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Improving online health information provision for older cancer patients

Online health information usage and its influence on patient outcomes

de Looper, M.

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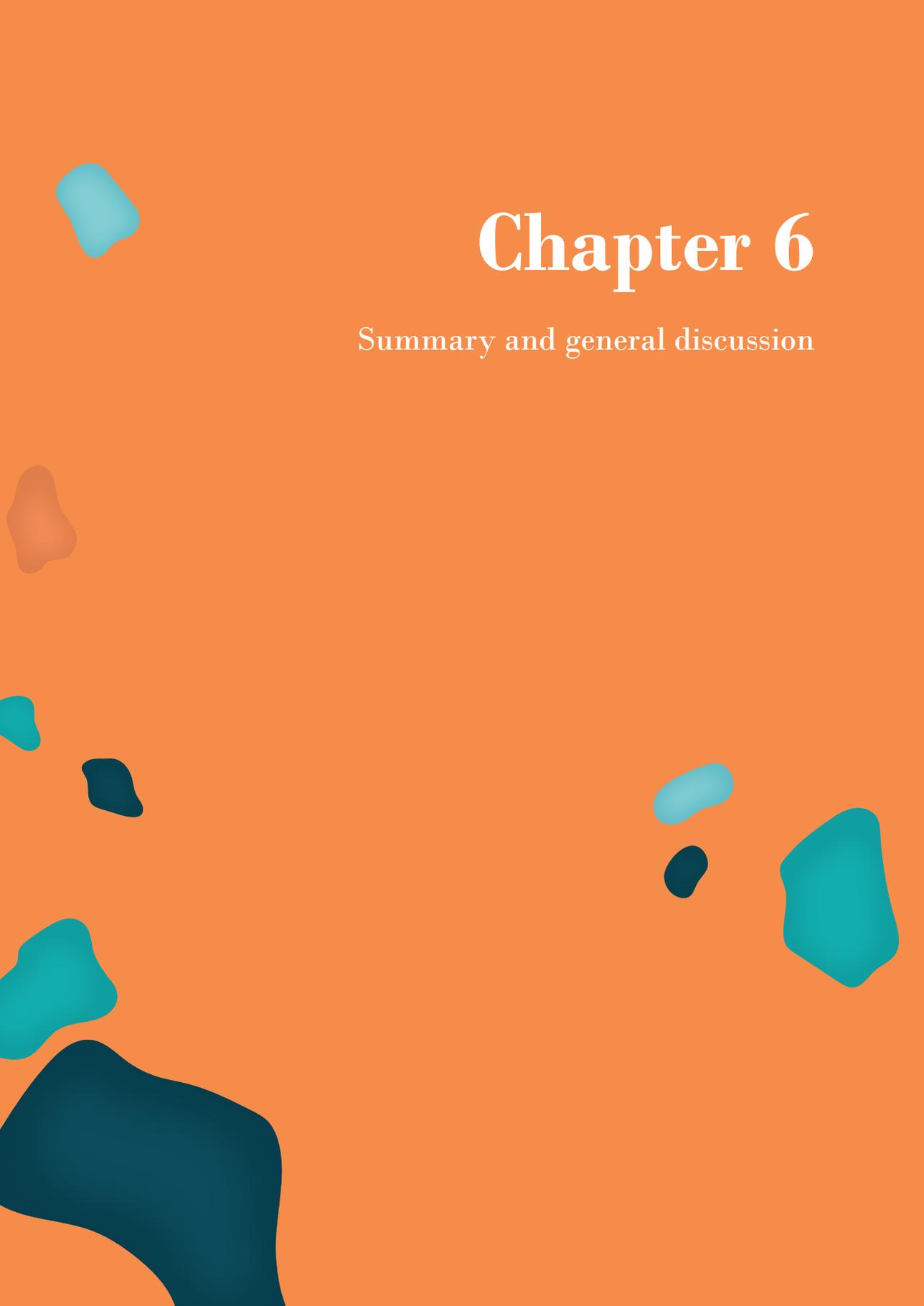
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Chapter 6

Summary and general discussion

Summary and general discussion

Online health information is widely used by cancer patients of all ages to prepare for consultations with healthcare providers or to find additional information after these consultations (Barnes et al., 2017). On the one hand, online health information can be a valuable information source aside from healthcare providers because it can increase a patient's knowledge (Jiang & Street, 2017), participation during consultations (Tan & Goonawardene, 2017), and informed treatment decision making (Jiang & Street, 2017). On the other hand, for older cancer patients who experience difficulties with understanding and recalling information due to declining cognitive abilities (Sparks & Nussbaum, 2008), seeking online health information can be complicated. Since cancer is more often found in older individuals (American Cancer Society, 2020; IKNL, 2020), attention should be paid to improve online health information for this population. Therefore, this dissertation addressed the following aims: first, to gain insight into the effects of patients seeking for online health information spontaneously on patient outcomes, while taking age into account; second, to test two promising communication strategies to present online health information to older cancer patients, i.e. multimodal information (spoken verbal information combined with animations) multimedia (written verbal information combined with illustrations) or and narrative information, in terms of patients' satisfaction, information recall and informed decision making; and third, to develop and implement an online health information tool for older cancer patients including promising communication strategies and features, and evaluate this tool in terms of patient outcomes.

Summary of the main findings

In **chapter 2**, the first aim was addressed. In this clinical field study it was investigated which patients engage frequently in spontaneous online health information seeking before a consultation with a healthcare provider, taking into account age and other patient characteristics (i.e. gender, education level, cancer-related stress, anxiety levels before the consultation, and coping style). Besides, it was studied how online health information seeking subsequently affected patient participation during a following consultation (the patient's absolute word count, the patient's relative contribution in terms of amount of words compared to the healthcare provider, and the number of questions and assertions expressed by the patient), anxiety, satisfaction with the consultation, and recall of information provided during the consultation. To get a clearer insight into cancer patients' spontaneous online health information seeking, this first study was carried out in a clinical setting including patients newly diagnosed with colorectal cancer, scheduled

for a consultation with a healthcare provider. Patients were recruited from six hospitals in different parts of the Netherlands ($N = 72$, $M_{\text{age}} = 69.93$). These patients filled out questionnaires before and after their consultation with a surgeon or specialized nurse. This consultation was audio-recorded. Results showed that patients who were younger, higher educated, had a monitoring coping style, and experienced more cancer-related stress sought online health information more frequently before their consultation than patients who were older, lower educated, had a less monitoring coping style, and experienced less cancer-related stress. In turn, online health information seeking was positively related to patient participation in terms of patient's absolute word count, meaning that patients who sought for online health information before the consultation used more words during the consultation. Furthermore, patient's absolute word use significantly mediated a positive association between online health information seeking and patients' satisfaction with the consultation. These results suggest that spontaneously seeking for online health information before consultations can increase patient participation in terms of word use and subsequently patient satisfaction with the consultation. However, since older patients engaged less in spontaneous online health information seeking than younger patients, the possibility of any positive effects of online health information seeking is lower for older patients than for younger patients. The absence of an effect of online health information seeking on other indicators of patient participation, such as question asking, and on anxiety and information recall points out a need for more effective ways of providing online health information to older patients with cancer.

An experimental study was conducted, described in **chapter 3**, to address the second aim, i.e. to gain insight into the effectiveness of information presentation strategies that might improve information processing for older cancer patients. Two promising strategies, that is multimodal (audiovisual) and narrative information, were tested on outcomes related to decision making (satisfaction, information recall and informed decision making) in an online experiment. A 2 (Modality: audiovisual vs. textual) x 2 (Narration style: narrative vs. factual) online experiment was conducted. Patients (with a history of) being diagnosed with cancer ($N = 232$; $M_{\text{age}} = 63.98$) were asked to imagine a scenario in which they were recently diagnosed with cancer and needed to make a decision regarding their treatment. Participants received one of the four versions of the tool (audiovisual narrative information, textual narrative information, audiovisual factual information, and textual factual information), to support them in making an informed treatment decision. Findings showed that presenting online health information in audiovisual format, compared to textual format, increased patients' satisfaction with the information and subsequently improved recall of the online health information. In turn, higher recall resulted in better informed treatment decisions. Presenting online health information in narrative format, compared to factual format, increased patients' satisfaction with the

information, but not information recall or informed decision making. The positive effects of both audiovisual and narrative information presentation style were found for older patients as well as younger patients, hence there were no age differences. Based on these results it can be concluded that presenting online health information in audiovisual and narrative format positively affects patient outcomes related to decision making. Patients of all ages benefitted from audiovisual information and, regarding satisfaction, also from narrative information. Therefore, using these strategies is promising regardless of the patient's age.

In **chapter 4** the second experimental study is described in which the effectiveness of information presentation strategies were tested that were comparable to the strategies in the first experiment. In this experiment, the effectiveness of multimedia information was tested by combining textual information with illustrations, instead of multimodal information as in the first experiment, to test a less costly multimedia strategy than audiovisual information. Textual information was combined with either affective illustrations or cognitive illustrations. In this second experiment it was investigated why multimedia and narrative information presentation strategies could be effective for older cancer patients, by taking into account cognitive load, as underlying process, and patient characteristics. Effectiveness was again tested in terms of outcomes related to decision making (satisfaction with the information and information recall), while taking into account perceived cognitive load and patient characteristics (age and decision-making style). An online experiment with a 3 (modality: textual information vs. textual information + affective illustration vs. textual information + cognitive illustration) x 2 (narration style: narrative text vs. factual text) between-subjects design was conducted. Analogue cancer patients ($n = 432$; $M_{\text{age}} = 58.19$, $SD_{\text{age}} = 18.53$; 49.3% male; 32.6% low, 33.8% middle, 33.6% high level of education) participated in the experiment. Contrary to our expectations, modality and narration style did not affect cognitive load, and subsequently satisfaction and recall. Furthermore, a match between the type of illustration and type of narration style was not found to be of influence on these outcomes. Moreover, age and decision-making style did not influence the effects of information presentation styles on cognitive load. Independent of information presentation styles, however, a decrease in cognitive load resulted in increased satisfaction and in turn increased recall. For patients with an intuitive decision-making style perceived cognitive load was higher than for patients with a rational decision-making style, despite of the way in which the information was presented. Interestingly, patients with an intuitive decision-making style were more satisfied with narrative information than with factual information as compared to patients with a rational decision-making style, but did not experience less cognitive load. The results of this study suggest that multimedia and narrative information presentation styles might not be effective in decreasing cognitive load within the context

of online decision aids for patients in general. However, based on the results it can be concluded that some information presentation styles, such as narrative information, might be more beneficial for specific patients, such as patients with an intuitive decision-making style.

The third aim of this dissertation was addressed in **chapter 5**, where it is described how an online tool aimed at information provision to older cancer patients was systematically developed, implemented and evaluated in a clinical setting. The purpose of this tool, which included communication strategies that were found to be effective in **chapter 3**, was to inform newly diagnosed patients with colorectal cancer before their consultation with a surgeon. The online health information tool, the Patient Navigator, was developed and evaluated following the four phases of the MRC framework. The first phase encompassed the development of the Patient Navigator. During the second phase, the Patient Navigator was pilot-tested. Subsequently, during the third phase, the Patient Navigator was implemented in four Dutch hospitals. In the fourth phase the Patient Navigator was evaluated by means of a pilot RCT among 45 patients recently diagnosed with colorectal cancer ($M_{\text{age}} = 69.07$). Patients either received usual care (control condition) or usual care plus the Patient Navigator (experimental condition). The effectiveness of the Patient Navigator was evaluated in terms of usage, measured with a built-in tracker function, user experience (i.e. satisfaction, involvement, cognitive load, active control, perceived relevance of the tool), patient participation (i.e. patients' absolute word count, patients' relative contribution in terms of words compared to the healthcare provider, and the number of questions and assertions expressed by patients), and patient outcomes (i.e. anxiety, satisfaction with the consultation, and information recall of the consultation). Results showed that the tool was well used by patients ($M = 17:58$ minutes) before the consultation and was evaluated positively. Patients who received the Patient Navigator experienced less anxiety two days after the consultation than patients in the control condition. However, patients who were provided with the Patient Navigator contributed less during the consultation in terms of word use than patients who did not receive the Patient Navigator. No effect of usage of the Patient Navigator was found on satisfaction with the consultation. Besides, no differences between younger and older patients were found regarding anxiety and words used. This study indicated that a carefully developed online health information tool which is evaluated positively by patients, does not necessarily result in increased patient participation, as assessed by means of word count, and satisfaction with the consultation. Even though patients who used the tool participated less in terms of word use, anxiety levels decreased if patients used the tool. Thus anxiety and satisfaction were not compromised by patients using less words. All in all, since the Patient Navigator was evaluated positively and decreased anxiety in both younger and older patients, it can be concluded that such tools might be a

valuable addition to the information provision by healthcare providers, not only for older patients with cancer, but also for younger patients with cancer.

General discussion

Overall, this dissertation suggests that online health information tools are a potentially valuable form of online health information provision for older cancer patients. Below, the aforementioned results and their implications will be addressed. Particularly some inconsistencies between the results of the separate studies as well as other unexpected findings call for more in-depth discussion.

Differences between spontaneous information seeking and receiving a tool

Surprisingly, using the Patient Navigator led to lower patient participation in terms of the amount of words used during the consultation as compared to patients who did not use the Patient Navigator (**chapter 5**). This seems inconsistent with the results from **chapter 2** where patients who sought for online health information spontaneously used more words, than patients who did not. An explanation for the differences in patient participation between **chapter 2** and **chapter 5** can be that the Patient Navigator already fulfilled patients' information needs, thereby decreasing patient participation in terms of word use. For example, the Patient Navigator included a QPL function that provided patients with questions to ask during the consultation, but also computer-generated answers to some of these questions. Patients feeling well enough informed might have been less inclined to participate during the consultation. On the other hand, if patients seek online health information spontaneously, they could come across information that is difficult to understand, biased and/or incorrect (Diviani et al., 2015). If patients find such information it might lead to confusion, possibly resulting in more patient participation during following consultations to clarify the information found online.

In addition, the differences in patient participation between **chapter 2** and **chapter 5** can be explained by the manner in which the patients received the information. An important reason why online health information seeking can lead to more active participation during consultations is because it gives patients a feeling of empowerment (Tan & Goonawardene, 2017) and a feeling of being in control of their medical condition (Broom, 2005). The act of actually seeking information spontaneously could contribute to these feelings of empowerment and control. Receiving an online health information tool, especially when the tool is presented as a tool offered and, in the case of **chapter 5**, even recommended by the hospital, possibly does not evoke these same feelings as seeking independently and therefore may result in patients feeling less empowered to

participate during consultations than when patients seek spontaneously. In contrast, it can be argued that an online health information tool offered by the hospital can be perceived by patients as a trustworthy source of information, which could contribute to their feelings of empowerment. For future research it is therefore important to consider the influence of the source and the method of offering an online health information tool when studying effects on patient participation.

Differences between the experimental studies (chapter 3 and chapter 4)

Multimodal vs. multimedia information. Whereas in the first experimental study, multimodal information in the form of audiovisual animation showed promising effects regarding satisfaction with, and recall of the information presented in a decision aid, these results were not replicated in the second experiment for multimedia information in the form of static illustrations. In line with the latter results, previous studies did not convincingly point at static illustrations being effective either (Bol et al., 2016; van Weert et al., 2011). It could be that adding static illustrations is not substantial enough to decrease cognitive load and therefore not as likely to subsequently influence satisfaction and recall compared to including audiovisual animations. This idea can be substantiated by the modality effect (Mayer & Moreno, 1998), which states that multimodal information can decrease cognitive load because the information can be processed via multiple sensory systems. Thus, information presented via audiovisual animations will be processed via both visual and auditory sensory systems, therefore decreasing the risk of cognitive overload in one of these systems. According to the multimedia effect (Mayer, 2002) the combination of text with static illustrations will be processed via separate processing channels, i.e. illustrations via the visual/pictorial channel and text via the verbal/auditory channel. However, both will be initially received visually which could make text combined with illustrations less effective than audiovisual animations. Based on these two experimental studies it can be concluded that audiovisual animations are preferred over static illustrations in the context of providing information in decision aids. Nevertheless, according to the cognitive-affective theory of learning with multimedia, CATLM, static visuals could also decrease cognitive load since they tend to increase interest and motivation to process the information (Mayer, 2014; Moreno & Mayer, 2007). According to previous research, some illustrations are more effective to improve learning than others, for example illustrations with faces result in better comprehension of information (Plass et al., 2014). Results found in a study by Um and colleagues (2012) show that visuals that include both an affective component, such as faces and social situations, and a cognitive component, such as an explanation of information, were most effective in decreasing cognitive load, as compared to visuals that comprised only

affective information or only cognitive information. Future research could investigate whether specific static illustrations, for example illustrations in which both an affective and cognitive component are present, are more effective than illustrations with only an affective component or only a cognitive component within the context of decision aids.

Narrative information. Another difference between the two experimental studies concerned the effects of narrative information. In the first experiment, narratives proved to be effective in increasing satisfaction with the information and improve information recall, whereas in the second experiment no effects of narrative information were found. First, it has to be noted that when taking into account all outcome variables of the first experiment, the results found in that study were not unreservedly convincing, since narrative information did not affect recall. A previous review study showed that although narratives have shown to positively influence affective outcomes, such as attitudes, there is only limited evidence if narrative information positively affects cognitive outcomes, such as recall and decision making (De Graaf et al., 2016). Since the main goal of using a decision aid is to make an informed decision regarding a medical treatment, it could be that narratives are less suited to be incorporated in decision aids.

Second, it could be argued that narratives can be effective, but not for all patients. The results of the second experiment seem to support this argument since an interaction effect of narrative text and decisional style of the patient was found on satisfaction with the information. Based on this result, narratives seem to be more effective for patients who base their decisions mainly on emotional and affective information instead of factual information as compared to patients who mainly focus on factual information when it comes to decision making.

Based on the findings of the two experimental studies discussed in this dissertation, it can be concluded that the effects found regarding narrative information should be interpreted with caution. Future research could investigate if narrative information can be effective within the context of medical decision making and for which patients narratives might be more beneficial than factual information.

Usage of the Patient Navigator and patient participation

As described in **chapter 5**, usage of the Patient Navigator did not lead to an increase in patient participation in terms of expressing assertions and asking questions, but did lead to a decrease in words used by the patient. Several factors could explain this unexpected finding. First, it could be explained by how patient participation was operationalized. In the studies conducted for this dissertation, patient participation was measured quantitatively by means of number of words used by the patient, and number of questions or assertions expressed by the patient. However, using more words, expressing more assertions, or

asking more questions does not necessarily mean that the communication between the patient and the healthcare provider is more effective. Effective communication with healthcare providers could also mean that patients need less words to convey their message to the healthcare provider. Patients who received the Patient Navigator, were possibly better informed which improved the efficiency of their communication with healthcare providers, thus resulting in using less words during consultations. The finding that patients used less words in the experimental condition compared to the control condition, raises the question whether only quantitative measures of speech acts are sufficient to measure patient participation. Qualitative measures, such as analysing the content of speech acts, could provide more insight into which topics are discussed by patients. Even though quantitative speech count measures are widely used in previous research on patient participation (e.g. Ford et al., 2000; Schinkel et al., 2015; Zandbelt et al., 2007), future researchers interested in a complete picture of patient participation, including the content of the consultations, are advised to analyse this concept both quantitatively as well as qualitatively.

Moreover, because the highly informative nature of some specific features of the Patient Navigator, such as the QPL function which presents both questions and computer-generated answers to these questions, usage of the tool could also already have satisfied some patients' information needs. Patients who used the QPL function possibly already received an answer from the Patient Navigator. Following this line of reasoning, it could be expected that patients who received the Patient Navigator would ask less questions than patients in the control condition. However, it should be noted that patients who received the Patient Navigator did not differ from patients in the control condition regarding number of questions asked or assertions expressed. It might be possible that the Patient Navigator provided patients with answers to their questions, but patients may have double-checked if the information they received via the Patient Navigator was correct and supported by the healthcare provider during consultations. Such a quick check could result in these patients asking the same amount of questions as patients in the control condition, but the use of the Patient Navigator might have enabled patients to formulate more concise or direct questions than patients in the control condition. Notwithstanding of the line of reasoning above, it has to be noted that this QPL function, which was specifically included in the Patient Navigator to increase patient participation, was only used by half of the patients. Therefore findings regarding patient participation could have been different if more patients would have used the QPL function.

Besides, it is relevant to consider the content of the online health information used by patients. If patients seek for health information online spontaneously, they could come across both expert-generated information providing informational support, and peer-generated information providing social and emotional support (Sanders et al., 2020).

Since the main goal of the Patient Navigator was to inform patients about their medical condition, treatment options and aftercare, the tool did not include functions addressing social and emotional patient support, for instance pages where patients could exchange experiences with other patients. Nevertheless, previous research showed that online social and emotional support, for example via discussion forums or peer-to-peer social support groups, contribute to patients feeling empowered (van Berkel et al., 2015; van Uden-Kraan et al., 2009) and their willingness to actively participate during consultations (Oh & Lee, 2012). Patient empowerment arising because of using such online information can thus increase a patient's confidence to participate in consultations with healthcare providers (van Uden-Kraan et al., 2009). It is plausible that seeking online health information spontaneously results in finding more emotional and social information as compared to being offered an online tool which mainly provided informational support. In that case, these patients could have experienced less social and emotional support than patients who did seek online health information spontaneously. The absence of support on an emotional and social level could have contributed to patients feeling not empowered enough to actively participate during consultations. This calls for further research to investigate how social and emotional information in an online health information tool could contribute to feelings of empowerment and patient participation. Possibly, the Patient Navigator can be expanded with features providing social and emotional information, such as a discussion forum where patients can share their experiences with each other.

Lastly, according to Street's linguistic model of patient participation, the behaviour of the healthcare provider plays a role in patient participation (Street & Epstein, 2008). Possibly, solely using an online health information tool is not enough to increase patient participation. In line with this, previous research pointed out that the behavior of healthcare providers during consultations can either facilitate or impede patient participation (Puts et al., 2012; Zandbelt et al., 2007). Healthcare providers' communicative behavior during consultations might even influence the effectiveness of specific features included in online health information tools. For example, previous research regarding the effects of QPL usage on patient outcomes showed that using the QPL only had a positive effect if the healthcare provider actively invited patients to ask questions from the QPL (Brown et al., 2001; van der Meulen et al., 2008). Perhaps, the behaviour of the healthcare provider did not actively stimulate patient participation in this study, explaining the absence of an effect on patient participation.

Absence of an effect on information recall in clinical pilot RCT

Contrary to our expectations, patients who used the Patient Navigator did not perform better in recalling the information provided to them during the consultation as compared

to patients who did not use the Patient Navigator. This was surprising because the tool included the communication presentation strategies that were tested in the experimental study and found to improve recall. In addition, different elements especially designed to improve information recall such as the QPL, an audio-facility, and a self-tailoring function, were included in the Patient Navigator. However, patients in the pilot RCT were not instructed to use these features, resulting in only half of the patients using the QPL and hardly any patients using the audio-facility and self-tailoring function. The fact that few patients in the pilot RCT were exposed to these features could have contributed to the absence of positive effects on information recall. Regarding the limited use of the self-tailoring function, the design of the Patient Navigator could have contributed to this. Patients entering the Patient Navigator received a default mode including all information and presentation modes, thus self-tailoring would have resulted in a decrease of information. In a previous comparable study where the default mode of the online health information tool included limited information, meaning self-tailoring increased the amount of information, patients did engage in self-tailoring (Nguyen et al., 2019).

Furthermore, in the clinical pilot RCT study actual patients who were recently diagnosed with cancer were included as participants, whereas in the experimental study (**chapter 3**) the effects were studied among analogue patients who were instructed to put themselves in the position of a patient recently diagnosed with cancer (van Vliet et al., 2012). It is likely that patients who just received a cancer diagnosis handle the information they receive differently than analogue patients, who imagine themselves to be in such a situation. For example, anxiety levels in patients with cancer are high right after receiving the diagnosis (Bronner et al., 2018). Since, higher levels of anxiety are known to impede information processing and information recall in patients (Dillard et al., 2017), participants in the clinical study could have processed the information less effectively than participants in the experimental study, which might explain why their information recall did not improve.

In addition, the online health information tools used as stimuli in the experimental study only covered information about two comparable treatment options while the Patient Navigator encompassed a much greater body of information about a variety of topics (i.e. possible treatment options, diagnostic tests, aftercare). The amount of information presented has been linked to information recall in such a way that an increase in the amount of information leads to a relative decrease in recall of that information, especially for older cancer patients (Jansen et al., 2008). To minimize the risk of overloading patients with too much information, the self-tailoring feature was included in the Patient Navigator. However, hardly any patients engaged in self-tailoring the modality or the content of the Patient Navigator. Previous research showed that usage of an online health information tool in which patients decreased the amount of

information by self-tailoring, resulted in better information recall than the same tool including all information (Nguyen et al., 2017). Therefore, usage of the Patient Navigator could have positively influenced information recall if more patients would have used the self-tailoring function. Even though the Patient Navigator was carefully developed to include communication strategies and features, such as self-tailoring, that were known to improve recall, the amount of information provided in the tool could have neutralized a possible positive effect on recall.

Age differences

Although the main aim of this dissertation was to improve online health information provision for older cancer patients in particular, the results did not differ for older cancer patients as compared to younger patients in any of the studies described in the chapters. For the experimental study, data was collected via an online panel, meaning that all participants were individuals who actively decided to be part of an online panel to fill out questionnaires regularly. In the clinical pilot RCT, patients could only be included in the study if they had access to the internet and were willing to receive the information about the study and the first questionnaire via e-mail. By using these sampling methods, we possibly did not reach vulnerable older individuals and might have mainly included older patients who did not experience much age-related declines and already had experience with processing online information. The average frailty level of patients in the pilot RCT was also relatively low ($M = 2.71$, $SD = 2.14$, range: 1–7), supporting this idea. Therefore, bias in the participants that were included in the studies for this dissertation might explain why the expected age differences were not found.

The sampling method for the pilot RCT study also resulted in a relatively small sample size, making it impossible to compare the effects of the Patient Navigator for younger versus older patients. However, age was positively related to time spent on using the Patient Navigator, with older patients spending more time using the tool. This finding may suggest that older patients experience a higher need for online health information tools than younger patients. Previous research showed that older patients need more time to process online information due to age-related cognitive declines (Bol et al., 2016). Besides, older patients may be more inclined to follow up on the recommendation to use a tool that is offered to them by the hospital.

Effectiveness versus usage of communication strategies and features

Our findings also point at a discrepancy between the effectiveness of certain features (i.e. QPL, audio-facility, self-tailoring function) and patients' usage of these features. Although multimodal information was effective in increasing satisfaction, recall and

informed decision making in the experimental study, hardly any patients in the pilot RCT viewed the videos and animations included in the Patient Navigator. Additionally, the QPL (Brandes et al., 2015; Dimoska et al., 2008; Driesenaar et al., 2020; Sungur et al., 2020), audio-facility (Driesenaar et al., 2020), and self-tailoring function (Bol et al., 2020; Lustria et al., 2009; Nguyen et al., 2017; Nguyen et al., 2018; Nguyen et al., 2019) have all shown to be effective in increasing patient outcomes, but these features were rarely used by patients. Several reasons could explain why some elements in the tool were hardly used. First, it could be caused by patients not being aware of the features. For example, certain features could have been not obvious enough and might have been overlooked by patients. Second, patients that were aware of the features, might not have been motivated to use them. Possible reasons for a lack of motivation could be, for example, that patients thought using these features took too much time or that they were unable to see the added value of these features. Lastly, even if patients were aware and motivated to use these features, it is possible that using the features was simply too cognitively demanding and difficult for some patients, although this was tested in the pilot testing phase of the Patient Navigator.

Follow-up research should investigate which of these three factors limits usage of these features the most, since each limiting factor asks for a different approach to increase usage. For example, adding specific elements in the tool that draw attention to these features or having healthcare providers instruct patients to use certain features in the tool, could increase awareness. Motivation to use the features could also possibly be increased by the healthcare provider, for example by stressing the significance of using effective features. In addition, the features should be user-friendly and attractive to use for patients. In the case of cognitive limitations, the usability of the features could be re-evaluated possibly leading to redesign of the features. Aside from feature-specific improvements, options to improve usage of the features could involve providing patients with instructions on how to use certain features, for example via an instructional video, or letting patients use these features while being helped by informal companions, such as family members, or healthcare providers.

The results of this dissertation indicate that no matter how effective a feature is, awareness, motivation and ability should be considered as well to minimize the risk of effective features not being used by patients. To gain more insight into the extent to which online health information tools should be based on effectiveness versus usage, future research should investigate why certain effective features, for example an audio-facility function, are not used by patients. This could be done by conducting qualitative interviews after patients used the tool.

Theoretical implications

Within the literature on age-related changes in information processing and decision making, two perspectives can be identified. First, earlier research has provided a theoretical and empirical foundation for the cognitive decline in older individuals' information processing capacity (Bruine de Bruin et al., 2012; Finucane & Gullion, 2010; Mata et al., 2007; Mata et al., 2010; Mata et al., 2012; Sparks & Nussbaum, 2008; van Gerven et al., 2002). Predicated on this acknowledged age-related cognitive decline, scholars have pointed out the need to consider specific communication strategies to inform older individuals (Bruine de Bruin et al., 2012; Finucane & Gullion, 2010; Mata et al., 2007; Mata et al., 2010; Mata et al., 2012; Paas et al., 2005; Sparks & Nussbaum, 2008; van Gerven et al., 2002), for example using multimedia communication (Paas et al., 2005). In line with this, according to the cognitive aging principle, age-related limited information processing capacity can be improved by multimodal communication (Paas et al., 2005). Additionally, the cognitive theory of multimedia learning states that presenting multimedia information could decrease cognitive load and improve information processing (Leahy & Sweller, 2011; Mayer & Moreno, 2002; Mayer, 2005; Sweller, 2011).

This dissertation answered to the call of testing a multimodal and multimedia communication strategy among older individuals within an online health communication context. The results show that presenting online health information via multiple modalities to older patients with cancer, is indeed effective in increasing patient outcomes related to decision making. These results demonstrate the cognitive theory of multimedia learning and the cognitive aging principle can be combined and are not only applicable for processing information in general, but can also be applied to information processing in an online health information context. Thereby, the insights provided by this dissertation contribute to the theoretical knowledge about older individuals' processing of multimodal and multimedia online health information.

Second, a motivational perspective of age-related changes in cognitive processing can be identified in the literature. According to the socioemotional selectivity theory, when the end of life is near, emotional goals become more important than cognitive goals (Carstensen et al., 1999; Carstensen, 2006; Lockenhoff & Carstensen, 2004). These changes could also influence how older individuals process information and could lead to older individuals processing information more affectively instead of deliberatively, because their focus has shifted more to emotional information (Peters et al., 2008). Furthermore, the age-related cognitive decline older patients experience also influences their ability to process information deliberatively. Since this information processing mode relies upon cognitive processes and resources, older patients' difficulties with cognitive processes also further contributes to the shift to more affective information processing (Peters et al.,

2008; Peters et al., 2007). Based on this change in older patients' information processing mode, scholars pointed out the importance of taking into account both affective and deliberative information processing when designing online health information for older adults (Peters et al., 2008).

This dissertation considered older patients' change in information processing mode and acknowledged possible affective processes by testing the effectiveness of narrative online health information as a communication strategy. By taking on this theoretical approach of testing effective online health information, the results of this dissertation contribute to theory regarding affective processing of online health information in older patients. The findings provide limited evidence that narrative information might be effective in improving older patients' affective outcomes such as satisfaction with the information. We found no influence on other patient outcomes related to medical decision making. This is in line with previous research in which comparable narratives including experiences and feelings of the character were effective in increasing satisfaction with the information (Yilmaz, 2020), but not necessarily in affecting cognitive outcomes (de Graaf et al., 2016). Theoretically, the results of this dissertation, combined with the results of previous research, could indicate greater importance of affective processes for older individuals with regards to affective outcomes, such as satisfaction, than with regards to cognitive outcomes, such as recall. Future research should further investigate whether narrative information mainly induces affective processes and whether outcomes related to decision making are more influenced via cognitive processes.

Aside from theories regarding aging, the results of this dissertation also have some implications for theory regarding patient participation. Based on the linguistic model of patient participation in care, in which gaining knowledge is seen as one of the important enabling factors for patients to participate during consultations (Street & Epstein, 2008), it was expected that providing patients with online health information would positively affect patient participation and patient outcomes. However, in this dissertation providing patients with an online health information tool (the Patient Navigator) did not influence all patient participation outcomes measured. Even though the absence of effects on patient participation could be caused by methodological tradeoffs, for example the small sample size, the absence of these effects could also point at implications for patient participation theory. On the one hand, the results of this dissertation support the notion that providing patients with knowledge can be seen as an important factor in increasing (some aspects of) patient participation, as stated in the linguistic model of patient participation (Street & Epstein, 2008). On the other hand, it might be argued that other aspects of patient participation, such as question asking, could be more strongly affected by one of the other enabling factors mentioned in the linguistic model of patient participation, for example the communicative behavior of the healthcare provider (Street, 2001). Therefore, the

findings of this dissertation point at the importance of investigating the role of other factors described in the linguistic model of patient participation in care, in addition to focusing on the effect of mere information provision on patient participation.

Strengths, limitations and directions for future research

The findings of this dissertation should be interpreted in light of several strengths and limitations. One of the strengths of this dissertation is the multimethod approach of combining studies conducted in both an experimental setting and in a clinical setting. By testing the effects of multimodal, multimedia, and narrative communication strategies in an experimental setting, the influence of other factors that could have played a role in the effects, such as the amount of medical knowledge or internet use of patients, was controlled for and thereby minimized. By testing the effects of providing patients with online health information in a clinical setting, we were able to translate these experimental results to a real-world situation and evaluate an online health information tool under circumstances where other factors could interfere. This approach of conducting both experimental and clinical studies therefore contributes to the ecological validity of the results.

The varying patient samples used in the different studies is a second strength of this dissertation. By including actual patients who just received their diagnosis in the clinical studies, the Patient Navigator was evaluated and used during a time period (right after diagnosis) where patients have high information needs (Rutten et al., 2005), are most anxious and experience a lot of uncertainty (Bronner et al., 2018). Therefore an online health information tool can be especially helpful to patients during this period. However, the inclusion of actual patients right after their diagnosis also resulted in a smaller sample size, limiting the statistical power, possibly explaining the absence of certain effects in the pilot RCT. For the experimental study analogue patients were included, instead of actual newly diagnosed patients, to obtain a larger sample and thereby evading statistical power problems in the experiments. The larger sample in the experiment made it possible to compare younger and older patients, while testing the whole path from providing patients with online health information to informed decision making, via satisfaction and recall.

Another strength of this dissertation worth mentioning is that both self-reported data (questionnaire data) and observational data (tracking data regarding usage of the Patient Navigator and recordings of the consultations with surgeons) were collected to test an online health information tool and its effects in a natural setting. Using a built-in tracker to collect usage data of the Patient Navigator is innovative and allowed us to study the natural use of an online health information tool in a clinical setting. In addition, patient participation was measured by audio-recording the consultations, which seemed

to go unnoticed by patients once the consultation started. These methods of data collection contributed to the ecological validity of the results of this dissertation.

However, some of these methodological choices also resulted in limitations. First, the analogue patients included in the experimental study might have differed from the actual patients in the clinical pilot RCT, possibly explaining the inconsistency between the effectiveness of multimodal information in the experimental study and the limited use of videos and animations in the pilot RCT. Even though including analogue patients is a validated method (van Vliet et al., 2012), it might not have been a representative sample for patients who just received their diagnosis. Therefore, for future research it is advised to attempt to attain larger samples consisting of patients newly diagnosed with cancer. Because of this population's vulnerable nature, researchers should think of ways to increase the inclusion process, for example by working together with healthcare providers, who can stress the importance of patients participating in the study. Even though healthcare providers were involved in the study, they did not actively stimulate patients to participate in the study.

Second, the method of measuring natural usage of the Patient Navigator also came with a limitation. Since patients were not specifically asked to use the Patient Navigator in a certain way, specific promising features (i.e. QPL, audio-facility, self-tailoring function) and communication strategies, such as multimodal information, included in the Patient Navigator were not or hardly used by patients. Therefore, we were unable to draw conclusions about the effectiveness of these features and strategies included in the context of an online health information tool provided to actual patients in a clinical setting. Future research could investigate the effectiveness of similar features in a clinical setting by explicitly asking patients, either directly or via their healthcare provider, to use these features. Even though this would detract from the ecological validity, such research would provide more insight into the effects of certain features in a natural setting. Besides, additional experimental research could be carried out to test the effectiveness of specific features.

A third limitation is linked to the inclusion method used in the experimental study and the pilot RCT as we might not have been able to include the oldest and frailest patients with cancer. The frailest patients might have declined participation in our studies as they could have experienced it as too burdensome given their situation. Additionally, since using the internet was a prerequisite for inclusion in the experimental study and the pilot RCT, older and more vulnerable patients might not have been reached with the sampling methods used for this dissertation. According to previous research, among older individuals (over 65 years old), age differences in internet use still exist and internet use is less common as age increases (Friemel, 2016; Hunsaker & Hargittai, 2018; Schehl et al., 2019). Even though the majority of the individuals between 65 and 75 years old use

the internet daily (78.3%), only half of the individuals over 75 years old use the internet every day (48.5%) (CBS, 2020). Therefore, it is unclear if the results of this dissertation are generalizable to older vulnerable and frail patients with cancer. Even though our sampling method contributed to the generalizability of our results for patients with cancer who use the internet, future research should investigate whether these results are further generalizable to the older patients who use the internet less often. Researchers could try to reach these patients via different media, for example by providing patients with an online health information tool already installed on a tablet they could use in the waiting room of the hospital, followed by a questionnaire.

It can be expected that a generational shift will automatically cause an increase in internet use. This is already clearly visible in recent internet usage data. While approximately 10 years ago, less than half of the individuals over 75 years old had access to the internet (42.2%) with only 12.2% of them seeking for health information online, now the majority of this older population has access to the internet (77.2%) and more than one third searches for online health information (36.4%) (CBS, 2020). These numbers demonstrate how quickly internet use increases in this age group. However, these results also show how much more there is to win with regards to online health information, since still more than half of these older adults do not use the internet to seek online health information spontaneously. This calls for future research investigating how specifically offering certain online health information to these patients can be improved. For example, healthcare providers could play a role in this by more actively directing patients to appropriate tools or websites.

Practical implications

This dissertation provides practical implications and guidelines for developing online health information for older cancer patients. First, the results of this dissertation indicate that approximately half of the older patients seek, to some extent, for online health information spontaneously before consultations with healthcare providers, but this behaviour decreases when a patient's age increases. Since the Patient Navigator was well used and resulted in less anxiety, it can be concluded that offering patients such tools is valuable for patients and is thereby recommended for practice. Usage of the Patient Navigator also resulted in patients using less words during consultations, leading to shorter consultations. This creates possibilities for practice, for example to use the time already reserved for consultations to have more personal and in-depth consultations or to specifically address issues raised by the usage of online health information. Healthcare providers could invite patients to ask questions about information they found online,

stress the value of using certain tools, or point them in the right direction where to find specific information.

Second, the results showed that presenting online health information via multiple modalities positively affects patient outcomes related to decision making, when compared to textual information only. Health communication professionals developing online health information tools for (older) patients with cancer should therefore consider incorporating this communication strategy in such tools. Additionally, this dissertation found mixed results regarding the effects of narrative information on patient outcomes. According to our findings, narratives might improve satisfaction with the information, but possibly only for certain patients. Therefore, healthcare professionals should be careful when considering this communication strategy. Besides, in a natural setting, including such strategies might not be enough since the findings showed that effective strategies and features were not necessarily used by patients. The results suggest that attention and motivation of patients could play a role in the actual usage of multimodal and narrative information and other features included in the tool. Therefore, it is advised to actively increase awareness and motivation in patients, for example by presenting patients with clear instructions on where to find specific information in an online health information tool.

The positive effects already found without taking into account the communicative behaviour of healthcare providers, combined with the encouraging role healthcare providers could play, point to the potential of online health information tools for practice. Ideally, hospitals should integrate online health information tools as much as possible in their healthcare procedure. This could be done both in terms of having healthcare providers actively promote usage of these tools, but also logistically by already referring patients to the tool in a first appointment letter.

Final conclusion

Because of the increase in online health information use, especially in older patients, it is crucial to look into how this behaviour can lead to positive patient outcomes, including those related to informed decision making. This dissertation aimed to do so by first, gaining insight into the effects of patients spontaneously seeking for online health information on patient outcomes, while taking age into account; second, by testing promising communication strategies to present online health information to older cancer patients, multimodal, multimedia, and narrative information, in terms of satisfaction, information recall and informed decision making; and third, by developing, implementing and evaluating an online health information tool for (older) cancer patients in terms

of patient outcomes, including promising communication strategies and features. By addressing these three aims, this dissertation investigated online health information use in a broader context, by looking at the whole path from patient characteristics that lead to online health information use to the effects of online health information use on patient participation during consultations and patient outcomes afterwards.

First, this dissertation showed that older patients engage less in spontaneous online health information seeking than younger patients, while the results showed online health information seeking resulted in more patient participation in terms of word use and more satisfaction. Second, multimodal, and possibly narrative, communication strategies in an online health information tool positively influenced (older) patient outcomes related to decision making. Third, the results of the experimental studies described in this dissertation show the importance of satisfaction with and recall of information in positively influencing informed decision making, and the role of cognitive load in increasing satisfaction and improving information recall. Lastly, the pilot RCT showed that usage of an online health information tool systematically developed for older patients with colorectal cancer, including communication strategies proven effective in the previous study, resulted in less patient participation in terms of word used and less anxiety. The findings of this dissertation demonstrated the potential of online health information for older cancer patients in terms of outcomes related to decision making and anxiety. The results regarding words used by the patient do not unambiguously point at a positive effect of online health information use on patient participation. However, by carefully considering the possibility that more efficient communication with healthcare providers could also lead to less word use of patients during consultations, it can be cautiously concluded that online health information could also potentially improve effective communication with healthcare providers.

The findings of this dissertation can support health communication researchers and online health information developers to improve the design and effectiveness of online health information for older patients with cancer. Furthermore, this dissertation contributed to the theoretical understanding of the effectiveness of online health information usage in older cancer patients by applying existing theories to an online health information context. Based on the results of this dissertation, the potential of online health information for older cancer patients should be acknowledged and online health information should be seen as a crucial factor in information provision for older patients with cancer.