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## **Shared decision-making about treatments for early breast cancer : preferences of older patients and clinicians**

Hamelinck, V.C.

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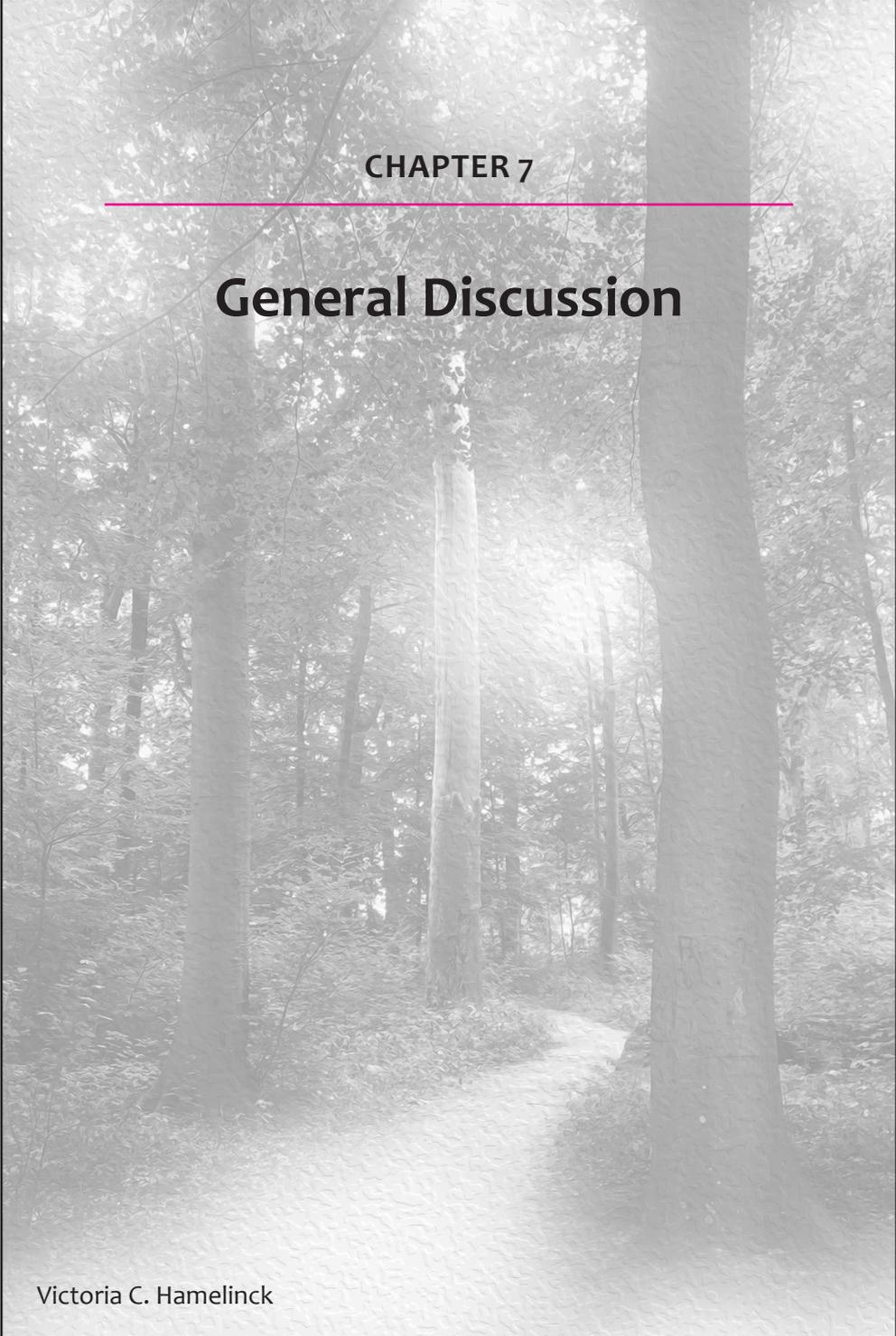


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**Author:** Hamelinck, V.C.

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CHAPTER 7

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# General Discussion

Victoria C. Hamelinck

## Background

Older patients with breast cancer and their clinicians often face difficult treatment decisions, including a decision between a mastectomy (MAST) or a breast-conserving surgery (BCS), and whether to add systemic therapy (i.e., chemotherapy or hormonal therapy). Treatment decision-making for older patients generally presents a challenge, as scientific evidence for the best treatment option is often limited,<sup>1</sup> older patients differ in a number of important aspects from younger patients, and as the older patient population itself is characterized by a wide diversity in health and functional status.<sup>2</sup> Consequently, a shared decision-making process has been advocated as the preferred way to individualize breast cancer treatment for older patients.<sup>1,3,4</sup>

Studies have shown that older patients are less likely to receive the same treatments as younger patients<sup>5,6</sup>: they less often undergo BCS, radiotherapy (following BCS) and adjuvant chemotherapy (aCT). It is unclear whether age-related differences in treatment reflect older patients' preferences or clinicians' preferences, or a combination of these. To optimize care for older breast cancer patients, knowledge about the treatment decision-making process with older women is urgently needed.

The research in this thesis aimed to gain insight into the preferences of older patients and breast cancer specialists, with a focus on the first group. We started by reviewing the literature on patient preferences for surgical and adjuvant systemic therapy. We then carried out a prospective study in which we included older patients with newly-diagnosed early-stage breast cancer and compared their preferences for treatment and participation in decision-making with those of younger patients. Finally, we explored the treatment recommendations of clinicians for older breast cancer patients, including how their recommendations were influenced by patient age and performance status, and by clinician specialty. In this chapter, the main findings are discussed and put into perspective. Subsequently, recommendations for practice, policy and future research are provided.

## Main findings

The systematic review (**chapter 2**) showed that factors related to body image and survival/recurrence determined the preferences of early-stage breast cancer patients for, respectively, BCS or MAST. A majority of patients considered small/moderate benefits in survival rate/life extension sufficient to make both aCT and aHT worthwhile, although individual preferences varied widely. Determinants of patient preference were most often significantly related to quality of life: a better perceived well-being during treatment was related to more willingness to accept systemic therapy. Socio-demographic (e.g., patient age) and disease characteristics were not consistent predictors of systemic treatment preference.

Results from the prospective study showed that both younger and older patients most frequently preferred BCS plus radiotherapy (69% and 56%, respectively) (**chapter 3**). Both age groups considered the clinicians' recommendation to be the most important influencing factor. However, older patients were more concerned than younger patients about the possible need for additional surgery and they attached less importance to the possibility of breast reconstruction. The latter was also reflected in their lower preference for breast reconstruction following MAST.

Further, older patients were less willing to undergo aCT (62% versus 92%, respectively) and aHT (59% versus 92%) than younger patients, although this was not statistically significant for aHT (**chapter 4**). The older patients willing to undergo aCT required similar benefits in 10-year disease-free survival as younger patients from aCT (median: 5% versus 4%) and aHT (median: 10% versus 8%). Main motivations for undergoing therapy included the wish to survive/avoid a disease recurrence and the clinician's advice (more often affecting older patients). Motivations against therapy were concerns about the treatment duration (mainly referring to aHT) and side effects. Older patients cited additional motivations against aCT including the wish to maintain quality of life/independence. Overall, patients who were single/divorced/widowed, who had a geriatric condition, or who preferred an active role were less likely to prefer aCT.

Finally, our results showed that older patients more frequently preferred to share the decision about type of surgery, aCT and aHT with the clinician (**chapter 5**). In contrast, younger patients more often preferred to make these decisions themselves or to defer these decisions. Regarding perceived actual roles, both age groups most frequently reported an active role in the decision between BCS versus MAST. Contrary to younger patients, older patients more often reported to have had a passive role in the decisions about adjuvant systemic therapy. The differences in preferred and perceived roles between the groups were not statistically significant.

The online survey among breast cancer specialists showed that treatment recommendations about radiation, surgical and medical oncology treatments did not differ much among the different specialties (**chapter 6**). In the hypothetical scenarios representing only patients >70 years of age, clinicians were more likely to recommend MAST for an older than for a younger patient with a small tumour, and more willing to omit radiotherapy after BCS in the older patient if this was the patient's preference. Also, all clinicians would recommend either aHT with or without chemotherapy for a patient at high risk of recurrence in good health, whereas they would less often propose therapy (and if so, their recommendation always involved only aHT) for the same patient in poor health. In other scenarios, neo-adjuvant hormonal therapy followed by BCS for a patient with a large tumour was recommended by one-third of the

clinicians, and aCT in case of triple-negative breast cancer would be considered by four in five clinicians (either with or without a strong treatment preference of the patient).

## Discussion of the main findings

### *Patient preferences for early-stage breast cancer treatments*

The elicitation of patient preferences for treatment and values regarding the benefits and risks of different treatment options is an essential component of shared decision-making between clinicians and patients. In decisions where there is no obvious best option, the patient's own values become more important.<sup>7</sup> Our systematic review of the literature identified numerous factors that breast cancer patients reported to influence their preferences for type of surgery (**chapter 2**). A main finding was that different decisive factors were found, namely patients who preferred BCS mostly valued body image-related factors, whereas patients who preferred MAST were mostly driven by concerns about survival or disease recurrence. The fact that early-stage breast cancer patients reported preferring MAST over BCS because they believe MAST will offer a better chance of survival is disconcerting as this may indicate that patients received inadequate information or, alternatively, that they were unconvinced about the equivalence of the options, despite being fully informed. It is therefore important that patients who are in a position to choose between BCS and MAST receive complete and balanced information about both surgical options and that their understanding of what they were told is checked to correct possible misconceptions. The results of the review showed that patient concerns about body image and disease recurrence are important topics that should be discussed between the patient and her clinician. Treatment-related factors, including the follow-up with radiotherapy, also appeared to be influential factors. However, most studies in the review included patients who had already made a treatment decision or who had already undergone surgery and radiotherapy. Factors that determined preferences may therefore not be extrapolated to patients who have yet to face the decision. Findings of the prospective study involving newly-diagnosed patients (**chapter 3**) support that fear of disease recurrence and concern about the loss of a breast are predominant concerns, but also show that patient preferences are strongly influenced by an aversion to more surgery, and to a smaller extent, by concerns about radiotherapy.

Patients with early-stage invasive breast cancer also often face the dilemma of whether to undergo a treatment that could potentially improve disease-free survival but is associated with unpleasant side effects. **Chapter 2** described the finding that a majority of patients who were treated or had already made a treatment decision, were willing to undergo a systemic therapy for small or moderate chances of benefit, regardless of the side effects and inconvenience of the treatment. This is in line with findings of the prospective study (**chapter 4**), where we found that overall, most newly-diagnosed patients would accept aCT for small benefits and aHT for moderate benefits. Both the systematic review and the

prospective study showed that some patients would even choose therapy if there was no additional benefit, a finding also found in many other cancer contexts.<sup>8-12</sup> Patients often reported to do everything possible to fight the cancer in order to live as long as possible and/or to minimize their risk of local recurrence (**chapter 4**). Still, willingness to accept treatment for no or small extra chances of survival seems illogical or irrational, and clinicians should carefully question whether treatment should be given in these cases. Clinicians should know about their patient's reasons for wanting or not wanting a burdensome treatment.

Another important finding was the large variation in patient preferences for surgical and adjuvant systemic therapy and the different factors that shape their preferences (**chapters 2-4**). Together, these findings suggest that clinicians should be aware of the different preferences between individual patients. However, evidence shows that patients rarely have individualized discussions with their clinicians and that exploration of patients' treatment preferences is often done implicitly.<sup>13-17</sup> Clinicians seldom inform patients of different treatment options or that a treatment decision needs to be made and seldom ask about their preferences. Other studies show that treatment plans often appear to have been already made at the multidisciplinary team meetings without knowing the patient's preference.<sup>18</sup> It is known that patients and clinicians think about different determinants when making treatment decisions,<sup>11,19,20</sup> with clinicians mainly focusing on the medical aspects of treatment. Consequently, there is a high probability that the recommended treatment plan will be unworkable in case the plan needs a revision if a patient becomes involved in a later stage.<sup>18</sup> The failure to incorporate patient preferences in clinical decision-making is disconcerting, given the preference-sensitive nature of the decisions in early breast cancer,<sup>21,22</sup> but also in light of growing consensus that patients should be actively involved in their healthcare.<sup>23</sup> We also found that the input of the clinician was a highly influential factor for patients' preference (**chapter 3 and 4**). Patients often tend to ask for guidance from their clinician as they believe that their clinician would know best. However, clinicians need to be aware that the preferences of patients might be different from theirs<sup>19,24</sup> and that the preferences of (new) patients are not easily predicted based on their socio-demographic characteristics (e.g., patient age) or on actual health status (**chapter 2-4**). It is therefore crucial for clinicians to explicitly explore the values and preferences of their patients. Even though a strong influence of clinicians on patient's preference does not automatically imply that patients' values are left out in the treatment plan, we recommend that clinicians carefully plan communicating a treatment recommendation. Providing treatment advice early in the consultation may lead to patients believing that their own preferences and values no longer matter in the decision process, that the doctor knows what is best. It is also important that treatment information is provided without implicit persuasion. A recent oncology study<sup>14</sup> regarding the decision about adjuvant systemic therapy demonstrated that clinicians often steered patients towards a particular treatment choice by the way they presented the information about the treatment

during the consultation. Even though clinicians are most likely unaware of this behaviour, patients may have the impression that they are pushed towards an option, possibly leading to an undesired decision. Therefore, only after balanced presentation about the treatment options, and patients' preferences have been adequately discussed, clinicians could explicitly recommend a treatment that reflects the concerns of the patient.

#### *The influence of age on patients' preferences for treatment*

Although the need to gain insight into the treatment preferences of older patients is evident, only one study in our systematic review provided information on older patients and none of the included studies specifically explored age-related differences (**chapter 2**). Understanding which factors drive older patients' preferences is important to tailor information provision and to assist clinicians in helping older patients in making treatment choices that fits their preferences. In daily practice, it is often assumed that older patients more frequently prefer MAST than younger patients. Potential explanations assumed are that older patients are less concerned about body image, are less willing to attend the subsequent visits for radiotherapy they would receive after BCS (due to limiting mobility or reliance on others for transportation), and that they do not desire more surgery.<sup>25</sup> According to the results of our prospective study (**chapter 3**), older patients most frequently preferred BCS, although to a lesser extent compared to younger patients. Perhaps more importantly, the proportion of older participants preferring BCS was larger than those preferring MAST. We also found that both age groups attached high importance to the same influencing factors, including body image. In line with other studies,<sup>26-29</sup> breast conservation appears to be relevant to older patients during the last decades of life as well. Its importance should therefore not be underestimated and body image and the option of breast reconstruction should be a part of the conversation with older patients. Our findings do confirm the assumption that older patients may have a stronger aversion to possibly requiring further surgical procedures. In addition, older patients seemed to be more concerned about the possible side effects from radiotherapy and the frequent hospital visits, although they were not overly put off by these factors. These factors should also receive attention in discussions with older patients. The opinions of older patients about the omission of radiotherapy (after breast-conserving surgery) is a topic that is currently explored in the Tailored Treatment in Older patients study (TOP<sup>30</sup>), a research project initiated at the Leiden University Medical Center and in collaboration with the Dutch Breast Cancer Association. Based on our findings, BCS is something that older patients are interested in discussing and considering in a similar way as younger patients and when indicated, BCS should therefore be offered to eligible patients alongside the option of MAST.

Another prevailing presumption among clinicians is that older patients have a lower willingness to undergo systemic therapy, because they consider their quality of life to be

more important than a small, possible gain in disease-free survival.<sup>31,32</sup> Our study seems to confirm the finding that older patients are less willing to add a systemic therapy than younger patients (**chapter 4**), but the difference in willingness was only statistically significant for aCT, and not for aHT. On the other hand, we also found that the older patients who would accept therapy, desired it as strongly as younger patients, and some even considering therapy for a 1% benefit. This finding may be considered somewhat surprising, but corresponds with the finding that many older patients would be willing to accept burdensome treatment. Like younger patients, older patients placed much importance on the possibility to reduce their risk of disease recurrence as well as on avoiding possible side effects. Based on our findings, the option of adjuvant systemic therapy should be discussed with them, and information on benefits and risks concerning a treatment with or without systemic therapy should be fully and neutrally delivered, so that patients can make an informed treatment preference. Both age groups considered the same main motivations for and against systemic therapy, but regarding aCT, older patients had reported that they wanted to keep their current quality of life and to continue their daily life activities. They also feared losing their independence after undergoing aCT. When communicating the risks and benefits of adjuvant systemic therapy with older patients, the impact of treatment on these aspects should deserve specific attention.

There were no overt differences regarding aHT between the age groups, and it was notable that older – like younger - patients also reported to be concerned about the side effects and treatment duration. Adjuvant hormonal therapy is often regarded as a treatment that is milder and easier to use than aCT, although treatment lasts for a considerably longer time. It is often the only available systemic treatment option for older patients, in particular for those with comorbid conditions. However, higher discontinuation and nonadherence rates have been observed in older patients,<sup>33-36</sup> with up to 49% discontinuation rate reported.<sup>37</sup> Research has shown that patients find the side effects to be burdensome,<sup>38</sup> and that the side effects were the most common reason for discontinuing treatment before completion of the recommended five years.<sup>39</sup> As aHT is an important option for older patients, more attention should be given to the impact of treatment before they start treatment in order for them to better cope with the possible side effects and to improve therapy adherence/persistence.<sup>40</sup>

An essential question arising from these findings is whether treatment decision-making with older patients requires a different approach than that with of younger patients. It is important to acknowledge that reasons unique to this age group were found, but also that many influencing factors were the same for both younger and older patients. Older patients may have a lower willingness to undergo BCS or adjuvant systemic therapy than younger patients, but the variation in preferences and the weight put on different factors within the older – as within the younger – patient population illustrate the importance of eliciting and

taking into account older patients' preferences, not just those of younger patients. That such an approach is needed is strengthened by the finding that patient preferences were influenced more by social support, health status and decisional role preference than by their age (**chapter 4**). Older patients were more likely to indicate the clinician's advice as the most significant influence on treatment preference. Because the treatment recommendation of the clinician is more highly valued by older patients (also slightly seen in **chapter 3**) and by those who were undecided about their preference (who were in particular older patients), clinicians should be aware of the factors that older patients consider important (and that are different than those of younger patients). For example, older patients differed most in their preferences from younger patients with regard to aCT, which indicates the need for age-specific information provision about aCT. Our findings fits the current shift seen in oncology from a 'one-size-fits-all' approach towards personalized medicine.

#### *The influence of clinician's preference on treatment of older patients*

Understanding the variation in treatment between younger and older patients also requires insight into the ideas that clinicians have regarding the management of breast cancer in older patients. Using hypothetical scenarios, we found that most clinicians of the different breast cancer specialties seemed to take a similar approach to our treatment scenarios under investigation. However, the discrepancy between the overall selected treatment recommendations and the actual treatment of older breast cancer patients (**chapter 6**) raised the question which factors may lead clinicians in deciding whether or not to treat older patients. In the scenario about locoregional therapy, a majority of the clinicians would be willing to omit radiotherapy for a patient over the age of 70 years, but in practice older patients, like younger patients, almost always receive radiotherapy.<sup>41</sup> The TOP study will assess whether radiotherapy after BCS can be omitted in specific older breast cancer patients without negatively affecting their disease recurrence or survival, and possibly resulting in reduced costs. To that end, comparative effectiveness research will be performed, as well as surveys among older breast cancer patients and specialists about their opinions regarding omission of treatment.<sup>30</sup> Results of this study will provide more clarity regarding this topic. It is possible that clinicians find it difficult to advice omission of a treatment that is well-established in clinical guidelines, despite the fact that there is strong scientific proof from trials that the option of radiotherapy may be questioned in certain selected older patients.<sup>42</sup> Our findings imply that although clinicians seemed to acknowledge this evidence, they have a strong tendency to adhere to the guidelines. Possibly, we might have to consider to change current guidelines by incorporating age- or subgroup-specific sections.

Another finding was that some clinicians would recommend or consider aCT for an older patient in otherwise good health at high-risk for recurrence, however, the actual uptake of aCT in older patients is very low.<sup>41</sup> A barrier that clinicians may encounter is that the

guidelines advocate the consideration of chemotherapy for ‘fit’ older patients without specifying this definition. Consequently, this lack of information may hinder the application of this recommendation.<sup>43</sup> Clinicians may also be particularly reluctant to recommend current recommendation in older patients because they are uncertain about the benefits. Although clinicians selected treatment in accordance with current evidence, their uncertainty to recommend aCT seems to be a reflection of the guidelines. Possibly, more trials are needed to guide decisions about extensive treatment and to fine-tune current guidelines for chemotherapy at older age.

While abovementioned factors may contribute to the age-based variation in treatment, recent attention has been directed to the strong influence of a patient’s chronological age on treatment options presented to patients by clinicians.<sup>44-46</sup> A study showed that although performance status was cited the most important factor affecting their treatment decisions, 96% of the clinicians would choose an intensive treatment for a 60-year-old breast cancer patient, compared to only 13% for an 85-year-old patient who had the same characteristics as the younger patient.<sup>47</sup> Other vignette studies also found that patient’s age was considered the most influential factor when making treatment decisions for older patients.<sup>48</sup> Similarly, clinicians in our study made different recommendations for locoregional therapy based on patient age. Although it was quite obvious for them to notice that we were interested in the age factor, they still provided different treatment recommendations, which raises the possibility of a different approach towards older adults based on their chronological age. Although it is inarguable that ageing is associated with an increase in medical and social problems, and that older patients may generally not benefit as much as younger patients from certain treatment, ageism can lead to misconceptions as to what is best for the patient.

A number of potential explanations have been offered for a different approach.<sup>44</sup> It is often expected by society that older adults are mentally and physically weak, and are dependent on others.<sup>18</sup> These negative perceptions are further strengthened by the portrayal of older patients in the media. Further, breast cancer in older patients is often portrayed to be less aggressive and less deadly compared to younger patients, although some studies show otherwise.<sup>49,50</sup> Also, perceptions about older patients not wanting certain treatments or not wanting to share decision-making<sup>51</sup> may lead to clinicians behaving – consciously or unconsciously – differently towards older patients. It may result in elderspeak (speaking slower/louder when talking to an older individual<sup>44</sup>), less consultation time spent with older patients,<sup>52</sup> and being directer about their own preferences.<sup>3,53-55</sup> Despite best intentions (e.g., protecting older patients from unacceptably harmful treatments), making unilateral decisions or withholding treatment options based on unsounded beliefs about an entire group of patients may jeopardize clinicians in fulfilling their obligations to inform eligible patients about available options, and also denies older patients becoming involved in decision-making.

It is important to be aware of this, because most older adults are different from how they are stereotyped, and most are still independent and fully capable of cognitive and physical activities. In addition, there are indications that older patients are becoming more assertive during consultations, desire more information and want to be above all kept informed about their disease and treatment options.<sup>56,57</sup> Also, they use the Internet more to seek health information.<sup>58,59</sup> As discussed earlier, results of the prospective study (**chapters 3-5**) run counter to the prevailing presumptions about the preferences of older breast cancer patients. Altogether, this raises interesting questions on how to approach older patients in clinical care and how to change the current views about older patients. Suggestions to improve clinical practice and health care policy are discussed in the following paragraphs.

### **Methodological considerations**

In the previous chapters, we described the various strengths and limitations of the studies in this thesis. In the following paragraphs, some general strengths and limitations are discussed in detail.

An important strength of this thesis is that we captured the perspectives of older patients and clinicians. A strength of the studies performed among patients was its prospective design. The innovative aspect was that preferences were assessed even before patients received a treatment recommendation from the surgical oncologist or information about a possible referral to a medical oncologist. In retrospective studies, the patients may have had a strong preference for the treatment they underwent, which may be caused by a psychological mechanism (i.e., cognitive dissonance reduction or post-hoc justification<sup>60</sup>). Even in previous prospective studies, in which preferences were assessed before the start of treatment, but after a treatment decision had been made, patients may already have had a more positive attitude towards their recommended treatment.<sup>60</sup> As a result of our study design, we could minimize the possible influence of cognitive dissonance reduction or justification.

Nonetheless, several limitations should be considered. A main shortcoming of the studies among patients is the smaller number of older patients who participated in the study compared to that of younger patients. In two studies, one third of the sample were aged  $\geq 65$  years and in one study, the percentage of older patients was around 30%. These percentages are smaller than the estimated 40% of the new breast cancer cases in older women. As earlier addressed, we were unable to include more older patients, as many of the older patients who were approached and participated in the study, were identified with a previous malignancy later on, after review of their medical records. This previous experience could have influenced their opinion about the treatment under investigation. We acknowledge that comparisons between younger and older patients could have been more properly explored using a larger sample of older patients (to increase statistical power). However, we did compare the

characteristics of our older patients with those older patients in a population-based cohort study in the Netherlands<sup>61</sup> and this showed that the samples were comparable with regard to median age and presence of comorbid and geriatric conditions.

Second, in the study among clinicians, the number of radiation and medical oncologists was lower than the number of surgical oncologists. Consequently, results may greater imply the views of the latter group. Further, we did not directly assess agreements between what clinicians report to recommend versus what they actually recommend. Therefore, it is not clear from our work which factors may lead clinicians in deciding whether or not to treat older patients.

### **Next steps to further improve decision-making in older women with breast cancer**

In the Netherlands, approximately 60,000 (60%) of all newly-diagnosed cancers currently occur in older adults.<sup>62,63</sup> This number will rise due to the ageing of the Dutch population. Consequently, a trend will be seen in which all subspecialties of oncology will primarily deal with the care of older patients. Paradoxically, there is limited knowledge about the treatment and psychosocial needs of older cancer patients.<sup>64,65</sup> Fortunately, it has become well-recognized that the focus needs to be on this patient group. Between 2011 and 2014, the Dutch Cancer Society prioritized its agenda onto geriatric oncology and funded projects involving older individuals with cancer.<sup>58</sup> Similarly, the Dutch Breast Cancer Association focused their policy on older patients between 2012 and 2014 and conducted a project to explore their information needs.<sup>66</sup> Further, national (e.g., Geriatric Oncology Netherlands<sup>67</sup>) and international (e.g., SIOG<sup>1</sup>) societies and organizations committed to geriatric oncology have made great efforts to raise awareness in the medical community and to exchange information about best care between clinicians, patient associations and researchers with an interest in geriatric oncology. However, it is clear that still much work is to be done, especially in the field of breast cancer. If current demographic trends continue, older patients will comprise 52% of the new breast cancer cases by 2030, compared to 40% in 2012.<sup>68</sup> Consequently, more data are required to guide treatment decision-making; however, still only 2% of the ongoing clinical trials specifically focus on older patients.<sup>64</sup>

In the following sections, implications for health policy and clinical practice are discussed based on the findings of this thesis. Also, recommendations for future research are given.

#### *Implications for practice and policy*

Our findings prove the need for clinicians to explicitly explore older patients' preferences, as their preferences varied widely. Even more so important, older patients reported preferences that deviated from previous assumptions (e.g., older patients would be willing to undergo breast-conserving surgery or adjuvant chemotherapy). If clinicians assume that they know their older patients' preferences based on the patient's age without explicitly asking them,

they may erroneously believe that older patients do not want certain treatments and propose a treatment plan that is not consistent with their preferences. Therefore, it is important that clinicians discuss all available treatment options and explicitly explore the older patient's wishes, regardless of whether or not the patient defers the final decision.<sup>69</sup> They need to be asked about their wishes as early as possible in the decision process, so that their preferences can be taken into account in multidisciplinary team meetings as much as possible.

What can be done to help clinicians to further optimize elicitation of older patients' preferences? A practical step could include the development and use of patient decision aids tailored to the needs of older patients. Decision aids are tools that help make the decision explicit by outlining the available treatment options and associated benefits and risks, and have been overall successful in clarifying patients' values and preferences.<sup>70</sup> These tools may well be effective in supporting older patients' decision-making and improving patient-clinician communication.<sup>71-73</sup> Our results on the unique concerns of older patients could inform on the benefits and risks to be included in new<sup>71,74</sup> or existing<sup>75</sup> patient decision aids (**chapters 3 and 4**).

It may also be useful to add a separate module dedicated to older patients to the current breast cancer treatment guidelines. Such an addition would likely create more awareness among clinicians about the severity of the disease in this patient group. Throughout the module the emphasis should be on the older patient's preference, especially in decisions for which there is limited scientific evidence about the best treatment option. It would be helpful to mention the specific treatment decision points for which there is a high need to explicitly explore the older patient's preference. The current breast cancer guidelines briefly remark that patient preference should be taken into account for the decision between breast-conserving surgery versus mastectomy, but do not elaborate on the reason to inform patients about treatment options and to discuss their values, nor acknowledge that an individualized approach may lead to different treatment advices. Additionally, a comment that older patients' expectations, preferences and motivations can be different from those of previous generations of elderly could be helpful, supported by a description of research data about current older patients' preferences. Our results have highlighted which topics clinicians should clearly consider bringing into their conversations with older patients (**chapters 3 and 4**).

As described above, we argued that clinicians should more intensively ask the older patient about her preferences. However, this may not be sufficient to improve shared decision-making between the clinician and older patient. Most importantly, the mindset of clinicians needs to be changed with regard to older patients. It is important for them to acknowledge that views of older patients about their desired role in decision-making may have changed over time,<sup>76,77</sup> and that their treatment preferences may deviate from what was previously

expected. This change in the current group of older patients means that, consequently, a change in the perceptions among clinicians about older patients is required to reflect this reality. If clinicians fail to recognize this, then all abovementioned recommendations will most likely not be followed or considered. Implementation strategies must therefore rather focus on making clinicians aware of the possible impact of their attitude towards older patients, and on educating them about communication methods with older patients through training sessions. These sessions could be done by using role playing to practice communication skills. Previous research has shown that such interventions may result in increased knowledge about and a more positive attitude towards older patients.<sup>40,78</sup> More general, clinicians can be trained more thoroughly in shared decision-making to create awareness about their important role therein.<sup>79</sup> Current national campaigns stimulating the implementation of shared decision-making in hospitals (Beslist Samen! and Betere zorg begint met een goed gesprek<sup>80</sup>) are great initiatives to better equip clinicians with the tools to facilitate a shared decision-making conversation.

Aside from the clinician's role, it is also important to stimulate older patients themselves to become more involved in decision-making. Older women are especially in need of support since they seem more likely to experience lower levels of patient involvement than younger patients (**chapter 5**) and also more likely encounter specific barriers (e.g., not really allowed to decide, lower health literacy<sup>81</sup>) next to general and well-known barriers (e.g., time constraints). Further, older patients may be exposed to negative stereotypes, but they themselves may also be biased (e.g., breast reconstruction is not appropriate at older age<sup>43</sup>), which may prevent them from bringing up important topics. As shared decision-making starts with the clinician inviting the patient to make the decision together, the clinician is according to our belief the most important person to empower older patients and to guide them in the decision-making process. It has been shown that clinicians serve as a useful first resource of information<sup>58,82,83</sup> and that clinicians create a trustful environment in which the patient feels comfortable to express her values and concerns.<sup>69,84</sup> Additionally, there are general initiatives to help older patients prepare better for their consultation, such as the ask-three-questions ('what are my options?'; 'what are the possible benefits and harms of those options?'; 'how likely are each of those benefits and harms to happen to me?'<sup>85</sup>). Encouraging patients to ask a few key questions can already lead to higher quality information about treatment options from their clinician and thus greater patient involvement.<sup>86</sup> Also, decision support tools may be helpful in supporting the participation of the older patient in decision-making. Therein also lies in part a responsibility of the Dutch Breast Cancer Association to stimulate them in taking an active role in their healthcare. Based on their information needs project, they have undertaken several actions to provide older patients with tailored patient education, one of which included the addition of segments about breast cancer at older age on their webpage and to their magazine.<sup>87</sup> Further, they developed a checklist of relevant questions for older

patients during the consultation (i.e., B-bewust checklist<sup>88</sup>).

#### *Implications for research*

An important area for future research would be to assess the preferences within the older patient population itself. Due to the low number of patients above the age of 75 years, we were unable to compare preferences between different age groups within the older patient sample. Since the heterogeneity of older patients drastically increases with increasing age, it would be important to know which factors may be more relevant for the older-old (often referred to as adults aged over 75) compared to the young-old (those aged 65-74 years). Further, it could be argued that with the changing demographic population, another cut-off for older patients (e.g., 75 years and above) would provide greater meaning. It would be important for future research to recruit sufficient older-old patients to take into account their larger possibility of being excluded from the study, as in our case based on a previous malignancy. Possible solutions could be to recruit at more hospital sites (within the limits of financial resources and time available), or to recruit more older-old compared to young-old patients (for example, according to a 2:1 ratio). The findings of such studies can be compared with the findings of the patients in our studies, and could provide insight into whether our observed (dis)similarities hold in a larger sample. Aside from comparing age categories, it would be particularly relevant to assess whether treatment preferences are related to different levels of comorbid conditions, activities of daily living, social environment and quality of life in an older patient population.

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More research is needed on the factors that frequently affect older patients' decision about whether to have breast reconstruction following a mastectomy. We noticed that the proportion of older patients who would prefer breast reconstruction was much lower than that of younger patients, but we had no information on the reasons for their different preferences. Based on our findings regarding their surgical treatment preference, older patients were less willing to deal with multiple surgeries, and this factor could be carefully extrapolated to breast reconstruction, as this procedure often entails multiple surgeries and is also a more extensive surgery. Other reasons of breast cancer patients, including being content with a prosthesis, could particularly apply to older patients,<sup>89</sup> but it is also possible that older patients may believe that a breast reconstruction at old age is inappropriate.<sup>90</sup> It is therefore necessary to enhance our study with results of other studies, to gain insight in reasons unique to older patients, and to (better) educate older patients about the possibility of breast reconstruction.

Another important recommendation for future research is to more fully assess the decision-making process by clinicians. If we want to stimulate the occurrence of shared decision-making with older patients, it is not only relevant to assess how patients make decisions,

but also how clinicians make these. We would therefore argue for a combination of clinical encounters studies and self-reported data from clinicians to gain more insight into the decision-making process with older patients. Such findings could provide valuable insights for the development of interventions to optimize treatment decision-making with this patient group.

Another key priority of future research is the development a decision tool, which not only predicts (disease-free) survival with or without therapy for an older patient, but also provides information on other outcomes, such as the quality of life or functional decline after specific breast cancer treatments. Such patient-centred outcomes are likely to be equally or more important to older patients and can be important considerations in decision-making. Current prediction models that are frequently used to communicate prognosis to patients, such as Adjuvant! Online, are based on basic patient and tumour characteristics and do not include outcomes such as functional decline. A prediction tool that not only includes traditional outcomes, but also focuses on other highly relevant outcomes for older patients could be particularly useful for both clinician and older patient in evaluating treatment options and in making more individualized treatment decisions.

Finally, a general recommendation is to conduct more randomized clinical trials and prospective observational studies in older breast cancer patients to increase the evidence base. Fortunately, several (observational) studies have recently been initiated, such as the Climb Every Mountain study (functional, psychological, social and cognitive decline after treatment in older breast cancer patients<sup>91</sup>) and the TOP study.<sup>92</sup> The studies described in this thesis were part of one of the largest studies among older patients, namely the FOCUS study (Female breast cancer in the elderly: Optimizing Clinical guidelines USing clinico-pathological and molecular data<sup>93</sup>), which combined information from various sources (e.g., population-based national cancer registries, clinical trials and tumor tissues). The FOCUS study has recently been granted funding by the Dutch Cancer Society for a research project to develop a prediction tool, as earlier described, that should include both traditional and patient-centred endpoints.<sup>94</sup> Findings of these and future studies in older patients will hopefully advance our knowledge and better guide clinicians and older patients in deciding which treatment option is best.

## CONCLUDING REMARKS

The findings that this thesis brought to light will help in providing more understanding to the preferences of older patients and will assist clinicians in tailoring their information provision for this growing patient group. It showed that younger and older patients had many similar – but also some dissimilar – preferences. Although age-related differences need to be kept in mind, it is even more crucially important that an individualized approach is followed in older –

as in younger – patients. We consider it necessary that older patients are invited in treatment decision-making too, are informed about the risks and benefits of available treatment options, and are asked about their individual preferences and concerns. Our findings indicate that older patients may have certain preferences that run counter to the assumptions prevailing in oncologic clinical practice. Our findings suggest that this patient group could therefore profit considerably from the assessment of their preferences. In this process, a change in the behavioral culture of the medical community towards geriatric oncology is needed. More work is also needed on research level. Until then, the practical and policy recommendations mentioned in this thesis provide guidance to clinicians and policy makers, and contribute to improving the quality of care for older breast cancer patients in the very near future.

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