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### Aging in modern times

*Geriatric perspectives on online information provision and multidisciplinary decision making for patients*

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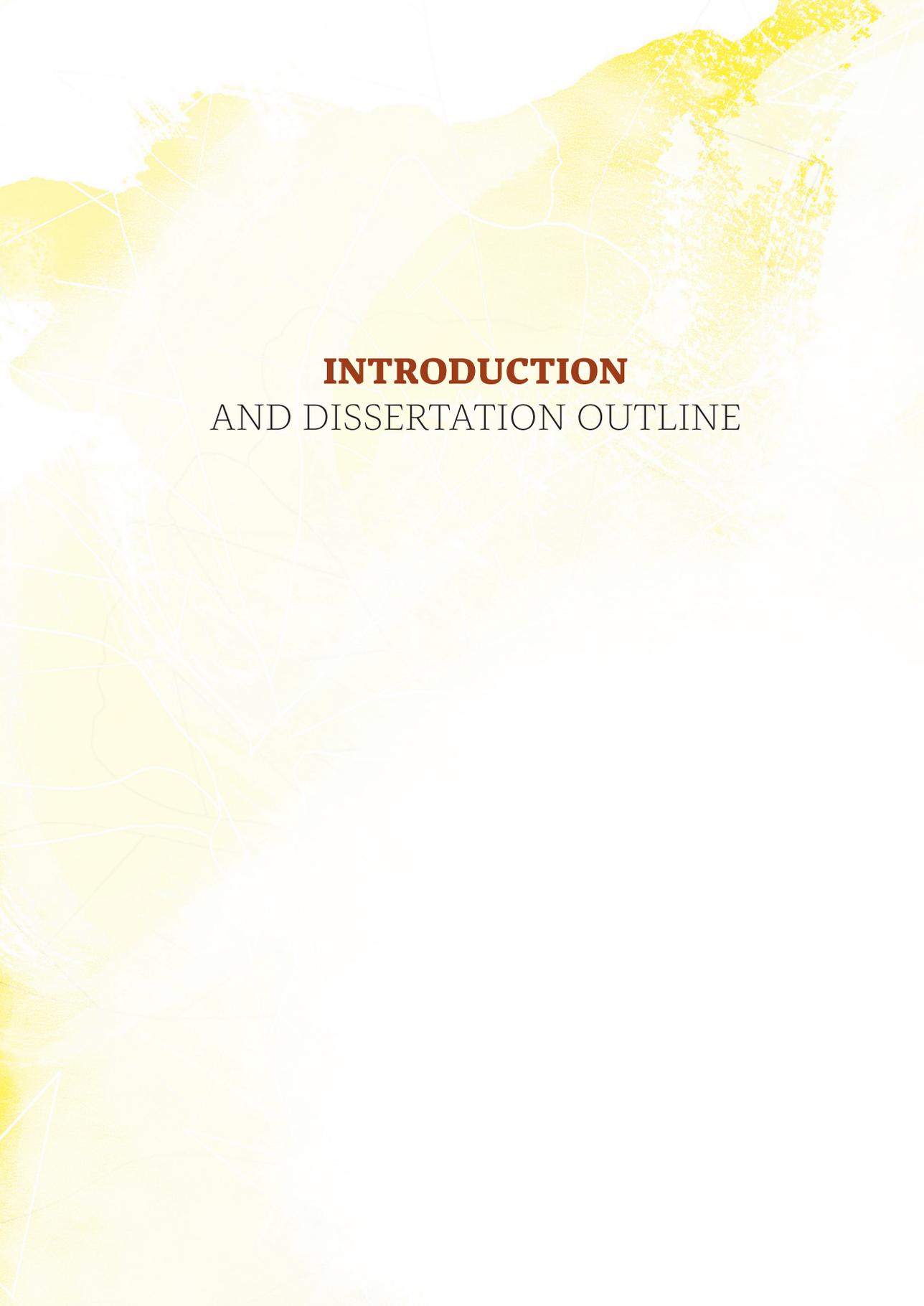
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**INTRODUCTION**  
AND DISSERTATION OUTLINE



## Introduction and dissertation outline

As a result of our aging population in Western societies, the patient population is aging as well (König et al., 2010). As a consequence, the incidence of serious, age-related illnesses such as cancer is also increasing (Siegel, Miller, & Jemal, 2016; Torre et al., 2015). As older adults ( $\geq 65$  years) face several age-related problems (cognitive, physical, and functional problems), they are at high risk of poor communication with their health care providers (Adelman, Greene, & Ory, 2000). To find solutions for age-related communication issues, we do not only need to understand what happens inside the consultation room, but we also need to investigate what both the patient and healthcare provider bring to the table as input for the communication during their consultation. Although a growing body of literature is concerned with communication with older cancer patients (Cohen et al., 2017), we still lack knowledge on relevant communication processes in the context of the consultation. This dissertation addresses this gap.

Two major relatively recent communication developments are important to consider. The first development regards the input of the patient to the consultation. The Internet is increasingly used to search for health information. To illustrate, in 2012, almost half of the Dutch population used the Internet to search for health information. In 2017, this number has increased to 66.4%. Compared to younger age groups, this increase is substantial for the Dutch population aged 65 years and older. In 2012, 27.6% of this group used the Internet to search for health information. Five years later, more than half of them used the Internet for health purposes (Statistics Netherlands, 2018). This also applies to the field of oncology, where both younger and older patients were found to use the Internet as health information source (Van Weert, Bolle, & Muusses, 2014). Research shows that the motivation for patients to search for online health information is related to their consultation with a health care provider. They want to prepare for a consultation, or they want to complement, validate, or challenge the outcome of the consultation (Caiata-Zufferey, Abraham, Sommerhalder, & Schulz, 2010). The first aim of this dissertation is to increase our understanding of the effectiveness, use, and value of online information provision for older cancer patients.

The second development is related to the input the healthcare provider can bring to the encounter with the patient. In the last decades, multidisciplinary team meetings have become standard practice in oncology in The Netherlands (Van Drielen, De Vries, Ottevanger, & Hermens, 2012), as well as other countries such as Germany (Hahlweg et al., 2015) and the UK (Lamb, Wong, Vincent, Green, & Sevdalis, 2011). During these meetings, healthcare providers from different disciplines exchange information on patients' diagnosis and treatment plan (Taylor et al., 2010). What is proposed as diagnosis or treatment plan, subsequently needs to be discussed with the patient. Moreover, what is discussed or decided with the patient during a consultation can in turn be used as input for the discussion during multidisciplinary team meetings. A relatively new, but

highly relevant development, is the participation of geriatricians in multidisciplinary team meetings (Hamaker, Schiphorst, Ten Bokkel Huinink, Schaar, & Van Munster, 2014) to ensure optimal patient-centered care, tailored to individual age-related problems and patient preferences. The second aim of this dissertation is to increase our understanding of the decision-making process during multidisciplinary team meetings from a geriatric perspective.

### **A geriatric perspective on communication**

Older adults experience several cognitive, physical, functional, and psychological age-related changes that can affect communication processes inside and outside the clinical setting. The extent to which these age-related changes occur can determine the vulnerability or frailty of a patient (Shahrokni, Kim, Bosl, & Korc-Grodzicki, 2017). For example, communication with vulnerable patients might be indirectly affected because a hospital visit in itself is considered a huge burden for patients, which might negatively influence their concentration and the ability to process information (Van Weert, & Jansen, 2017). Older adults experience age-related *cognitive changes* that may affect the patient's processing of medical information, the ability to recall medical information (i.e., the ability to remember and reproduce information), medical compliance and ultimately medical outcomes (Brown & Park, 2003). Furthermore, older adults process information more slowly than younger ones (Salthouse, 1996), perceive more difficulties in organizing and storing information (McGuire, 1996) and experience a reduced capacity to ignore irrelevant information (Zacks & Hasher, 1997).

Additionally, older adults experience age-related *physical changes* that can negatively affect the communication process with healthcare providers. Various studies report a relationship between a decrease in sensory functioning and a decrease in cognitive functioning (i.e., deterioration in visual or auditory acuity predict change in cognitive performance; Baltes & Lindenberger, 1997; Van Boxtel, Van Beijsterveldt, Houx, Anteunis, Metsemakers, & Jolles, 2000; Valentijn et al, 2005). Thus, sensory problems may directly affect the extent to which information is received (e.g., heard) and indirectly the extent to which it is processed, understood and memorized.

Furthermore, *functional changes* may result from age-related increases in comorbidity (i.e., having more than one (chronic) illness at the same time). Comorbidity is expected to influence the communication process in two ways. First, health problems such as heart disease and diabetes are, again, known to be related to cognitive problems (Brown, Glass, & Park, 2002; Verhaegen, Borchelt, & Smit, 2003). Second, the information that has to be provided to patients with comorbidity is more complex, because next to information provision about the cancer treatment, these patients also need additional information about their other diseases and treatments. This requires a lot of skills from the side of the provider, varying from estimating how different treatments and advices interact, but also to communicating this clearly to patients.

Finally, increasing age is associated with *psychological changes*. According to the socio-emotional selectivity theory, older adults seek more emotional support, whereas younger adults seek for information. Indeed, study results show that older cancer patients have more affective information needs (Bolle, Muusses, Smets, Loos, & Van Weert, 2012). Moreover, as their emotional goals move from long-term to short-term, they are more focused on how they feel in the moment itself (Carstensen, Isaacowitz, & Charles, 1999).

Although older cancer patients generally experience less anxiety and distress and can therefore better emotionally cope with the diagnosis (Linden, Vodermaier, Mackenzie, & Greig, 2012), they experience symptoms of depression more often compared to younger adults (Nelson et al., 2009). Depression is related to auditory and visual decline (Van der Aa, Hilde PA, Comijs, Penninx, Van Rens, & Van Nispen, 2015) and cognitive decline (Ravnkilde et al., 2002). The aforementioned age-related changes have implications for communication with older cancer patients.

### **Communication with older cancer patients during the consultation**

Until now, researchers that have addressed the provider-patient interaction specifically for older cancer patients, unveiled different communication problems that these patients and their providers face. We know for example that older patients only remember a small amount of information that has been provided during the consultation (Jansen et al., 2008; Van Weert, Jansen, Spreeuwenberg, Van Dulmen, & Bensing, 2011). Also, information and communication needs of older patients are not always fulfilled (Van Weert, Bolle, Van Dulmen, & Jansen, 2013). Furthermore, we know that older patients participate less actively during consultations compared to younger patients (Sparks & Turner, 2008), including asking fewer questions during consultations (Eggyly et al., 2006; Siminoff, Graham, & Gordon, 2006). Literature has also addressed the impact of the communication style of doctors on older cancer patients and found that a caring communication style resulted in highest satisfaction with their doctors (Finkelstein, Carmel, & Bachner, 2017).

### **Communication developments in the context of the consultation**

Consultations between patients and healthcare providers are not isolated communication processes. Both patients and healthcare providers are exposed to other communication processes, which can influence the communication during the consultation, such as the use of online information by patients and providers' participation in multidisciplinary team meetings during which diagnostic and treatment decisions are made for individual patients.

#### **Online information provision**

As the vast majority of older adults who search for health information on the Internet discuss this with their healthcare providers (Lindberg, 2001), we know that patients' use of online health information can affect the communication in the consultation room. Combining online health information with interpersonal communication during the consultation is even expected to lead to synergy effects in information processing. Syn-

ergy refers to the effect that occurs when the combination of multiple communication modalities exceeds the sum of their individual parts (Naik & Raman, 2003). A media source, such as the Internet, and interpersonal communication during consultations can both be considered as communication modalities. When people are exposed to multiple communication modalities, two psychological processes are expected to be activated (Voorveld, Neijens, & Smit, 2010). First, 'forward encoding' occurs when a message in the first modality 'primes' the interest for and attention to a message in the second modality. This is expected to result in a deeper processing of the second message (Dijkstra, 2002). Second, 'multiple source perception' may occur because a message conveyed via multiple modalities may be perceived as a more convincing and credible message (Bronner, Neijens, & Van Raaij, 2003). Because of the aforementioned problems with information processing, older patients can particularly benefit from synergy effects.

There are, however, also some difficulties in using the Internet as a source of health information. Both younger and older age groups are confronted with a high variability in the quality of health information online (Wald, Dube, & Anthony, 2007). Finding relevant health information online can be extremely difficult for older patients in particular (Taha & Czaja, 2017) as the cognitive abilities that are required to effectively search for health information online, such as higher processing speed, reasoning ability and executive function decline by age (Sharit, Taha, Berkowsky, Profita, & Czaja, 2015). This is possibly one of the reasons why older patients still heavily rely on their healthcare providers for diagnosis and treatment decisions and for information to make those decisions (Xie, 2009). Integrating tools for online health information provision in regular healthcare (e.g., health information presented on hospital websites, patient portals, online self-management tools, access to personal health records) can provide a solution for hard to find and/or low quality information. The online nature of these tools has several benefits in the provision of information. Information can easily be tailored to the individual needs of the patients and the information can be provided in different modalities (e.g., textual, visual, and audiovisual; Bol et al., 2016). Moreover, information can even be tailored to the modality preferences of the patient, which has found to be effective in improving recall of information on a website with cancer information in older adults (Nguyen et al., 2017). However, as Schulz et al. (2014) propose in a research agenda for health technologies and aging, research should focus on 'how to best shape and direct our efforts to optimize the developments and application of new technologies'. To do so, we need to gain insight into existing knowledge on the effectiveness of online health information tools for older patients and the conditions under which these tools are effective. Moreover, we still lack knowledge on how older cancer patients use and evaluate such tools. This is important to consider as aforementioned age-related changes can hinder optimal usage of online technologies (Becker, 2004; Loos & Romano Bergstrom, 2014; Nayak, Priest, Stuart-Hamilton, & White, 2006; Pernice & Nielsen, 2002). The first aim of this dissertation is therefore to investigate how online health information tools can be effective for older patients and how they are used and evaluated.

### **Multidisciplinary decision making**

Different healthcare providers are involved in the care of cancer patients. This does not only mean that patients are involved in multiple consultations where they communicate with different healthcare providers, but also that these healthcare providers, with different expertise, communicate with each other about the patient. One of the instances in which this formally takes place is during multidisciplinary oncology team meetings. The outcomes of this multidisciplinary communication can then be used as input for the communication with patients. Vice versa, when healthcare providers gather information during consultations with their patients, this can be used as input for deliberation with their peers. Multidisciplinary oncology team meetings have several advantages: better adherence to guidelines, better diagnostics and better adherence to formulated treatment plans (Basta, Bolle, Fockens, & Tytgat, 2017). However, we lack knowledge on whether and how age-related characteristics, that determine the frailty or vitality of patients are addressed during these meetings.

It is important for healthcare providers to gain insight into the frailty or vitality of older patients. Older patients that are vital enough for treatment sometimes are undertreated (Rutten, Den Dulk, Lemmens, Van de Velde, & Marijnen, 2008), whereas frail patients face the risk of overtreatment (Huysse, Stiefel, & De Jonge, 2006; Maas, Janssen-Heijnen, Older Rikkert, & Wymenga, 2007). Moreover, existing protocols to guide treatment decision making are based on clinical trials, from which older patients are often excluded, as they form a heterogeneous group due to their age-related changes (Hutchings, Unger, Crowley, Coltman, & Albain, 1999). Because of the lack of empirical evidence for treatment effectiveness for older patients, information gathering and geriatric evaluation should preferably play an important role in the decision-making process. Geriatric evaluation, comprising geriatric consultation, Geriatric Screening (GS) or a Comprehensive Geriatric Assessment (CGA), can be used to assess the frailty or vitality of the patient by mapping the age-related changes an individual patient is experiencing or dealing with. However, we do not know whether and how geriatric evaluation contributes to the decision-making process. The second aim of this dissertation is therefore to gain insight into the decision-making process concerning older cancer patients during multidisciplinary team meetings.

### **Dissertation outline**

**Chapter 2, 3, and 4** address the first aim of this dissertation. **Chapter 2** describes the results of a literature review to assess the effectiveness of online health information tools for older patients. These tools were found to be effective in facilitating immediate, intermediate and long term outcomes in older patients by providing information, enhancing information exchange, and promoting self-management. Since we discovered that online tools can be effective for older cancer patients, the next step was to find out which elements of these tools contributed to their effectiveness. Therefore, **chapter 3** aims to provide a more in-depth understanding (in terms of effective components and

usability) of the tools that were found to be effective in the systematic literature review described in chapter 3. Unfortunately, these tools were not publicly available (anymore), nor a description of the development process and/or usability issues. To address this gap, **chapter 4** empirically investigates the older adults' preferences for online health information tools, as well as usability they face when using these tools. This can be considered a start in the systematic development cycle of an online health information tool for older cancer patients (Kujala, 2003). With the results of this study we formed a list of recommendations to develop online health information tools for older cancer patients. To address the second aim, this dissertation investigates the decision-making process for older cancer patients during multidisciplinary oncology team meetings, where different specialists discuss patient cases (**chapter 5**). In addition, as this chapter considers the decision-making process for older patients specifically, also the role of geriatric evaluation and geriatric expertise is investigated in this study. This dissertation concludes with a summary of the findings and a general discussion (**chapter 6**).