



*Aging in Modern Times: Geriatric Perspectives on Online Information
Provision and Multidisciplinary Decision Making for Patients*

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Summary

Good communication between patients and their healthcare providers can lead to several beneficial health-related outcomes in patients (Street, Makoul, Arora, & Epstein, 2009). However, older patients (≥ 65 years) are more at risk of poor communication compared to younger patients (Adelman, Greene, & Ory, 2000). For example, we know that older patients recall less information (Jansen et al., 2008; Van Weert, Jansen, Spreeuwenberg, Van Dulmen, & Bensing, 2011), have several unfulfilled information needs (Van Weert, Bolle, Van Dulmen, & Jansen, 2013) and participate less actively during consultations (Sparks & Turner, 2008). In the process of finding solutions for these problems it is not only important to gain understanding of the communication process during the patient-provider interaction, but also to consider the context of the consultation in terms of the input both parties bring to the table.

The aim of this dissertation was to gain insight into the context of the communication of older cancer patients during consultations with their healthcare providers. This dissertation focused on two relevant communication developments in the context of the consultation with older cancer patients: (1) *online health information provision* that can support patients in information provision and preparation for consultations and (2) a geriatric perspective on *multidisciplinary decision making* during so-called multidisciplinary oncology team meetings for healthcare providers. The studies in this dissertation elaborate on existing literature and contribute to filling gaps in the fields of online health information provision for older cancer patients and multidisciplinary decision making surrounding consultations with older patients.

Summary of the main findings

Chapter 2, 3 and 4 are concerned with the first aim of this dissertation: investigating how older patients can benefit from tools that provide online health information and how older patients use and evaluate these tools. By reviewing the existing literature, the study described in **chapter 2** starts with the investigation of the effectiveness of online health information tools for older (≥ 65 years) patients. To give an overview of effectiveness of different online health information tools and the different outcomes they can have, we have proposed a two-dimensional framework of functions (i.e., information provision, information exchange enhancement, and self-management promotion) and outcomes (i.e., immediate, intermediate, and long-term outcomes). The review included 25 articles based on seven studies with a Randomized Controlled Trial (RCT) design. The methodological quality was assessed, and a Best Evidence

Synthesis (BES) was conducted. This allowed us to attribute various levels of evidence (i.e., evidence, limited evidence, indicative findings, no/insufficient evidence) for the effectiveness of the assessed online health information tools. The review shows promising results for the use of online health information tools for older patients. We found evidence for improvement in the intermediate outcome self-efficacy for online health information tools with minimally information provision and information exchange enhancement functions. We also found evidence for a positive effect on the long-term clinical outcomes 'blood pressure', 'hemoglobin levels', and 'cholesterol levels'. The majority of online health information tools that were effective in improving these outcomes had two or three functions. Limited evidence was found for an effect on the intermediate outcomes 'knowledge' and 'perceived social support' and the long-term outcomes 'glycemic control', 'quality of life', and 'exercise performance'. Again, the online health information tools effective in improving these outcomes had at least a combination of two functions.

To follow up on the outcomes of this study, the aim of the next study (**chapter 3**) was to evaluate the development and usability of the online health information tools for which we found evidence in improving intermediate and long term outcomes. To evaluate the development of the online tools we distinguished between various steps or cycles based on development models (i.e., Medical Research Council's (MRC) framework and the Spiral Technology Action Research (STAR) model). Overall, the reporting of the development of the online health information tools turned out to be too succinct. Specifically, only one article reported that a theoretical basis was used to develop the online health information tool (first step in development process). Moreover, we were unable to evaluate the usability of online health information tools as none of them were publicly available (second step). The implementation was only described for two online health information tools (third step). However, nothing was reported on the usage of the online health information tools, which would have been valuable as the tools consisted of several components. Therefore, we cannot make any assumptions on the effectiveness of the separate components or functions of the tools.

As we found online health information tools to be able to deliver promising results for older patients, but lacked knowledge on how to develop them, **chapter 4** reports on a study in which the question on how older cancer patients use and evaluate online health information is answered. The aim of this study was to gain insight into usability

issues and the perceived usefulness of cancer-related online health information tools. We used think-aloud methodology in which we observed cancer patients and survivors ($n = 15$) and their partners ($n = 8$) while using existing online health information tools. The existing online health information tools that we examined in our study consisted of three websites providing cancer-related information, three online question prompt lists (QPLs; i.e., structured lists of questions or topics that patients can use to prepare for a consultation by choosing questions they would like to ask their healthcare provider), and one online values clarification tool (i.e., a decision aid that helps patients make decisions about their treatment by informing them of the treatment options and helping them clarify their values). Regarding how participants *use* online health information tools, we unveiled navigation problems, such as difficulties in navigation through websites that have multiple navigation bars, difficulties in clicking on small buttons or visual difficulties due to similar colors. Regarding how participants *evaluate* online health information tools, we found that participants prefer information presented in different modalities (i.e., a combination of textual, visual, and or audiovisual information). Older patients varied in the amount of information they want. When participants had the possibility to self-select the amount of information this was highly appreciated. Based on the outcomes of this study and based on existing usability literature we give recommendations to develop online health information tools for older cancer patients and their partners.

In **chapter 5**, we turn to the second aim of this dissertation: investigation of decision making communication during multidisciplinary oncology team meetings from a geriatric perspective. This chapter addresses the results of an observational study in which the communication surrounding the decision-making process for ($n = 171$) older cancer patients during multidisciplinary oncology team meetings in five hospitals was unveiled. Moreover, we investigated the contribution of geriatric experts, such as a geriatrician or a geriatric nurse, to the decision-making process and to what extent geriatric evaluation of age-related characteristics of older cancer patients was used in the decision-making process. First, we found that discussion of alternative treatment options and arguments in favor of or against treatment options were often not part of the decision-making process. Second, we found that information on age-related patient characteristics and patient preferences was often left out of the discussion. Third, there were only few remarks during the meeting suggesting geriatric evaluation. Moreover, the contribution of geriatric experts, such as geriatricians or geriatric nurses, to the discussion was limited.

The results of the studies in this dissertation suggest that both for online health information provision as for multidisciplinary decision making it is important to take individual preferences and age-related characteristics into account.