



UvA-DARE (Digital Academic Repository)

Enhancing patient participation among older and migrant cancer patients through eHealth

Yilmaz, N.G.

Publication date

2020

Document Version

Other version

License

Other

[Link to publication](#)

Citation for published version (APA):

Yilmaz, N. G. (2020). *Enhancing patient participation among older and migrant cancer patients through eHealth*.

General rights

It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations

If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: <https://uba.uva.nl/en/contact>, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

CHAPTER 8

General discussion of the findings
and conclusion

GENERAL DISCUSSION OF THE FINDINGS

Part I

The first part of this dissertation addressed how patient participation in a general population of older cancer patients can be enhanced through eHealth: online Hospital Report Cards (HRCs) and Patient Decision Aids (PDAs). The first research question was: *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?* The findings of **Chapter 2** suggest that for patients and survivors, the most relevant information could be displayed prominently to improve their information processing. The findings of **Chapter 3** and **Chapter 4** raise two questions, namely the question of whether and how audiovisual information should be incorporated in HRCs and PDAs, and how future studies should investigate the effects of narratives. Below, these points are discussed further.

Theoretical reflections

Visual attention is considered to be one of the key initiators of cognitive processes such as information processing (Godefroy et al., 2010). Generally, only after visual attention has been established, information can be processed. Our eye-tracking study (**Chapter 2**) showed that visual attention is being devoted more to information that is perceived to be relevant than to information that is perceived to be less relevant for a hospital choice. This might imply that visual attention to information in the HRC is for a great part driven by top-down attention (Ebaid & Crewther, 2019), which is goal-oriented and relates to intrinsic motivation to attend to the information (Madden, 2007). **Chapter 2** also suggested that prior knowledge of women with a breast cancer history (as compared to disease-naïve women) about what information is relevant for decision-making results in more in-depth information processing among older patients. The findings of **Chapter 2** together, thus, seem to indicate that the information in the HRCs is – at least for a great part – processed through heuristics, which is a characteristic of System 1 processing. As described in the **Introduction**, System 1 processing entails intuitive reasoning that is rather automatic, quick and effortless information processing, because one can rely on heuristics or rules of thumb (Bekker et al., 2013; Kahneman, 2003).

Whether the use of heuristics resulted in more in-depth information processing in the HRC should be interpreted cautiously. Especially prior knowledge among older patients about what information is relevant for them seemed to lead to more in-depth information processing, i.e. longer visual attention. Patients in general, compared to non-patients, are likely to have already constructed their preferences because they experienced the disease and were treated in certain hospitals, and, hence, are likely to have built knowledge and more adequate mental models about hospital quality. The particular group of older patients have accumulated more life experience than younger patients. As such, older

patients might use heuristics, for instance the elimination-by-aspects heuristic (Victoor et al., 2012), more easily when processing information from an HRC (System 1 processing), while younger patients probably need to elaborate more deliberately on the information (System 2 processing). This likely explains why older patients seemed to use the information that was relevant for them quite effectively. However, longer visual attention might also be a result of difficulties in understanding the information. If information was difficult to process, it is also possible that older patients made use of the recognition heuristic (Goldstein & Gigerenzer, 2002) or the affect heuristic (Slovic et al., 2007). This, thus, does not necessarily mean that information was processed more in-depth.

Once visual attention has been established, and information is going to be processed, it is important to aim for presentation formats that require little cognitive effort. All in all, information processing is not only driven by top-down attention, but also by bottom-up attention that is related to the characteristics of the provided information (Ebaid & Crewther, 2019; Madden, 2007). In light of this aim, **Chapter 3** and **Chapter 4** showed that audiovisual information has several beneficial effects on information processing compared to textual information. The evidence concerning the beneficial effects of audiovisual information is quite robust in diverse fields. For example, a study about the effects of audiovisual information on the recruitment of participants for clinical trials showed that audiovisual information can improve patients' knowledge (Hutchison et al., 2007). Another study regarding prenatal screening showed that audiovisual information can enhance both informed choices and satisfaction with the information (Björklund et al., 2012). More recent studies also showed that audiovisual information can lead to better information recall in older adults (Bol et al., 2013; Bol et al., 2015; Meppelink et al., 2015).

The findings of **Chapter 3** and **Chapter 4** concerning presenting information audiovisually are supported by the Cognitive Theory of Multimedia Learning (CTML). As described in the **Introduction**, the CTML asserts that people process visual and auditory information through separate channels, which have both a limited capacity to process information (Mayer, 1999). Unimodal information presentation formats activate information processing through one of both channels (e.g. textual information activates the visual channels). Multimodal information presentation formats, such as audiovisual information, activate both channels. A modality effect, which entails that more information can be processed before cognitive overload occurs when information can be divided over both the auditory and the visual processing channels, can occur when information is presented in auditory format combined with moving visuals, such as in an animation (i.e. audiovisual information) compared to information in written format only (Dunn et al., 2004; Ginns, 2005; Sparks et al., 2013). The modality effect is likely to explain the beneficial effects of audiovisual information on information processing variables found in our online experiments. By activating both the visual (i.e. animated video) and

the auditory (i.e. voice-overs) channel, information load was probably divided over these channels, lowering the cognitive load needed to process the abstract information in the HRC or PDA, and enhancing information processing.

Several studies show mixed results concerning the effectiveness of narratives in decision support tools. In line with these mixed results, in **Chapter 3** and **Chapter 4**, we found different, but limited effects of different types of narratives. Overall, we found little support for the beneficial effects of narrative information (compared to factual information) on information processing, which might be a result of issues that are discussed in the section *Practical reflections*. Nevertheless, it should be mentioned that narrative information did not have negative effects on information processing. It is also important to mention that the narrative used in **Chapter 3** yielded a beneficial effect on decisional conflict (i.e. less uncertainty about the hypothetical decision), while the narratives used in **Chapter 4** yielded a beneficial effect on satisfaction with the emotional support from the information. Although it is speculative and should be interpreted with caution, these findings might imply that the narrative used in **Chapter 3** for a treatment choice served System 2 processing or the central route of information processing (see Elaboration Likelihood Model described in the **Introduction**) because it had effect on decisional conflict, while the narratives used in **Chapter 4** for a hospital choice might have served System 1 processing or the peripheral route of information processing because it had effect on satisfaction with the information. In **Chapter 4**, experience narratives even led to higher satisfaction with emotional support from the information in older women. This finding can likely be explained by the Socio-emotional Selectivity Theory (SST). As shortly mentioned in the **Introduction**, the SST asserts that older adults, compared to younger adults, are more motivated to process emotionally meaningful information than statistically meaningful information (Carstensen, 2006; Carstensen et al., 2003; Carstensen et al., 1999). In our experiment, the experience narrative, compared to the factual information and the process narrative, presented rather affective information about the process of choosing a hospital. As older adults are likely to focus more on emotional information, this more affective content of the experience narrative probably induced higher satisfaction with emotional support from the information. Whether higher satisfaction with emotional support from the information was positive or negative for actual information processing or the decision-making process remained unclear in our studies.

Practical reflections

Practically, the findings of our eye-tracking study (**Chapter 2**) suggest that for (older) patients, the most relevant information could be displayed prominently in an HRC to improve their information processing. This approach is similar to the mental models approach that aims to deliver information that patients believe to be relevant (Strough et al., 2015). However, this approach can have some downsides. Patients, especially

older patients who already have prior knowledge and experience, might use heuristics (e.g. recognition heuristic or affect heuristic). If information that is perceived to be most relevant is being presented prominently, this might bias the decision-making process. Older patients might entirely skip or less deliberately process the information that they perceive to be less relevant, while that particular information might be important to weigh during decision-making. For (older) patients, therefore, it might be considered to provide them with information that is presented in a way that increases their motivation to also attend information they perceive less relevant. One approach might, for instance, be that all information is framed positively, as it is known that a positivity bias exists in older adults (Strough et al., 2015).

For younger and newly diagnosed patients, however, some guidance in what information elements might be important to consider when making informed decisions could contribute to enhanced information processing. Younger patients, compared to older patients, have less prior experience to rely on and to make decisions faster. Newly diagnosed patients often have no prior experience at all and need to construct their preferences based on provided information. In light of this, younger and newly diagnosed patients might benefit from value clarification exercised they would need to complete before using an HRC. Value clarification methods help patients to define their values and to confine decision aspects that are most important to them (Fagerlin et al., 2013).

The information we provided participants with in our online experiments was mainly aimed at explaining the risks and benefits of treatment options (**Chapter 3**) and the process of choosing a hospital (**Chapter 4**), and, hence, could be considered as guidelines needed by newly diagnosed patients when they need to make a choice. Given the positive effects that audiovisual information showed in both experiments, an answer to the question “*Should audiovisual information be incorporated in HRCs and PDAs?*” could be that an audiovisual format seems promising, and might be recommended to be used when presenting abstract information about quality indicators (HRCs) or risks and benefits of (treatment) options (PDAs). Some practical considerations should also be borne in mind. As discussed in **Chapter 3** and **Chapter 4**, participants who received our audiovisual materials could not self-pace the information. This is likely the reason why we did not find beneficial effects of audiovisual information (compared to textual information) on information processing outcomes such as better information recall. Self-pacing, therefore, might be important when providing (older) patients with audiovisual information.

Besides enabling self-pacing, it needs to be minded that audiovisual information should not be considered as a replacement of conventional textual information, but rather as an addition to textual information for two main reasons. First, with older age, people are more likely to experience physical inabilities, such as hearing impairments, and might prefer

written information (e.g. in a leaflet) which they could read over audiovisual information to which they would have to listen. As shown in **Chapter 4**, also a lower level of education or health literacy likely negatively influences the effectiveness of audiovisual information in enhancing information processing, particularly in older patients. Second, given the reflections described in the paragraphs above, (re)designs of HRCs and PDAs should preferably adopt several user options, such as the option to select relevant information after value clarification exercises, the option to use both text and audiovisual information, and the option to self-pace audiovisual information. This means that no ‘one-size-fits-all’ approach can be used, and this might be technically complex and costly, especially if system-generated tailoring is being used instead of user-generated tailoring.

In contrast to audiovisual information, the use of narratives in HRCs or PDAs seemed to be less strongly speaking for itself. Therefore, based on the findings of this dissertation, there seems to be little ground to recommend the incorporation of narrative information – compared to factual information – in online decision support tools. From our online experiments, two main conditions that might play a role in the effectiveness of narratives could be extracted: (1) the type of narrative, and (2) the type of decision to be made. As for the type of narrative, scholars in the field of decision-making have distinguished three relevant types of narratives that can support the decision-making process: outcome narratives, process narratives, and experience narratives (Shaffer & Zikmund-Fisher, 2013). In our first experiment (**Chapter 3**) we used one narrative that was a mix between a process and an experience narrative, and in our second experiment (**Chapter 4**) we explicitly distinguished between a process and an experience narrative. In both experiments, the narrative conditions were elaborated versions of the information from the factual conditions to which contextual information was added. This could be considered as a strength, as the effects we found could only be attributed to the contextual information added to the factual information. However, it is also plausible that for reaching effects of narratives on information processing, the content of the narrative should be as short as the content of the factual condition (in order to avoid information overload) and/or more different in nature from the factual condition (in order to induce the immersion effect). The length of information might affect information recall. It is also known that especially older adults might experience difficulties in distinguishing between the main information and side issues (Brown & Park, 2003). Hence, the length of the information could have distracted (older) patients’ attention from the core message of the narratives.

As for the type of decision to be made, we distinguished between a treatment decision (**Chapter 3**) and a hospital choice (**Chapter 4**). Although sound evidence is absent, a treatment decision, compared to a hospital choice, might be considered a more affective choice, because treatment can have a rather direct and persistent effect on one’s health and quality of life. A hospital choice, in contrast, might be perceived as less affect-laden since

the overall quality of care is high in the Netherlands. In our online experiments we found other effects of narratives on treatment decisions than on hospital choices, supporting the possibility that the effects of narratives are context-specific, which is in line with findings of a recent review (Woudstra & Suurmond, 2019). Altogether, for practice, it could be recommended to bear in mind that narratives in HRCs and PDAs seem to have little effect on information processing. Besides, narratives seem to have context-specific effects (i.e. effects on different outcome measures in different types of decision-making contexts). This might make the development of adequate narratives a costly approach without a guarantee for better informed decisions.

Methodological reflections and future research

The studies described in **Chapter 2** to **Chapter 4** have some strengths and limitations. One of the strengths is that the materials used in the studies (i.e. audiovisual and narrative information) were all carefully and systematically developed with an eye on the latest scientific insights, involvement of experts and patients, and pre-tests among patients. This allowed for a thorough overview of what elements of the materials needed to be adapted, what elements needed to be remained intact, and what additional elements were needed. Another strength is that the effects of audiovisual and narrative information on information processing were thoroughly investigated in different types of online decision support tools in rather heterogeneous samples in terms of level of education. This allowed for insight into the effects of these information presentation formats in different types of online decision support tool.

One of the major methodological downsides of our studies was that we pre-tested our stimulus materials on whether information was perceived as factual or narrative, but not on difficulty to understand a quality indicator (**Chapter 2**), or on whether the core messages from the narratives are being understood (**Chapter 3** and **Chapter 4**). Pre-testing the quality indicators on difficulty to understand them, would have enabled us to make more firm statements about whether longer visual attention to certain indicators was attributable to greater interest in the indicator or to perceived difficulty to understand the indicator. Pre-testing whether the core messages from the narratives are being understood would have enabled us to be surer about the extent to which contextual information was distracting and cognitively burdensome for participants. Future research, hence, could pay attention to these types of pre-tests by asking (gist) comprehension questions in a smaller sample of participants before starting actual data collection.

For future research, it could be worthwhile to study the effects of self-pacing audiovisual information in HRCs and PDAs on information processing. For narratives, it could be recommended to try to gain more insight into the conditions under and context in which narratives have what types of effects. As such, it could be recommended that future studies

do not primarily focus on the question ‘*Do narratives have an effect?*’ anymore, but rather try to gain insight into the conditions under which narratives have an effect. For example, we studied the effects of process narratives and experience narratives in an HRC. Future studies could focus on the effects of process narratives and experience narratives in PDAs. Finally, cost-effectiveness studies could be conducted to help HRC and PDA developers in gaining insight into the costs and benefits, and whether they are in balance, of adding audiovisual information (and narratives) to online decision support tools.

Part II

The second part of this dissertation addressed how patient participation in a specific population of older cancer patients, namely older Turkish-Dutch and Moroccan-Dutch cancer patients, can be enhanced through eHealth: the multilingual *Health Communicator*. The second research question was: *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?* The findings of **Chapter 5** and **Chapter 6** suggest a discrepancy between what is known from the literature concerning migrant patients’ information-seeking and participatory behaviors, and their actual needs and preferences concerning information and participation. Second, the findings of the evaluation study (**Chapter 7**) implied that the *Conversation Starter*, the oncological module we developed to be integrated into the *Health Communicator*, might be a promising tool to enhance patient participation albeit to a certain extent.

Theoretical reflections

Existing literature on health communication and migrant patients shows that migrant patients do often not seek information (e.g. ask fewer questions than native patients) (Schouten & Meeuwesen, 2006; Schouten et al., 2007), and do not actively participate during medical encounters (e.g. leave decisions to the healthcare professional) (Björk Brämberg et al., 2010; Schinkel et al., 2015; Shaw et al., 2015). However, the findings of our systematic literature review (**Chapter 5**) revealed that (older) ethnic minority cancer patients have high information and participation needs and preferences. This finding was supported by our interview study (**Chapter 6**) in which Turkish-Dutch and Moroccan-Dutch older cancer patients reported to have high preferences for information, and high affective needs. These needs frequently remained unfulfilled due to several factors.

The discrepancy between migrant patients’ high need for information that emerged in **Chapter 5** and **Chapter 6**, and their highly passive information-seeking behavior reported in existing literature seems to imply that there is a gap between migrant patients’ willingness and their ability to get information. This gap might be understood by means of the Comprehensive Model of Information-Seeking (CMIS). The CMIS asserts that one’s

information-seeking behavior is partly influenced by characteristics of the information-seeker, such as his or her demographics (Johnson & Meischke, 1993). The fact that migrant patients have high information needs but do often not seek much information is likely related to some other demographic characteristics than are currently proposed in the CMIS. Literature that applies and even adapts the CMIS focuses on demographics like age, gender, level of education, and income (Basnyat et al., 2018; Sheng & Simpson, 2015). Our findings, especially from **Chapter 6**, imply that factors like language proficiency also highly influence information-seeking ability, and, as a result, information-seeking behavior. The effects of ethnic background and factors related to ethnic background, however, are not being investigated and incorporated in the CMIS. Our findings concerning the factors related to ethnic background that seem to play a role in information-seeking ability and behavior might provide some suggestions for the extension of the widely used CMIS. For the extension of the CMIS, this model could be synthesized with a more culture-specific information-seeking model that considers ethnicity, cultural background, and language proficiency as antecedents of information-seeking (Schouten & Meeuwesen, 2006). Extending the CMIS with factors specifically related to migration background affecting information-seeking behavior could allow research and further developments to (1) apply the CMIS in a broader context, (2) gain more insight into characteristics of migrant patients that contribute to the gap between their preferences and needs, and behaviors, and (3) develop interventions, such as multilingual eHealth tools, that target factors that impede information-seeking in migrant patients, which in turn also affects their level of participation in healthcare.

The discrepancy between older migrant cancer patients' high participation need that emerged in **Chapter 5** and **Chapter 6**, and their passive participatory behavior reported in existing literature seems also to imply that there is a gap between migrant patients' willingness and their ability to participate actively. This gap can be explained by the Linguistic Model of Patient Participation in Care of Street (Street, 2001). This model proposes that patient participation is determined by three main categories of factors: predisposing factors, enabling factors, and provider responses. Predisposing factors refer to a patient's cultural background (e.g. views on doctor-patient relationship), social background (e.g. level of education), and psychological characteristics (e.g. anxiety and coping styles). In our sample (**Chapter 6**), some patients did not want to know about their disease. Being uninformed seemed to serve as a coping mechanism for them to handle the disease. This predisposing factor might contribute to migrant patients' rather passive participation, despite their need for active participation. Enabling factors refer to a patient's resources (e.g. prior experience with or knowledge about a topic, and health literacy) and skills (e.g. communicative skills) required to participate, and to contextual factors (e.g. participation routines of the patient). The most obvious enabling factor that would stimulate active patient participation is, as explained above, language proficiency.

In our sample (**Chapter 6**), a low language proficiency was one of the major barriers patients faced. This enabling factor probably contributed to migrant patients' inability to participate actively, despite their motivation to participate. Provider responses refer to whether and how a healthcare professional reacts on a patient's verbal and non-verbal cues. A provider response that would stimulate active patient participation is that healthcare professionals respond to patients' affective needs. However, in our sample (**Chapter 6**), healthcare professionals reported to be uncertain about the extent to which they could show affective behaviors. Altogether, although we did not formally test what factors cause or contribute to the discrepancy between migrant patients' participation needs and preferences and their actual participatory behaviors, our results from **Chapter 5** and **Chapter 6** suggest that factors that are expected to stimulate patient participation were – to a large extent – absent in our samples.

As the language barrier is one of the major factors contributing to migrant patients' inability to getting their instrumental and affective needs fulfilled and to showing passive participatory behaviors, a tool that targets the language barrier is likely to contribute to better fulfilment of their needs and to enhanced patient participation. As expected, in **Chapter 6**, the *Health Communicator* seemed to show this potential, and in **Chapter 7**, the *Conversation Starter* (the newly developed oncological module) seemed to show this potential. The findings from **Chapter 6** and **Chapter 7** concerning patients' views on and attitudes towards the *Health Communicator* and the newly developed oncological module are in line with the Technology Acceptance Model (TAM). As described in the **Introduction**, the TAM asserts that once an eHealth tool is perceived as useful and easy to use, one's attitude towards the use of that tool and the behavioral intention to use the tool will be higher (Davis, 1985). In **Chapter 6**, patients and survivors perceived the *Health Communicator* as useful but difficult to use. Therefore, they did not intend to use the *Health Communicator* in its existing format. In **Chapter 7**, we provided patients and survivors with the newly developed oncological module which was developed with an eye on points of improvement mentioned by patients themselves. This newly developed oncological module was perceived as useful and as rather easy to use, resulting in a positive and higher intention to use the module in future encounters. The fact that our findings are supported by the TAM suggests that it is important to measure technology acceptance among the target population when new eHealth tools are going to be developed.

Practical reflections

Existing literature often focuses on migrant patients' communicative and participatory behaviors, which are reported to be passive. The passive behavior of migrant patients is often explained by patients' low language proficiency in the dominant language of the host country (de Maesschalck et al., 2011; Paternotte et al., 2015), and this explanation could lead to a stereotyped, and incorrect, image of migrant patients. Healthcare professionals might

thus erroneously believe that migrant patients do not want to be informed or to participate actively, while in fact, they report a high need for information and participation. Likely as a result of both patients' passive behaviors, and healthcare professionals' misperceptions regarding the cause of these behaviors, the literature shows that in intercultural medical encounters, healthcare professionals build less rapport with migrant patients or engage migrant patients less (Butow et al., 2011; Meeuwesen et al., 2006; Schouten & Meeuwesen, 2006; Schouten et al., 2008). Studies implied that migrant patients' lack in ability to be informed or to participate can negatively influence their participatory behaviors (Schinkel et al., 2016; Schinkel et al., 2013). In our study (**Chapter 6**), Turkish-Dutch and Moroccan-Dutch older cancer patients showed high willingness to be informed and to participate actively. However, as reported by older patients, their ability to participate seemed to be hampered by the language barrier, and this barrier often causes instrumental and affective needs to remain unfulfilled. Hence, the first step to diminish the gap between Turkish-Dutch and Moroccan-Dutch patients' willingness to participate and their ability to participate is to solve the language problem.

In an attempt to contribute to solving the language barrier, we developed the *Conversation Starter*, a multilingual oncological eHealth module that could be integrated with the existing *Health Communicator*. **Chapter 7** showed that, overall, Turkish-Dutch and Moroccan-Dutch older cancer patients and healthcare professionals evaluated the *Conversation Starter* positively and perceived themselves to be more active in comparison to previous consultations. Healthcare professionals echoed this result. As such, the *Conversation Starter* is a promising tool to bridge at least a part of the language barrier and to contribute to more active patient participation among older migrant cancer patients. It should be borne in mind, however, that the *Conversation Starter* does probably not provide the complete solution to the language barrier perceived among migrant patients and healthcare professionals, and that the tool should be considered as a supporting tool rather than a tool that could bridge all problems faced during intercultural medical encounters. For example, **Chapter 7** shows that although patients and healthcare professionals report the patients to be more active after using the oncological module, the healthcare professionals are still leading the conversations and asking most questions. Besides, even after choosing a QPL, for example the QPL about patient rights, healthcare professionals ask more questions about the topic of the chosen QPL (e.g. patient rights), but patients do not. These findings imply that the *Conversation Starter* works well on informing the healthcare professional about patients' needs and making them discuss topics they might otherwise not have discussed, can help patients before and after the medical encounter because they can select QPLs and watch patient education videos in their own language, but that there is room for further improvement in order to help patients during medical encounters. This is most likely a result of the fact that the oncological module is not able to completely polish off the low language proficiency among patients. Hence, during the

medical encounter patients are still not able to ask the questions, and even maybe not even able to understand the information, about the topics that they would like to be informed about, which calls for more conventional solutions to the language barrier faced during medical encounters.

The restrictions bound to the ability of the *Conversation Starter* to diminish the language barrier during medical encounters implies that there is still a need for professional interpreters to be present during medical encounters. As **Chapter 6** showed that the involvement of informal interpreters is perceived as a major barrier to informing and engaging patients by healthcare professionals, they are not suitable to bridge this language barrier. As mentioned in the **Introduction**, a relatively recent report showed 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). This is partly due to the fact that since 2012 budget cuts led to scarcer free availability of professional interpreters in healthcare in the Netherlands. Nevertheless, The Netherlands Institute for Human Rights published in 2017 a statement in which calling in interpreters is seen as a basic human right (Goudsmit & Dute, 2017). Engaging interpreters in intercultural medical encounters is, among others, important for informed consent purposes. For informed consent, it is crucial (i.e. a patient right) that patients are being well-informed about their health problem, the treatment options, and the steps to follow. Hence, healthcare professionals are obliged to adequately inform patients. When informing migrant patients, healthcare professionals need to bear in mind that information should be adapted to the language proficiency level of the patient. Without ensuring that migrant patients fully understand the information, informed consent cannot be officially obtained from these patients, which contrasts with patients' rights. Hence, there is an evident need for adaptations of daily intercultural medical encounters and an embedding of language-related policies in healthcare. It could be recommended that, next to implementing the oncological module, professional interpreters are made available again for free in order to support patients and healthcare professionals in bridging the language barrier.

Methodological reflections and future research

The studies described in **Chapter 5** to **Chapter 7** have some strengths and limitations. One of the major strengths is that the materials used in the studies (i.e. QPLs and patient education videos) were all carefully and systematically tested and developed with an eye on the involvement of and pre-tests among patients and healthcare professionals. This allowed for a thorough overview of what elements of the materials could be clearly understood, and what elements were unclear and needed to be adapted.

For future research, it might be valuable to conduct more studies on the possible solutions that could diminish the gap between migrant patients' passive behaviors and their high

instrumental and affective preferences and needs. The discrepancy between what is known from literature about migrant patients' behaviors and what appeared in our studies to be their preferences and needs, might hamper effective doctor-patient communication in intercultural medical encounters. Creating awareness about this discrepancy among healthcare professionals might reduce stereotyped views and enhance the communication process. In the light of reducing stereotyped views, it might also be interesting to focus future studies more on perceived stereotyping and discrimination. As patients most often chose the QPL and patient education video, this might imply that they felt stereotyped or discriminated by their healthcare professional and wanted to learn more about their rights.

Cost-effectiveness research of the free availability of professional interpreters might also be a worthwhile field of study. The free availability of professional interpreters was mainly abolished because of financial reasons. The scarce body of literature, however, suggests that the presence of professional interpreters during encounters might on the longer term be more effective because it diminishes among others the chances of misdiagnoses by healthcare professionals and the number of revisits by patients (Bischoff & Hudelson, 2010). Therefore, future research could be performed concerning the cost-effectiveness of either or not engaging professional interpreters in intercultural medical encounters on the longer term.

OVERALL CONCLUSION

If online decision support tools are to be optimized in order to enhance patient participation among older cancer patients, it can be recommended to incorporate audiovisual information in HRCs and PDAs. Incorporating narrative information in HRCs and PDAs could also be considered, especially if the online decision support tool aims to enhance satisfaction with the information.

If patient participation among older migrant cancer patients is to be enhanced, first the language barrier experienced by migrant patients should be vaporized. The oncological module *Conversation Starter*, which can be integrated with the *Health Communicator*, seem to succeed – at least to a certain degree – in bridging the language barrier.