Jagsi, 2015).

Patient participation in older and migrant cancer patients

Medical encounters are likely to go differently with older patients than with younger patients (Macrae, 2018). For example, healthcare professionals might spend less time with older patients than with younger patients (Macrae, 2018), which is likely to influence patient participation among older patients. Previous studies also revealed that medical encounters with migrant patients in Dutch primary care were considerably less adequate compared to intracultural medical encounters (Meeuwesen et al., 2006; Schinkel et al., 2013; Schouten et al., 2008). For instance, general practitioners appeared to engage migrant patients less in medical decision-making than Dutch patients (Schouten et al., 2008). This might affect patient participation in migrant patients.

Older cancer patients have been shown to prefer participation in important decisions such as decisions about treatment (Atherton et al., 2013; Chewning et al., 2012; Paillaud et al., 2017; Tariman et al., 2010). However, they often seem to leave the final decision to the healthcare professional (Ekdahl et al., 2010; Ekdahl et al., 2011; Noordman et al., 2017). Likewise, studies have shown that migrant cancer patients prefer participation in decision-making (Hawley & Morris, 2017; Hughes et al., 2018; Mead et al., 2013; Perez Jolles et al., 2019; Shaw et al., 2015). Nevertheless, migrant patients often show less participatory behavior (e.g. ask less questions) than Dutch patients (Meeuwesen et al., 2006; Schouten & Meeuwesen, 2006; Schouten et al., 2007). Migrant patients also often leave the final decision to the healthcare professional (Hawley & Morris, 2017; Hughes et al., 2018; Mead et al., 2013; Shaw et al., 2015). Altogether, mentioned passive behaviors of older and migrant patients may lead to stereotypes of these patients not wanting to be fully informed and to participate actively during medical encounters.

Factors negatively influencing patient participation in migrant patients are low Dutch language proficiency and cultural differences in views on the doctor-patient relationship (Meeuwesen et al., 2006; Schouten & Meeuwesen, 2006; Schouten et al., 2007). Dutch language proficiency is lowest among Turkish-Dutch people, followed by the Moroccan-Dutch population (Huijnk & Dagevos, 2012): one third (33%) of first generation Turkish-Dutch migrants and 24% of first generation Moroccan-Dutch migrants experience difficulties in speaking the Dutch language (Huijnk et al., 2015). A traditional method to tackle the language barrier in intercultural medical encounters is the use of professional or informal interpreters (Zendedel et al., 2016, 2018a, 2018b). In the Netherlands, however, cuts in the healthcare budget have been performed since 2012, leading to a substantially scarcer (free) availability of professional interpreters. A report from 2016 revealed that in only 10% of the medical encounters in primary care where a professional interpreter was needed, general practitioners involved a professional interpreter (Triemstra et al., 2016). Informal interpreters (often a family member of the patient), are not necessarily a good substitute for professional interpreters, because informal interpreters have been shown to translate information inadequately and to hide information from the patient (Zendedel et al., 2016, 2018a, 2018b). This calls for a need for alternative solutions that could bridge the language barrier in practice, without involving professional or informal interpreters.

The importance of information processing in patient participation

For successful patient participation, in particular in SDM, adequate health communication and information processing among patients are crucial prerequisites. As for health communication, healthcare professionals need to inform patients about their disease, the choices to be made (e.g. hospital choice or treatment choice), the options available (including the option not to get treated), and the risks and benefits of the different (treatment) options (Stiggelbout et al., 2015). Furthermore, healthcare professionals should give room to patients to ask questions and to express their concerns (Damman et al., 2020). Patients, in turn, need to be able and willing to participate (Bomhof-Roordink et al., 2019; Fisher et al., 2018; Street & Millay, 2001), and to seek and give information (Thompson, 2007). Patients also need to be able to understand and process information provided by the healthcare professional (Coulter, 2012; Hibbard & Peters, 2003; Stiggelbout et al., 2012). The effectiveness of information processing is driven by several factors, both characteristics related to individual patients (e.g. age and age-related working memory capacity, health literacy, numeracy, and ethnic background and related language proficiency) and characteristics of the information (e.g. familiarity, complexity, and presentation format of the information).

Information processing

In cognitive psychology, information processing in decision-making is commonly believed to occur through two modes of thinking, namely intuitive reasoning and deliberative

reasoning (Kahneman, 2003). Intuitive reasoning (i.e. System 1 processing) entails automatic, quick and effortless information processing, such as the use of heuristics or rules of thumb (Bekker et al., 2013; Kahneman, 2003). Deliberative reasoning (i.e. System 2 processing) entails controlled and slow information processing that is cognitively more demanding, such as analytically weighing the pros and cons of choice options (Bekker et al., 2013; Evans, 2008; Kahneman, 2003). System 1 processing is thought to be independent of an individual's working memory capacity or general intelligence, while System 2 processing is thought to be limited by an individual's working memory capacity, and to be linked to intelligence (Evans, 2008). In general, System 1 processing is thought to be associated with heuristic judgments, which can lead to biases by delivering memories and perceptions, whereas System 2 processing intervenes with System 1 processing and is generally thought to improve judgments (Evans, 2008). Effective information processing is thought to occur when patients both think (System 2) and feel (System 1) through their decision (Hibbard & Peters, 2003). As such, integrating intuitive and deliberative reasoning is likely to lead to the most optimal decision-making (Peters et al., 2008; Peters, Hess, et al., 2007).

Information processing: the interplay between patient and information characteristics

The effect of patient characteristics and information characteristics on information processing can often not be determined in isolation from each other. For instance, reduced working memory capacity is a 'patient characteristic' that influences information processing. Older cancer patients are likely to experience difficulty in deliberative information processing (System 2) and recalling information, and are in general less motivated to put effort into processing information that is complex and elaborate (Mata et al., 2007). A recent study showed that information recall in older patients is influenced by the ability and motivation to process information rather than by chronological age (Bol et al., 2018). Information characteristics that relate to patients' ability and motivation to process the information are, among others, familiarity and complexity of the information: older patients will probably need more time to process unfamiliar and complex information than familiar and easy information. An example of complex information is information for multi-attribute decisions, where often conflicting attributes need to be compared (Carpenter & Niedenthal, 2018; Hibbard et al., 1997). An important step in facilitating information processing among older cancer patients, therefore, is that strategies are being found that can lower the cognitive effort needed to process information while simultaneously increasing motivation to attend carefully to the information.

Another example of interrelated patient and information characteristics are health literacy and information language. Health literacy can be defined as "*the ability to read, understand, and act upon health information*" (Coulter, 2012, p. 82). In order to recognize that a decision needs to be made and to structure choice options, patients need to be

able to read and understand information (Woudstra et al., 2019). Furthermore, in order to make a decision, to participate in decision-making, and to interpret results, patients need to be able to apply information to their own situation (Woudstra et al., 2019). Many migrant patients, however, are illiterate (i.e. cannot read) and/or experience a language barrier. Therefore, the modality (e.g. audiovisual) and language in which information is being provided, which are ‘information characteristics’, will determine to a great extent whether older migrant patients can process the information. Therefore, an important step in facilitating patient participation for migrant cancer patients are tailored audiovisual strategies that can diminish the language barrier.

Information processing in older and migrant cancer patients

Older patients in general, irrespective of whether they experience a language barrier, face difficulties in adequately processing information (Gaissmaier & Gigerenzer, 2008; Peters, Hibbard, et al., 2007; Reyna, 2008). First, although the intuitive mode of reasoning remains mainly intact in older adults (Peters et al., 2008; Peters, Hess, et al., 2007), the efficiency of using deliberative reasoning diminishes. Older adults – compared to younger people – need more time to process information, and are known to recall and understand information worse (Finucane et al., 2005). They also tend to rely gradually more on System 1 and less on System 2 reasoning than younger adults (Peters, 2011; Peters et al., 2008; Peters, Hess, et al., 2007), seek less information, and make decisions faster (Mata et al., 2007). Importantly, in older adults, age-related declines in working memory capacity occur (Bopp & Verhaeghen, 2005; Murman, 2015). These declines limit older patients’ cognitive capacity to process information. For example, they may face cognitive overload more easily than younger patients (Brown & Park, 2003), which likely induces dissatisfaction with the information and higher decisional conflict (Parrott et al., 2008). Dissatisfaction with information, in turn, might cause lower information comprehension (Brown & Park, 2003) and recall (Bol et al., 2014).

Due to the language barrier, migrant patients are less able to understand information provided by their healthcare professional (Hawley & Morris, 2017), leading to difficulties in sharing their preferences, needs, and concerns (Paternotte et al., 2017; Shaw et al., 2015). In other words, the language barrier is likely to impede migrant patients in asking questions (i.e. seeking information), and expressing concerns and giving responses assertively (i.e. giving information) (Mead et al., 2013; Perez Jolles et al., 2019; Thompson, 2007). Healthcare professionals, in turn, experience difficulties in understanding these patients and providing them with information that matches patients’ language proficiency level and their concerns (Priebe et al., 2011). As a result, migrant patients might not even reach the opportunity to participate in medical encounters and in SDM particularly. The language barrier might also lead to unfulfilled patient needs, lower information comprehension (Butow et al., 2010; Hyatt et al., 2017; Kwok & White, 2011; Richardson

et al., 2006), and less satisfaction with care and communication with the medical team (Leonhardt et al., 2018).

Towards better information processing and patient participation: eHealth interventions

As outlined in the paragraphs above, older patients and older migrant patients experience barriers to patient participation and information processing. New strategies to support patient participation in healthcare and to increase SDM should target the enhancement of information processing. In this context, the implementation of eHealth interventions in medical practice, such as online decision support tools and online multilingual tools, are highly relevant (Stacey et al., 2017). According to an often-cited definition, eHealth refers to “*health services and information delivered or enhanced through the Internet and related technologies*” (Eysenbach, 2001, p. 1). Over the last decade, eHealth has gained significant attention (Cushing & Steele, 2010). Several types of eHealth tools, such as online decision support tools (e.g. hospital report cards and patient decision aids) and (general) communication tools (e.g. multilingual eHealth tools), can be distinguished. In care for older patients who need to choose a provider or treatment option, online decision support tools can be implemented. In care for older migrant patients, multilingual eHealth tools can be implemented.

Online decision support tools

Online decision support tools typically aim to support patients’ decision making when important decisions have to be made (Bekker et al., 2013; Cardona-Morrell et al., 2017; McAlpine et al., 2018; Stacey et al., 2017; Zdenkowski et al., 2016). These tools are often available as standalone tools on the Internet but can also be used during the medical encounter with healthcare professionals. For example, in oncology, patients are faced with decisions about treatment options, as well as with the decision about where to undergo their treatment. Tools to support SDM in treatment decisions are often referred to as ‘patient decision aids’ (PDAs) and tools to support provider choice as ‘hospital report cards’ (HRCs). This dissertation focuses on PDAs and HRCs, because these online decision support tools have been shown to be successful in enhancing the quality of patient decision-making. For example, for PDAs, it has been shown that its use typically decreases decisional conflict concerning feeling uninformed and remaining indecisive about personal values, while it increases satisfaction with the decision and the process of (preparing for) decision-making (Stacey et al., 2017). The use of PDAs also leads to more active participation in decision-making, and to better doctor-patient communication (Stacey et al., 2017). For HRCs, it has been shown that the use of HRCs can significantly influence hospital choice (Emmert et al., 2019).

However, the uptake of online decision support tools remains low, and most of those tools still adopt a one-size-fits-all approach and have not been aligned to the needs and abilities

of the more vulnerable patients, such as older patients (Damman et al., 2012; van Weert et al., 2016). For example, still much information about risks and benefits of treatment options as well as information about hospital performance is displayed in textual format without accompanying graphical aids (Damman et al., 2010; Sander et al., 2015). This can pose problems for information processing because it is known that numerical information without graphical aids is difficult to comprehend (Gigerenzer et al., 2007; Kurtzman & Greene, 2016; Peters, Dieckmann, et al., 2007). Moreover, textual information might not always attract (visual) attention – which is considered to be one of the first steps in information processing – and to trigger motivation to process information, especially among older patients. Second, information in HRCs and PDAs often tends to be extensive and is communicated in technical language, likely exceeding (older) patients' abilities regarding information-processing (i.e. cognitive overload) (Kurtzman & Greene, 2016; Peters, Dieckmann, et al., 2007). Alternative presentation formats, such as an audiovisual modality or a narrative narration style, seem needed in order to facilitate information processing, while increasing motivation to use information.

Modality: textual vs audiovisual

The effect of modality on information processing has been addressed in the Cognitive Theory of Multimedia Learning (CTML; (Evans et al., 2008; Mayer, 1999)). The CTML is a dual coding theory based on three main assumptions. First, the CTML assumes that humans have separate channels to code (i.e. process) visual and auditory information. Second, the CTML supposes that both the visual working memory channel and the auditory working memory channel are limited in their capacities to process information. Third, the CTML assumes that meaningful learning (i.e. actual information processing) involves actively selecting relevant information, organizing it into coherent visual and auditory mental models, and making connections between the visual and auditory mental models and prior knowledge. Altogether, the CTML explains that people process visual and auditory information through separate channels, which are both limited in the amount of information they can process (Mayer, 1999). A modality effect, however, can occur when information is presented in auditory format combined with moving visuals, e.g. in an animated video (i.e. audiovisual information), compared to information in written format only (Dunn et al., 2004; Ginns, 2005; Sparks et al., 2013). Information can then be divided over different processing channels and, consequently, more information can be processed before cognitive overload occurs; this occurs in part by connecting mental models from the visual channel and mental models from the auditory channel to each other and to prior knowledge (Leahy & Sweller, 2011; Mayer, 2002).

Recent studies suggest that audiovisual information as compared to (only) textual information can enhance information processing (Bol et al., 2013; Bol et al., 2015; Leahy & Sweller, 2011; Meppelink et al., 2015). Especially older patients are expected to benefit

from combining multiple modalities (i.e. auditory and visual information) (van Gerven et al., 2003), because they experience declines in working memory capacity and often experience cognitive overload faster than younger adults (Brown & Park, 2003).

Narration style: factual vs narrative

The effect of the narration style on information processing can be explained by the dual processing theory (Evans, 2008; Evans et al., 2008). Narratives, i.e. stories of other patients' experiences with a particular healthcare choice (Greene et al., 2019), provide patients with illustrative examples of other patients' experiences that are relevant to the decision (Winterbottom et al., 2008), and are thought to influence both the intuitive (System 1) and deliberative (System 2) mode of information processing (Bekker et al., 2013).

The intuitive mode of information processing is considered to be induced by several characteristics of the narrative, such as the credibility of the character in the narrative and affective descriptions used in the narrative (Bekker et al., 2013; Moyer-Gusé, 2008). In a narrative, a character models the decision-making process (Bekker et al., 2013). The Social Cognitive Theory asserts that people not only learn through experiences, but can also learn by observing models (Bandura, 2001). Not all observed behaviors, however, are being copied. One of the most crucial cognitive processes that leads to observational learning is motivation. People intrinsically try (i.e. are motivated) to understand the story of another person. This motivation, in turn, can enhance information processing by improving information recall (Bol et al., 2015). Narratives also have the ability to immerse (i.e. to induce identification with the narrative's character through a disconnection with the physical and psychological environment) and transport the audience into the story of the character in the narrative (Shaffer et al., 2018), which might lead to less counter-arguing (Kreuter et al., 2007; Moyer-Gusé, 2008), and a personalization effect (Shaffer, Hulse, et al., 2013; Shaffer & Zikmund-Fisher, 2013). The personalization effect entails that using a narrative, conversational, narration style increases interest, which in turn enhances the motivation to actively process information (Mayer et al., 2004).

Narratives are also thought to induce elements of the deliberative mode of information processing. The dual processing theory, the Elaboration Likelihood Model (ELM) asserts that information processing occurs through two routes: the central and the peripheral route (Cacioppo & Petty, 1984; Petty & Cacioppo, 1986). The central route refers to extensive and effortful information processing and is similar to System 2 processing. The peripheral route refers to information processing that requires less cognitive effort and is similar to System 1 processing. Whether the central or the peripheral route is being activated, depends on a patient's motivation and ability to process information. A higher motivation and ability will likely activate the central route of information processing (Cacioppo & Petty, 1984; Petty & Cacioppo, 1986). Narratives can increase people's

motivation to attend to the information, by making information more memorable and salient through linking events together in the temporal and causal framework (i.e. mental models) (Bekker et al., 2013). Narratives can provide patients with a coherent framework of experiences, and illustrate how people use technical knowledge to make healthcare choices (Bekker et al., 2013). This, in turn, may help patients in identifying decisions that need to be made, recognizing and weighting options, and making selections (Shaffer et al., 2018). Although some scholars claim that a ‘narrative bias’ can occur, i.e. exemplary stories of one or a small group of (fictitious) patients can undermine the effect of statistical information that is based on a larger and more representative group of patients (Bekker et al., 2013; Betsch et al., 2015; Elwyn et al., 2010; Winterbottom et al., 2008), recent studies suggest that narrative information more than factual information can enhance information processing (Bekker et al., 2013; Bol et al., 2013; Bol et al., 2015; Khangura et al., 2008; Kreuter et al., 2007; Shaffer et al., 2018; Shaffer, Hulsey, et al., 2013; Shaffer & Zikmund-Fisher, 2013).

Especially older patients are expected to benefit more from narratives than younger patients for several reasons. Firstly because older patients rely more on intuitive reasoning than on deliberative reasoning (Bekker et al., 2013), narrative information might quite naturally capture their attention. Besides, according to the Socio-emotional Selectivity Theory (SST), older adults’ motivation to process information becomes highly selective, focusing more on information that is emotionally meaningful rather than statistically meaningful (Carstensen, 2006; Carstensen et al., 2003; Carstensen et al., 1999). This focus on intuitive reasoning and emotional information might bias and lead to suboptimal decision-making in older patients, because the integration of both intuitive and deliberative reasoning is needed for optimal decision-making (Peters et al., 2008; Peters, Hess, et al., 2007). Narratives can compensate this bias by inducing both intuitive and deliberative information processing.

Multilingual eHealth tools

Multilingual eHealth tools typically aim to tackle the language barrier between migrant patients and their healthcare professional. Such tools, that may also contain question prompt lists (QPLs) and tailored patient education materials, have the potential to enhance information processing and to improve patient understanding of health information among older migrant patients (Jensen et al., 2012), because it can provide patients with information in the patients’ mother tongue (Cushing & Steele, 2010; Neuhauser & Kreps, 2008; Weiner, 2012). Ultimately, multilingual eHealth tools could thus contribute to more active participation of older migrant patients, among others because QPLs can induce that more questions being asked, which is a core concept of patient participation (Brandes et al., 2015).

In the Netherlands, an eHealth tool used in primary care is the *Health Communicator*¹. The *Health Communicator* is a multilingual tool consisting of medical anamnestic questionnaires and video-based patient educational videos. In the *Health Communicator*, patients can enter their medical history information in their own mother tongue (e.g. Dutch, English, Turkish, Arabic, Berber, Spanish, Polish). As questions can both be read or listened to, the *Health Communicator* can also be used by illiterate patients. Health-related information entered into the *Health Communicator* is being pre-translated into Dutch and sent to the healthcare professional. This way, the *Health Communicator* tries to reduce the language barrier during medical encounters by better preparing both the patient and the healthcare professional for their consultation. After the medical encounter, the healthcare professional can send video-based patient educational materials to the patient in the patient's mother tongue.

Providing patients with audiovisual narrative information could further contribute to a better understanding of the information (see previous paragraphs on audiovisual modality and narration style). Until recently, the *Health Communicator* was used by general practitioners in care for several chronically ill patients, such as diabetes patients. However, there was no multilingual eHealth module for older migrant oncology patients yet. To be able to develop a tool that could be effectively used by migrant patients, it is important to gain insight into their preferences and needs concerning the content and features of such a tool, as well as the professionals' views on the potential benefits and barriers of such a tool in medical practice. According to the Technology Acceptance Model, technology acceptance is strongly dependent on intended end users' perceptions regarding the usefulness and ease of use of the eHealth tool (Davis, 1985). Once the eHealth tool is perceived as useful and easy to use, uncertainty and fear to adopt the tool are likely to decrease. As a result, intended end users will show a more positive attitude and a higher behavioral intention towards using the eHealth tool. Finally, behavioral intention determines whether the technology will be actually used by the users or not (Davis, 1985).

Overall aim of this dissertation

Providing older and migrant cancer patients with eHealth interventions that entail alternative presentation formats such as audiovisual and narrative information (in their mother tongue) might help enhance patient participation in healthcare in general and in SDM more specifically by facilitating information processing. However, how such strategies work exactly for the specific vulnerable patient groups of older and older migrant patients remains unclear. First, the effects of alternative modalities and narration styles on information processing of those groups has not been systematically tested for

1 The Health Communicator has been developed by NedTalk; <https://nedtalk.com/producten/health-communicator/>

online decision support tools. Second, what a multilingual eHealth tool should exactly look like (e.g. what content should be in the tool) for migrant cancer patients is unknown. Therefore, this dissertation entails two aims. First, in order to better align online decision support tools with older patients' information processing abilities, we aim to optimize HRCs and PDAs by assessing the effect of audiovisual and narrative presentation formats on older cancer patients' information processing. Second, as older migrant patients often experience a language barrier, they are likely not able to use online decision support tools at all. For them, we aim to develop an effective eHealth tool, namely an oncological multilingual eHealth module for the *Health Communicator*, which can bridge existing language barriers in medical encounters. In order to achieve this aim, this dissertation tries to get insight into patients' and healthcare professionals' preferences, needs, and views concerning patient participation and the *Health Communicator*. Based on these insights, we developed and evaluated (pilot study) an oncological module for the *Health Communicator*.

Research Questions

In line with the first aim of this dissertation, the first research question is: *How can information processing of core decision-relevant information in online decision support tools (i.e. HRCs and PDAs) be optimized for older cancer patients?*

Visual attention is considered to be one of the first steps of information processing. Hence, a first step in optimizing online decision support tools is to explore what information users are viewing and using in their decision-making process. Therefore, as described in **Chapter 2**, we first conducted an eye-tracking study to explore how older women (both breast cancer patients and women who have not been diagnosed with breast cancer before) visually attend to decision-relevant information in a hospital report card.

As a second step, we conducted online experiments to identify presentation formats that could benefit older patients' processing of information provided in online decision support tools. The effects of modality (audiovisual information vs textual information) and narration style (narrative vs factual information) on information processing in a PDA were assessed in **Chapter 3**, while the same effects in an HRC were examined in **Chapter 4**.

In line with the second aim of this dissertation, the second research question is: *How can an oncological multilingual module for the Health Communicator be systematically developed and implemented in order to stimulate patient participation among older Turkish-Dutch and Moroccan-Dutch cancer patients, taking into account patients' and healthcare professionals' preferences and needs?*

In order to explore existing knowledge about the information and participation preferences and needs of (older) non-Western migrant cancer patients, a systematic literature review was conducted. **Chapter 5** gives insight into the information and participation preferences and needs of non-Western ethnic minority cancer patients and survivors.

The literature review yielded limited insight into the specific preferences and needs of older migrant Turkish and Moroccan cancer patients. Therefore, **Chapter 6** describes a qualitative study among older Turkish-Dutch and Moroccan-Dutch cancer patients and survivors in order to gain insight into their unfulfilled instrumental and affective needs. As mentioned, healthcare professionals can also experience difficulties in providing care to migrant patients. Hence, in this qualitative study healthcare professionals' (i.e. general practitioners and oncology nurses) barriers to fulfilling Turkish-Dutch and Moroccan-Dutch older cancer patients' needs were investigated as well. Ultimately, both patients' and professionals' views on the usefulness of the *Health Communicator* in fulfilling needs and bridging barriers were explored. In **Chapter 7**, the insights from **Chapter 5** and **Chapter 6** are applied to the development and evaluation of the oncological multilingual eHealth module.

This dissertation concludes with **Chapter 8** (general discussion) and **Chapter 9** (summary of the findings). *Figure 1* provides an overview of the topics and concepts addressed.

Figure 1. Overview of the topics and concepts addressed in this dissertation.

