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Enhancing patient participation among older and migrant cancer patients through eHealth

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CHAPTER 9

Summary of the findings

SUMMARY OF THE FINDINGS

Although patient participation in healthcare is a core value of the Western healthcare system, concerns exist that active patient participation, such as shared decision-making (SDM) in treatment and provider choices, is difficult to achieve for several unserved groups of patients (Ekdahl et al., 2011; Hawley & Jagsi, 2015). For example, older cancer patients are at risk of suboptimal information processing because of age-related declines in cognition and deliberate reasoning (Gaissmaier & Gigerenzer, 2008; Peters et al., 2008; Peters, Hess, et al., 2007; Reyna, 2008), and older migrant cancer patients also often experience an additional language barrier to patient participation (Hawley & Morris, 2017). In order to support patient participation of those more vulnerable patient populations, eHealth interventions can be implemented that bridge existing language barriers and problems in information processing. However, relatively little is known about how to achieve this goal, and how such eHealth tools can be made suitable for participation of older and migrant patients in oncological care.

This dissertation aimed at investigating eHealth approaches to enhance patient participation in older cancer patients and older Turkish-Dutch and Moroccan-Dutch cancer patients with low Dutch language proficiency. In general, for older cancer patients there is a need for strategies that could lower the cognitive effort needed to process essential health-related information while simultaneously increasing the motivation to process that information. For example, for SDM about treatment options in oncology, complex textual information about benefits and harms of options need to be processed. Another example of complex information is information for multi-attribute decisions, like hospital choices, where often conflicting attributes need to be compared (Carpenter & Niedenthal, 2018; Hibbard et al., 1997). Recent scientific developments imply that alternative information presentation formats for such information, such as audiovisual and narrative information, can contribute to this aim. For older Turkish-Dutch and Moroccan-Dutch cancer patients with low Dutch language proficiency, there is a need for strategies that could bridge language barriers while taking these patients' needs and preferences into account. This aim could be achieved by developing an oncological eHealth module which could be integrated into an existing tool, the *Health Communicator*. The studies in this dissertation investigated the effects of audiovisual and narrative information on information processing in older cancer patients. Furthermore, the studies in this dissertation investigated the needs and preferences of older Turkish-Dutch and Moroccan-Dutch cancer patients concerning information and participation. These insights, in turn, were used to develop and evaluate an oncological eHealth module.

Altogether, the studies in this dissertation addressed the following research questions:

1. 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?
2. 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?

Chapter 2 - First step in information processing: visual attention

If information is going to be used in choices, the first step is to visually attend to the information. Visual attention is important in relation to information processing because it precedes information encoding and storage in working memory. This dissertation started with a pilot study among analogue female patients with ($n=17$) and without ($n=20$) a history of breast cancer. A total of 17 participants were older and 20 were younger than 65 years. Participants were provided with a fictitious hospital report card (HRC) on a computer screen. An HRC is an online decision support tool aimed at facilitating patients' informed choice of a hospital. The fictitious HRC displayed three hospitals that were compared on ten quality indicators (i.e. a multi-attribute choice). The aims of the study were to (1) explore how women visually attend to information provided in an HRC that informs about the quality of breast cancer care, and (2) assess how visual attention of older women compares to visual attention of younger women.

The study combined eye-tracking with a short survey. Participants were asked to make a hypothetical hospital choice after viewing the fictitious HRC. The results showed that, overall, women looked longer at information about the hospital of their choice and at indicators they perceived to be most important for their choice. Although no differences existed between younger and older women in general, within the group of patients (but not among non-patients), per fixation older patients (compared to younger patients) looked longer at the hospital of their choice, as well as at the indicators they found most relevant. Altogether, visual attention patterns did not differ between older and younger women, but differences did exist in the group of patients. Therefore, **Chapter 2** concluded that prior knowledge about what information is relevant for decision-making results in more in-depth information processing among older patients.

After gaining insight into what information older (versus younger) people are looking for and use in their decision-making process, we conducted two experiments to study the effects of two alternative promising presentation formats of decision-relevant information, namely audiovisual and narrative information in a patient decision aid (PDA; **Chapter 3**) and an HRC (see **Chapter 4**). We tested the effects on patients' information processing and use (i.e. perceived cognitive load, satisfaction with information, comprehension,

information recall, and decisional conflict), and explored differences between older and younger patients.

Chapter 3 - Audiovisual and narrative information in treatment choices: what works?

Information in PDAs and HRCs remains difficult to process for many people, and especially for people facing difficulties in cognitive processing such as older adults. Information in those online decision support tools in general remains to be provided in large amounts of text and in a factual style. Especially for numerical risk information that needs to be weighed in a decision, this might be problematic. Presenting information in an audiovisual format and narrative style seem to be fruitful strategies to enhance information processing among older adults. The first experiment, described in **Chapter 3**, concerned the presentation of decision-relevant information in a PDA for early stage non-small cell lung cancer patients. The information concerned the pros and cons of two treatment options that a great part of early stage lung cancer patients can nowadays choose between: surgery and stereotactic ablative radiotherapy (SABR). The aim of the study was to assess the effects of audiovisual information and narrative information as used in the PDA on information processing and use in older patients compared to younger patients.

The experiment was conducted among 305 cancer patients and survivors (except lung cancer patients/survivors in order to avoid burden for those who need to choose a treatment or are already being treated). We used a factorial 2 (Modality: textual vs audiovisual) x 2 (Narration style: factual vs narrative) between-subjects design. Age [younger (<65 years) versus older (≥ 65 years)] was a potential effect modifier, and the data were analyzed by means of ANOVAs. The results showed that, irrespective of age, audiovisual information (compared to textual information) resulted in lower perceived cognitive load and more effective decisions (a subscale of decisional conflict), and in higher satisfaction with the (attractiveness of the) information. In younger patients, information in a narrative style (compared to factual information) was associated with reduced uncertainty about the (hypothetical) decision. Besides, in younger patients (compared to older patients), audiovisual factual information was associated with lower perceived cognitive load. In sum, **Chapter 3** suggests that, in order to support information processing, audiovisual information can be recommended to present information in a PDA. Narratives in general, however, had limited beneficial effects over factual information, implying that for the incorporation of narratives into PDAs to enhance information processing for (older) cancer patients further research is needed. Especially research into different types of narratives that could benefit information processing was recommended.

Chapter 4 - Audiovisual and narrative information in hospital choices: what works?

After being diagnosed with cancer, patients are not only expected to choose a treatment. They also have to choose the hospital where they will be treated. The second experiment, described in **Chapter 4**, was conducted among 631 disease-naïve women (i.e. women who had no history of breast cancer). The aim was to assess the effects of audiovisual information and two types of narrative information as used in the description of quality indicators in an HRC on information processing and use in older patients compared to younger patients. This experiment encompassed a 2 (Modality: textual vs audiovisual) x 3 (Narration style: factual vs process narrative vs experience narrative) between-subjects design. Unlike the previous experiment in **Chapter 3**, this second experiment thus distinguished between two types of narratives in order to get more insight into what might be more suited for older patients. The process narrative was characterized by a focus on the cognitive axis of decisions, while the experience narrative was characterized by an additional focus on the experiential axis (i.e. visceral experiences and emotions) of decisions. Age [younger (<65 years) versus older (≥65 years)] was considered a potential effect modifier, and the data were analyzed by means of AN(C)OVAs.

The results showed that, irrespective of age, audiovisual information (compared to textual information) increased patients' satisfaction with the attractiveness of information and with emotional support from the information. Unexpectedly, audiovisual information (as compared to text) was associated with worse information comprehension in older women. This effect was no longer existent, however, when we controlled for level of education or health literacy. Furthermore, in older women, experience narratives, audiovisual factual information, and textual process narratives were particularly associated with higher satisfaction with emotional support and with the comprehensibility of information. In younger women, compared to older women, especially textual factual information and audiovisual process narratives were associated with higher satisfaction with the comprehensibility of the information. In line with the findings in **Chapter 3**, the findings of **Chapter 4** also suggest that audiovisual information can be recommended to enhance the processing of decision-relevant information in online decision support tools. However, the use of narrative information – regardless of whether process or experience narratives are being used – does not seem to have major beneficial effects over factual information for patients from all age groups. Hence, narrative information in HRCs cannot necessarily be recommended for all patients. Nevertheless, the effects of narratives in older women suggest that it could be recommended to elaborate on the effects of experience narratives on information processing in older patients in future research.

Chapter 5 – To what extent do ethnic minority patients want to be informed and to participate?

While **Chapter 3** and **4** yielded insights into how existing online decision support tools can be optimized for older cancer patients in general, for older ethnic minority patients, more effort seems to be needed to make eHealth tools aimed at patient participation suitable for them. As a first step **Chapter 4** described a systematic literature review ($N=44$), which aimed to gain insight into the information and participation preferences and needs of non-Western ethnic minority cancer patients living in Western countries. Although the general stereotype of ethnic minority patients is that they do not want to be informed about their medical situation and that they remain passive during medical encounters, this review would enable us to get an idea of whether they prefer and/or need to be informed and to actively participate in medical encounters. The review encompassed a literature search in several databases, and thematic analysis was conducted to analyze the data.

The results showed that both older and younger non-Western ethnic minority patients preferred/needed to be informed about several topics, such as: (1) their diagnosis and metastasis, (2) cancer treatment and its aftermath, (3) their prognosis and cancer recurrence, (4) alternative medicine, nutrition, and physical activity, (5) causes, genetics and prevention of cancer, and (6) healthcare system and services in the host country. Being younger, female, and unmarried, and having better language proficiency in the country's dominant language seemed to be associated with higher information preferences (i.e. preference to be more informed). Latin-American and African-American patients/survivors mainly preferred shared or active participation, while Asian and Middle-Eastern patients/survivors mainly preferred passive participation. Although both older and younger patients/survivors had high participation preferences, a younger age, but also a higher level of education and acculturation seemed to be associated with a preference/need for active or shared participation. Moreover, the results seemed to support the concept of superdiversity, as not only differences in preferences/needs between non-Western ethnic minority groups, but also within these groups were apparent. These findings underscore the importance of tailoring information and level of involvement to the individual patient. In conclusion, **Chapter 5** suggests that there is a discrepancy between what is known from the literature concerning ethnic minority patients' information-seeking and participation behaviors (i.e. asking few questions and being passive during medical encounters) and their actual preferences and needs. This discrepancy seems to be caused, at least partly, by existing language barriers. To meet (older) migrant cancer patients' information and participation preferences/needs, and to actually enable them to participate in healthcare, a first step is to implement interventions – such as the *Health Communicator* – that target the language barrier.

Chapter 6 - What components should a multilingual eHealth tool contain to be effective for migrant patients?

A next step was to gain insight into the unfulfilled needs of our target populations (i.e. older migrant groups) concerning the instrumental and affective aspects a tool should contain to bridge the language barrier. Next to the views of patients, it was important to learn the views of healthcare professionals. **Chapter 6** describes a qualitative study among Turkish-Dutch ($n=10$) and Moroccan-Dutch ($n=9$) older cancer patients, and general practitioners ($n=7$) and oncology nurses ($n=5$). This study aimed to map the unfulfilled instrumental and affective needs of Turkish-Dutch and Moroccan-Dutch older cancer patients/survivors, to explore the barriers perceived by healthcare professionals in fulfilling these needs, and to assess how the *Health Communicator*, a multilingual eHealth tool aimed at patient participation, can support the fulfilment of patients'/survivors' needs, and decrease barriers experienced by professionals. Semi-structured interviews were held with older cancer patients/survivors, and focus groups were conducted with healthcare professionals.

The results showed that Turkish-Dutch and Moroccan-Dutch older cancer patients/survivors had unfulfilled *instrumental* needs concerning: (1) information about cancer (treatment), including information about lifestyle (e.g. physical activity and diet); and (2) information about the healthcare system, including information about services, patient rights, and clinical trials. Patients/survivors had unfulfilled *affective* needs concerning: (1) possibilities regarding psychosocial support, and (2) affective doctor-patient communication. Among healthcare professionals, the main barriers to fulfilling patients'/survivors' needs were: (1) patients'/survivors' low health literacy and language barrier, (2) cultural taboo, (3) lack of insight into patients' instrumental needs, and (4) patients'/survivors' lack of trust in Dutch healthcare. Both patients/survivors and professionals believed that the *Health Communicator* could support in fulfilling many unfulfilled needs and decreasing the barriers. Patients/survivors told that the *Health Communicator* should be intuitive to navigate and provide stories of peers. Ultimately, however, a majority of patients/survivors was hesitant to use the *Health Communicator*, because they perceived it too difficult to use. Our findings correspond with the findings from the literature review: patients/survivors want to be informed about a wide range of cancer-related topics. Moreover, the findings imply that the *Health Communicator* can be effective in bridging the language barrier to patient participation in healthcare if some recommendations mentioned by patients and healthcare professionals are taken into account when designing the tool. Altogether, **Chapter 6** suggests that content-wise, the *Health Communicator* should entail features to seek and ask for information about cancer and its treatment, and about the Dutch healthcare system, while simultaneously offering the opportunity to receive psychosocial support, and a more affective bond with the healthcare professional. Format-wise, the *Health Communicator* should be intuitive to navigate and consist of audiovisual narrative information.

Chapter 7 - Is a multilingual eHealth tool that is based on migrant patients' and professionals' preferences and needs promising to enhance participation?

Based on the insights from **Chapter 6**, an oncological module was developed for the *Health Communicator*, which aimed at increasing patient participation of older migrant cancer patients with low Dutch language proficiency. The module was evaluated in a pilot study. This evaluation study was performed among older Turkish-Dutch and Moroccan-Dutch cancer patients ($N=27$), and is being described in **Chapter 7**. The Spiral Technology Action Research model was leading for the development phase of the oncological module. Audiovisual Question Prompt Lists (QPLs) were developed containing questions about: (1) treatment, (2) lifestyle and services, (3) patient rights, (4) clinical trials, (5) emotional support, and (6) patients' information preferences. Moreover, patient education videos were developed regarding (1) patient rights, (2) clinical trials, (3) emotional support and (4) doctor-patient communication.

The results of the evaluation showed that patients most often chose the QPL and patient education video about patient rights. Although older age was negatively correlated with perceived ease of using the QPLs, overall, the QPLs were perceived to be relatively easy to understand and useful. Moreover, both patients and professionals reported that using the oncological module contributed to a more active patient participation compared to previous consultations. Patient education videos were perceived to be easy to understand, useful, and informative. Ultimately, the majority of patients (70.0%) intended to use the oncological module in the future. **Chapter 7** suggests that an oncological module that is tailored to the needs of migrant cancer patients can enhance patient participation. Moreover, including audiovisual narrative materials in the eHealth tool in the mother tongue of the older migrant cancer patient, seems to be a promising approach for patient education, in turn likely contributing to increased effectiveness of migrant healthcare communication, and, hence, to enhanced patient participation.

Conclusion

Overall, in order to enhance information processing, and ultimately patient participation, among older cancer patients incorporating audiovisual information in HRCs and PDAs seems to be a promising approach. Narratives might also be considered to be included in online decision support tools, but it should be kept in mind that narratives seem to have more effects on satisfaction with the information than on actual information processing (e.g. perceived cognitive load, comprehension, and recall). For older migrant cancer patients, patient participation can be supported by introducing a multilingual eHealth tool, such as the oncological module *Conversation Starter* which can be integrated with the *Health Communicator*.