Refining individualized medicine in older patients with breast cancer

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Older patients' barriers and facilitators for omission of locoregional breast cancer treatment

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ABSTRACT

Introduction. In older women with early breast cancer, individual components of locoregional treatment may have limited benefit with regard to recurrence and survival. Yet, the use of these treatments tends to persist after limited benefit is demonstrated. Patients play a crucial role in the decision to perform or omit treatment. This study therefore aims to assess patient barriers and facilitators for omission of specific locoregional treatments.

Methods. We conducted focus groups with patients aged ≥70 years to discuss omission of radiotherapy after breast-conserving surgery, axillary lymph node dissection (ALND) after positive sentinel node and replacement of primary surgery by endocrine treatment. Conventional content analysis was performed. Identified barriers and facilitators were presented as treatment scenarios in a survey among a larger group of older patients to identify the five most frequently occurring factors.

Results. Fifty-nine patients completed at least one treatment scenario in the survey. Fear of disease recurrence, feelings of receiving suboptimal treatment, and lack of social support were general barriers to omit radiotherapy and ALND. Barriers to omit surgery related to replacement by endocrine treatment. The relationship with the clinician and specialist nurse, information provision and trust in evidence were frequently mentioned general facilitators for all treatments. Avoiding long-term adverse effects of radiation and the risk of lymphedema after ALND were treatment-specific facilitators.

Conclusion. Reassurance on recurrence risks and involving family members for social support are two key actions clinicians and specialist nurses may take to enhance de-implementation of radiotherapy and ALND in patients with expected limited benefit.

INTRODUCTION

Since the number of older patients with breast cancer is increasing due to ageing of Western populations, efforts are made to improve the evidence for treatment effects in this patient population.[1, 2, 3, 4, 5] Previous studies have shown that for specific subgroups, the beneficial effect is very limited with regard to recurrence or survival due to a combination of low risk breast cancer and a shorter life expectancy. For example, it was shown that patients over 70 years with small tumors who are treated with endocrine treatment do not benefit from radiotherapy after breast-conserving surgery (BCS).[6] Surgery conferred no survival benefit over endocrine therapy alone in patients with hormone receptor-positive tumors and a life expectancy up to 2-3 years.[5, 7] Moreover, axillary lymph node dissection (ALND) did not add value for all aged patients with 1-3 positive sentinel lymph nodes who receive systemic treatment.[8]

However, to de-implement conventional treatments is more challenging than to implement a new treatment.[9, 10] Practice patterns show inconsistent de-implementation of individual treatments. Rates of radiotherapy after BCS have only modestly declined, whereas rates of ALND after a positive sentinel lymph node biopsy (SLNB) have decreased more rapidly.[11, 12] Furthermore, rates of surgery vary across countries and hospitals for patients over 80 years.[9, 13] Overall, practice patterns thus suggest that de-implementation could be improved, and that radiotherapy after BCS, as well as ALND after positive SLNB are likely still overutilized in older patients.

The differences in rates and varying trends of de-implementation cannot be explained by patient characteristics alone. Clinicians highlight that, besides their own views, patient views play an important role. In a survey on omission of radiotherapy (n=825), clinicians most frequently agreed on the statement that patients desire maximal treatment, even if the benefit is small.[14] Patient preference is the second most important factor after comorbidity to omit surgery according surgeons and specialist nurses (n=34).[15] Furthermore, patients' fear of lymphedema is mentioned as the strongest motivator (n=18) to omit ALND after a positive SLNB.[16] There could be other patient barriers preventing de-implementation, as well as facilitators that might help to overcome these barriers. Therefore, the aim of this study was to identify patient barriers and facilitators to omit radiotherapy after BCS, ALND after positive SLNB, and to replace primary surgery with endocrine treatment in older patients with early breast cancer.

METHODS

Study design

This was a mixed method study performed at the Leiden University Medical Center (LUMC) in collaboration with the national patient organization "Borstkankervereniging Nederland" (BVN). It was part of a larger project that aimed to identify locoregional treatments with limited added value in selected older patients with breast cancer. The current study was performed alongside to gain insight into factors influencing the de-implementation of such treatments.

In the first part, focus groups with patients were organized to identify barriers and facilitators for omission of treatments when proposed by the clinician. In the second part, the identified barriers and facilitators were presented to a larger group of older patients as treatment scenarios in a survey, to establish which five factors most frequently play a role. The study protocol and survey were approved by the medical ethical research committee of the LUMC (P17.152). The COREQ guidelines were used for reporting of the study.[17]

Participants and recruitment

Participants for the focus groups and survey were recruited through patient organization BVN by email and the outpatient Surgical and Medical Oncology departments of the LUMC, face-to-face or by mail. Consecutive patients who fulfilled the eligibility criteria were selected. Patients were eligible if they were treated for non-metastatic breast cancer aged 70 years or older. Time since diagnosis had to be at least six months to allow for recovery time and reflect on their experience. Understanding of the Dutch language was required. Patients with dementia were excluded. Participants for the focus groups were recruited until three groups of five participants could be organized.

Focus groups

In the period between February and May 2018, three focus groups were organized in the LUMC, each with five participants. The focus groups were conducted by a moderator (AB, MD, female) and assistant (NG, MD PhD, female). The assistant took notes and made sure all participants were heard and all relevant topics were covered. Both the moderator and assistant are experienced researchers in the field of breast cancer in older patients. Only the assistant was involved in clinical care at the time the focus groups were held, as a resident medical oncology. This information about the researchers was communicated with the participants, who had no prior relationship with either of the researchers. The researchers prepared for the conduct of the focus groups by studying literature, and guided by medical decision-making specialists experienced with conducting focus groups. A specific focus group guide was assembled based on literature and expert opinion (see appendix 1).

Each focus group took two hours. Three scenarios were discussed: the omission of radiotherapy after BCS, the omission of ALND after a positive SLNB, and the omission of primary surgery to be replaced by primary endocrine treatment (PET). The scenarios were introduced with the following question: "*if your doctor would propose treatment omission, would you have reasons to still want to undergo the treatment? If not, what are your considerations? If yes, what are your considerations?"* This question was sent by mail prior to the focus groups for preparation. The focus groups were audio-taped and transcribed verbatim. A conventional content analysis was performed by AB by deriving barriers and facilitators from the content, and coding similar items. The framework of Grol and Wensing was used to ensure the representation of factors on different levels. This generic framework was developed to assess barriers and facilitators for the implementation of new evidence on six levels of healthcare; the innovation itself, the professional and patient respectively, and the social, organizational, and financial context.[18] Data saturation was reached as no new items emerged during the third focus group. The transcripts and final results were not returned to the participants.

Patient perceived barriers were defined as reasons to insist undergoing treatment despite the proposition of the doctor to omit treatment. Facilitators were defined as reasons to follow the proposed treatment plan in which the treatment is omitted. A distinction was made between treatment-specific and general factors, with the latter applying to all three treatments.

Survey

Between May and October 2019, 90 patients agreed to participate in the survey. The survey included the same three scenarios as presented in the focus groups. All barriers and facilitators that were identified in the focus groups were included in a list of reasons following the statement "*I would still want to undergo the treatment despite the proposition of my clinician*" or "*I follow the proposition of my clinician not to undergo the treatment*." The respondent was asked to choose a maximum of five reasons. The barriers and facilitators were presented as quotes, for example *"because I think that more extensive treatment is always better*" or "*because I am afraid of the unknown long-term adverse effects of endocrine treatment*". An example scenario is presented in appendix 2. We computed the five most frequently mentioned barriers and the five most frequently mentioned facilitators for each treatment, while distinguishing between treatment-specific and general factors.

RESULTS

Patients

Median age of the 15 patients who participated in the focus groups was 74 years (range 71-86 years) and 72 years at time of diagnosis (range 70-85 years). All patients were surgically treated. Three underwent an ALND. Four patients underwent radiotherapy, out of 7 patients who underwent BCS. Four patients received adjuvant endocrine therapy, and 3 received chemotherapy.

Of 90 patients responding to the survey, 59 patients completed at least one scenario and were included in the analysis. Median age was 74 years (IQR 71-76 years) and 71 years at time of diagnosis (IQR 68-73 years). Three patients were treated with PET, and 56 patients underwent surgery of whom 13 underwent an ALND. Twenty-five patients underwent radiotherapy, out of 28 patients who underwent BCS. Thirty patients received adjuvant endocrine therapy, and 17 received chemotherapy.

General factors identified in the focus groups

We found factors applying to all three treatments on the level of the professional, the patient, and the social context (Table 1 including representative quotes). On the professional's level, all patients agreed that a trustful relationship with the clinician is the most important facilitator to agree with the proposal to omit treatment. Only one patient indicated a lack of trust as barrier. The feeling to be listened to and to be provided with sufficient information were other important facilitators. The specialist nurse was also valued by many patients.

Factors identified on the level of the patient were mostly barriers. It was mentioned that despite the knowledge that a treatment has no significant benefit, fear was a motivator to still want to undergo treatment. Similarly, some patients felt that more extensive treatment is always better. Others felt uncomfortable to receive substandard treatments, or different treatments than younger patients would receive. Similarly, trust in the scientific evidence was mentioned as barrier if patients were wary to be one of the first to be treated differently. Contrary, for others, trust in the scientific evidence was a facilitator.

Last, general factors on the level of the social context could act as either a barrier or a facilitator. For experiences from a familiar person, negative experiences seemed to have more impact than positive experiences. It was observed less often that a patient still wanted to undergo a treatment because of a familiar person with a good experience. Support from family members was predominantly brought up as facilitator.

Table 1. General barriers and facilitators for omission of treatments identified in the focus groups. B barrier; F facilitator.

Level	Barrier/facilitator	Sample quote	B	F
Professional	Relationship with doctor	"If you consider how clinicians guide you from the first step through surgery and after that, I don't believe they will make recommendations they don't support."		X
		"Clinicians don't tell you everything. Sometimes you come home and realize: if I had only put it like this, then maybe the clinician had explained it differently?"	X	
		"Trust in your clinician is most important. As a patient, you do not know much about scientific evidence."		X
	Relationship with specialist nurse	"I have consulted the specialist nurse several times. Her opinion and the fact that she examined me extensively gave me comfort during the process."		X
	Information provision	"The clinician took the time to explain everything and to let me talk. I really appreciated that he took the time to consider my personal preferences as well.		X
		"To be educated gives the patient comfort. Education is so important."		X
Patient	Fear of disease recurrence	"At the time, you don't give the surgical risks [of axillary lymph nodes dissection] a lot of thought. You think if only the cancer is gone."	X	
		"Fear is a bad advisor, but I can imagine that it can be a reason to choose to undergo the treatment anyway."	X	
	Trust in evidence	"You have to take a leap of faith. Back in the days it was only amputation, then there was breast conserving treatment. I think medical science will further move forward."		X
		"It is important to know how much research is done. You do not want to be the first they try it on."	X	
	Perception that extensive treatment is better	"[Despite the risk of lymph edema] I would still prefer to undergo an axillary lymph node dissection because if the cancer has spread to your lymph nodes, it also has access to the rest of your body."	X	
		"You want to do the best you can. If you are enjoying life, you do not want to die."	X	
	Important to receive the same treatment as younger patients	"I noticed that I had trouble with accepting treatments that are not standard, because it's effects are less known."	X	
		"The mass screening program stops at 75 years because there is no survival advantage, but what if you are an exception to the rule?"	X	
Social	Experience of family/friends	"One person I know told me I should never start with endocrine therapy, because it causes fatigue and painful joints."	X	
		"A person I know, her skin got really damaged by the radiotherapy."	X	
	Support by family/friends	"If you lack support at home, you may be more inclined to just undergo the treatment instead of considering different options."	X	
		"I had to get used to the idea not undergoing radiotherapy, but I discussed it with my husband and children."		X

Scenario 1. The clinician suggests to omit radiotherapy after BCS

The treatment-specific barriers and facilitators for omission of radiotherapy identified in the focus groups are presented with representative quotes in Table 2. Most patients expressed the fear of adverse effects due to radiation of the heart and lungs as a facilitator to omit radiotherapy. Some wondered whether the radiotherapy had something to do with general complaints they now experienced such as fatigue and sleeping problems. Several patients described that they were still very fit, and were afraid the radiotherapy would impact their physical condition. On the innovation level, some patients heard stories about poor wound healing, but this was not considered a strong facilitator. On the organizational context level, the avoidance of frequent hospital visits was a facilitator depending on the distance and functional status. Others did not mind the hospital visits, and some even felt they provided structure in their daily life.

From the survey, the five most frequently mentioned barriers and facilitators to omit radiotherapy are presented in Table 3. More respondents indicated facilitators (n=39, 66%) than barriers (n=20, 34%). The only treatment-specific factor was avoiding potential long-term adverse effects of radiation as facilitator. Most facilitators were on the level of the professional, whereas most barriers were on the patient level. If the clinician would propose to omit radiotherapy, a trustful relationship with the clinician and specialist nurse, and to be provided sufficient information could enhance this decision. In contrast, fear of disease recurrence, and wariness about the extensiveness of treatment were barriers. Lack of social support was also a frequently mentioned barrier. Trust in the scientific evidence was mentioned as both a barrier and facilitator.

Scenario 2. The clinician suggests to omit an ALND after a positive SLNB

The main facilitator discussed in the focus groups was avoiding the risk of lymphedema. The idea that lymphedema could diminish arm functionality was much feared. Some expressed worries about lymphedema being painful, potential sleeping difficulties, and the negative cosmetic effect. On the financial context level, it was mentioned that lymphedema therapy is only partially covered by insurance (Table 2).

The five most frequently mentioned barriers and facilitators in the survey for omission of ALND are presented in Table 3. More respondents indicated facilitators (n=29, 58%) than barriers (n=21, 42%). The only treatment-specific factor was avoiding the risk of pain and impaired arm function due to lymphedema as facilitator. Otherwise, the five most frequently mentioned barriers and facilitators were the same as for omission of radiotherapy.

Table 2. Treatment-specific barriers and facilitators identified in the focus groups. B barrier; F facilitator.

Level	Barrier/facilitator	Sample quote	B	F
Omission of radiotherapy after BCS				
Innovation	Risk of complications	"You might end up with all sorts of complaints such as painful ribs."		X
		"After surgery, the radiotherapy doesn't make the breast any prettier."		X
	Inconvenience	"The radiotherapy sessions were more inconvenient than the surgery. I had to keep my arm in a position which was almost unbearable."		X
Patient	Fear of adverse effects	"Since my tumor was located on the left side, my heart would be irradiated and I could end up becoming a heart patient."		X
		"The fatigue and sleeping problems, sometimes I think they are due to the radiotherapy. However, it could also be the endocrine therapy."		X
Organizational	Frequent hospital visits	"You already feel unfit, and then you have to go back and forth to the hospital. Sometimes you do not know what is best for you."		X
		"I did not mind the frequent hospital visits, the people were very kind and it gave me structure after the hectic period of diagnostics and surgery."	X	
Omission of ALND after SLNB+				
Innovation	Risk of lymph edema	"Due to lymph edema, the functionality of my right hand is reduced. I read about the surgical risks, but still, this was not what I expected."		X
		"Even if you are over 70 years of age, you still want to look good."		X
Financial	Costs of edema therapy	"You think it is something small the lymphedema [therapy], you get started, and then you have to pay hundreds of euros which insurance does not cover."		X
Omission of primary surgery by replacement with primary endocrine treatment				
Innovation	Breast cosmesis	"I could not at all endure the idea that my breast would be amputated. I just had a new partner. I would consider omission of surgery if it was safe."		X
	Risk or inconvenience of surgery	"Although my surgery went well, I would prefer not to undergo all the inconveniences, and they still have to cut in your body."		X
	Risk of side effects of endocrine treatment	"After a year on letrozole, I told my oncologist that I wanted to stop because the side effects had a negative impact on my quality of life."	X	
	Duration of surgery vs endocrine treatment	"I would choose surgery, because the inconveniences of surgery pass relatively quickly."	X	
		"I would say, gone is gone."	X	
Patient	Fear of surgery	"I would prefer the tablet. At my age, I have had enough surgeries."		X
	Perception about endocrine treatment	"A tumor does not belong there, thus should be removed [rather than controlled]."	X	
		"I think hormones are scary."	X	
	Fear of adverse effect endocrine treatment	"Nobody knows whether endocrine therapy is safe." "I heard on the television that endocrine therapy is harmful, that it can cause breast cancer."	X X	
Organizational	Hospital admission	"I had to arrange that my husband could stay in a nursing home for the days I was admitted to the hospital."		X

Abbreviations; BCS breast conserving surgery; ALND axillary lymph node dissection; SLNB+ positive sentinel lymph node biopsy; PET primary endocrine therapy.

Table 3. The five most frequently mentioned barriers and facilitators for omission of radiotherapy after breast-conserving surgery and omission of axillary lymph nodes dissection after positive sentinel lymph node biopsy in the survey.

Barriers	Level	Facilitators	Level
General factors for the omission of both treatments			
Fear of disease recurrence/progression	Patient	Trustful relationship with doctor	Professional
Perception that more extensive treatment is better	Patient	Trustful relationship with specialist nurse	Professional
Important to receive the same treatment as younger patients	Patient	Information provision	Professional
Lack of trust in evidence	Patient	Trust in evidence	Patient
Lack of support by family/friends	Social		
Treatment-specific factor for omission of radiotherapy after BCS			
		Avoiding fear of possible (unknown) long-term adverse effects of radiotherapy	Patient
Treatment-specific factor for omission of ALND after SLNB+			
		Avoiding risk of pain and impaired arm function due to lymphedema	Innovation

Scenario 3. The clinician suggests to omit surgery and treat with primary endocrine therapy

Facilitators discussed in the focus groups related to avoiding surgery. Some patients considered themselves too old to undergo surgery. One patient could not endure the idea of her breast being amputated. However, more patients preferred surgery because the inconveniences pass relatively quick, whereas side-effects of endocrine treatment persist for a longer time. It was emphasized that the advantage of avoiding surgery are outweighed by the risk of side-effects of endocrine treatment. Endocrine treatment was even considered unsafe by some patients. On an organizational context level, avoiding hospital admission could be a facilitator as one patient mentioned she had to arrange care replacement for her husband (Table 2).

The five most frequently mentioned barriers and facilitators in the survey for omission of surgery are presented in Table 4. In contrast to the previous two scenarios, respondents indicated mainly barriers (n=46 (87%)). Besides fear of disease progression, all barriers were treatment-specific. The risk of side-effects and fear of potential long-term adverse effects of endocrine treatment were frequently mentioned. Also, the fact that endocrine treatment should be used for a longer period, whereas you can have surgery and be done. Lastly, that a tumor needs to be removed instead of controlled. Again, the same four general facilitators were found with feeling too old to undergo surgery as the fifth facilitator.

Table 4. The five most frequently mentioned barriers and facilitators for omission of primary surgery by primary endocrine treatment replacement in the survey.

Barriers	Level	Facilitators	Level
General factors			
Fear of disease progression	Patient	Trustful relationship with doctor	Professional
		Trustful relationship with specialist nurse	Professional
		Information provision	Professional
		Trust in evidence	Patient
Treatment-specific factors			
Duration of surgery vs endocrine treatment	Innovation	Feeling too old to undergo surgery	Patient
Risk of side effects of endocrine treatment	Innovation		
Perception that a tumor needs to be removed instead of controlled with endocrine treatment	Patient		
Fear of possible (unknown) long-term adverse effects of endocrine therapy	Patient		

DISCUSSION

This study investigated patient barriers and facilitators to omit treatments demonstrated to have limited benefit in certain patient selections. In summary, the most frequently mentioned barriers and facilitators for omission of radiotherapy after BCS and ALND after positive SLNB were general factors; related to fear of disease recurrence and the relationship with health care professionals. Almost all respondents still wanted to undergo primary surgery if the clinician proposed PET, due to barriers related to PET; the risk of side-effects and treatment duration.

Our observations are mostly in line with a previous survey capturing patient views on omission of radiotherapy.[19] Similarly, it was indicated that worry about the cancer coming back was one the most important considerations. In contrast to our findings, receiving extensive treatment was considered less important in that survey. Also, avoiding potential long-term effects of radiotherapy was a frequently mentioned facilitator in our study, whereas in the previous survey, the avoidance of direct complications was more pronounced than the avoidance of irradiation per se. It should be noted that the studies had different designs.

In any case, clinicians opinion that patients seem to desire maximal treatment, even if the benefit is very small seems not justified based on both studies.[14] Although receiving extensive treatment and similar treatment to younger patients were important barriers, 66% (39 out of 59 patients) of our respondents reported that they would agree upon omission of radiotherapy if the clinician proposed so. The question to what extent treatment decisions

that can be based on patient preference are in fact based on the preference of the treating clinician was previously raised.[20] This treatment bias seems to occur both on the level of the patient and clinician.

In a recently study on barriers and facilitators to de-implement treatments that are considered unnecessary as part of the Choosing Wisely guideline, all 18 surgeons that were interviewed agreed on the omission of ALND in patients with a positive SLNB.[16, 21] However, a larger survey among 359 surgeons performed between 2013 and 2015 showed substantial variation in acceptance with approximately half still favoring ALND.[22] Furthermore, ALND rates of 45-46% after a positive SLNB are reported in Europe over 2015 and 2016 (most recent years available).[12] Although these studies did not address older patients specifically, overall, they indicate that ALND is overutilized. It was unexpected that 42% of our respondents (21 out of 50) still wanted to undergo ALND even when the clinician would suggest not to with fear of recurrence being an important factor. This observation emphasizes that in addition to focusing on the benefits of avoiding ALND, clinicians should inform and reassure a patient about the effect on recurrence risk.

The decision to omit surgery is a different situation since this requires replacement by endocrine treatment rather than omission of treatment only. Barriers and facilitators for both treatment options then have to be considered. Patient choice did not explain the omission of surgery in a UK cohort of 800 patients aged 70 years or older.[23] A smaller cohort study however showed that if surgery and PET were both discussed, which was the case in older patients with more comorbidities, 66 out of 112 chose to omit surgery.[24] We observed that 87% of the patients (46 out of 53) in our study still wanted to undergo surgery if PET was proposed as alternative treatment by the clinician. However, it should be kept in mind that almost all patients that participated in our study underwent surgery which likely influenced their opinion. The most frequently mentioned barriers related to the risk of side-effects of endocrine treatment and potential unknown long-term adverse effects, and that the inconvenience of PET lasts longer than of surgery. In light of the increased rates of omission of surgery, clinicians recommending this strategy may underestimate these barriers to PET.[25, 26] Moreover, PET is only a suitable strategy for a small fraction of the older patients, the very oldest or frail. Our recent study showed that even in patients over 80 years, omission of surgery is associated with worse survival.[13]

Based on the findings in the present study, several specific actions can be undertaken by clinicians and specialist nurses to support de-implementation. As can be expected, fear of disease progression is a major consideration that contributes to perceptions that extensive treatment is always better and treatments should be similar to younger patients. For omission of radiotherapy and ALND, facilitators were mostly general factors rather than related

to the treatment to be omitted specifically. The hospital visits and direct complications and inconveniences from radiotherapy were not among the frequently mentioned facilitators, nor were the general risks and inconveniences of surgery mentioned for omission of ALND. Avoiding potential long-term adverse effect of radiotherapy and the risk of lymphedema were the only frequently mentioned treatment-specific facilitators. Therefore, rather than focusing too much on the avoided risks when proposing to omit treatments, it is up to the clinician and specialist nurse to sufficiently inform and reassure the patient on recurrence risks. Furthermore, the survey also pointed out that a lack of social support was experienced as a barrier. It could therefore be helpful to involve patient family members in the treatment decision process to make sure that the patient receives sufficient social support for the decision made.

This study demonstrates how insight in patient barriers and facilitators could improve the actual omission of treatments with limited benefit in clinical practice. For health care professionals, they can guide actions that enhance de-implementation as best as possible. Also, a discordance between clinicians' perception on patient considerations and the actual considerations can come to the attention. Since performing this study, the American Society of Surgical Oncology has advocated not to perform an SLNB in patients aged 70 years or older if the results will not impact systemic therapy decisions.[27] Furthermore, the ongoing TOP-1 (Tailored treatment in Older Patients) study (BOOG study number 2016-01) investigates the omission of radiotherapy in patients aged 70 years or older with early breast cancer not receiving endocrine treatment. Therefore, the identification of patient barriers and facilitators will be needed to optimize future de-implementation of treatments once they prove to be of low value.

Our study had some limitations. Foremost, accrual of survey participants was slow, and a substantial part of the patients who agreed to participate did not manage to complete at least one treatment scenario. Despite a pilot survey (n=10), its complexity likely played a role, as patients had to imagine a hypothetical situation in which their clinician proposed to omit a treatment and objectify their considerations. This was mentioned in the survey remarks. Second, 12 survey participants were aged 66-69 years, and 8 were aged 60-65 years at diagnosis. We chose to include these patients to improve our sample size. Third, selection of older patients able and willing to participate in studies may have also reduced the generalizability of our findings. Last, it should be mentioned that patients are more likely to insist on a treatment they actually underwent based on a good experience, but also due to the need to justify previous decisions.

In conclusion, over half of the patients reported mainly facilitators to omit radiotherapy after BCS or ALND after a positive SLNB when proposed by the clinician, whereas up to

90% mainly reported barriers to omit primary surgery. Our findings indicated that reassurance on recurrence risks and involving family members for social support are two key actions that clinicians and specialist nurse could perform to enhance de-implementation of locoregional treatments with limited benefit in older patients with breast cancer.

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Appendix 1. Focus group guide

Introduction (10 minutes)

We have organized a group meeting to discuss your opinion on the treatment of breast cancer in women 70 year or older. You are asked to share your ideas and personal experiences. We would encourage you to react on each other and create a discussion. We ask that you respect one another's opinion. There are no wrong answers. We are interested in your opinion and what considerations play a role. To analyze the results, we will make an audio recording. The audio records will be anonymized. We will consider everything that is discussed here to be confidential and we ask you to do the same.

The aim of the study is to get insight in your opinion on the omission of parts of the breast cancer treatment. Scientific studies suggest that certain treatment can be safely omitted in selected patients. We would like to find out if patients have reasons to still want to undergo treatment if a clinician suggests to omission of a treatment. Some of you underwent the treatment we are discussing, others have not. If you did not undergo the treatment, please still try to imagine which factors you would consider if you had to make the decision or if a family member asks for your advice.

We will discuss the omission of three treatment separately. Before we start discussing a treatment, we ask you to write down on post-it's the factors that you would consider if your clinician would suggest to not undergo this treatment. We will use these post-it's as a way to guide the discussion. Of course, you can also introduce new factors during the conversation.

Participant introductions (*10 minutes*)

Situation 1. Omission of radiotherapy after breast conserving surgery (20 minutes)

We know from research that a selection of the older patients with breast cancer does not live longer with radiotherapy after breast conserving surgery than without the radiotherapy. There is always a small risk that the breast cancer recurs. Imagine the situation that new research shows that for selected patients, radiotherapy does not lower this risk of breast cancer recurrence either. You belong to this selection of patients, and therefore your clinician suggests to omit the radiotherapy. Do you have reasons to still want to be treated with radiotherapy? Or would you go for the suggestion of your clinician to omit radiotherapy? Could you write your considerations on the post-its? It may help to imagine what you would advise a family member or friend in this situation.

After finishing the post-its, ask if there are any questions about the treatment or side-effects. Try to let the participants answer each other's questions, but interfere or complement if needed. Use the post-it's to initiate and deepen the discussion.

Situation 2. Omission of surgery by replacement by endocrine treatment (20 minutes)

Imagine the situation that new research shows that for selected patients it is safe to treat the breast cancer with medication, endocrine treatment, instead of treated with surgery. You belong to this selection of patients, and therefore your clinician suggests to omit surgery by replacement by endocrine treatment. Do you have reasons to still undergo surgery? Or would you go for the suggestion of your clinician to omit surgery? Could you write your considerations on the post-its? It may help to imagine what you would advise a family member or friend in this situation.

After finishing the post-its, ask if there are any questions about the treatment or side-effects. Try to let the participants answer each other's questions, but interfere or complement if needed. Use the post-it's to initiate and deepen the discussion.

Break (15 minutes)

Situation 3. Omission of axillary lymph nodes dissection after a positive sentinel node biopsy (20 minutes)

During an axillary lymph nodes dissection, all lymph nodes in the axilla are removed. Imagine the situation that new research shows that this procedure can be safely omitted in selected patients with a positive sentinel lymph node biopsy. You belong to this selection of patients, and therefore your clinician suggests to omit the axillary lymph nodes dissection. Do you have reasons to still undergo the axillary lymph nodes dissection? Or would you go for the suggestion of your clinician to omit the procedure? Could you write your considerations on the post-its? It may help to imagine what you would advise a family member or friend in this situation.

After finishing the post-its, ask if there are any questions about the treatment or side-effects. Try to let the participants answer each other's questions, but interfere or complement if needed. Use the post-it's to initiate and deepen the discussion.

Extra time (20 minutes)

Appendix 2. Survey scenario for omission of radiotherapy after breast conserving surgery

Scenario 1 – Radiotherapy after breast conserving surgery

We know from research that a selection of the older patients with breast cancer does not live longer with radiotherapy after breast conserving surgery than without the radiotherapy. There is always a small risk that the breast cancer recurs. Imagine the situation that new research shows that for selected patients, radiotherapy does **not** lower this risk of breast cancer recurrence either. You belong to this selection of patients, and therefore your clinician suggests to omit the radiotherapy.

Question 1:

Do you have reasons to still want to be treated with radiotherapy? Check the box of one of the options and follow the instruction behind.

□ Yes → **answer question 2 and 3 on this page**

□ No → **answer question 4 and 5 on the next page**

Question 2:

Please check the boxes before the letters of reasons why you still want to be treated with radiotherapy. Try to choose as many reasons that are relevant for you, with a maximum of five reasons.

"Despite the suggestion of my clinician, I still want to be treated with radiotherapy..."

	A	"..due to a lack of trust in the clinician."
	B	"..due to a lack of a trustful relationship with the breast care nurse."
	C	"..because I was given insufficient explanation from the clinician."
	D	"..because I am afraid the cancer will come back. Even if I would know that radiotherapy would not lower this risk, because of this fear I would still want to be treated with radiotherapy."
	E	"..due to a lack of trust in the scientific evidence."
	F	"..because I think that more extensive treatment is always better."
	G	"..because the hospital visits give me structure in my daily routine after the surgery."
	H	"..because it is important to receive the same treatment as younger patients."
	I	"..because I am familiar with a person who has had a positive experience with radiotherapy."
	J	"..because the people around me support me in this."
	K	Other reason:

Question 3:

Please arrange the reasons that you just chose in order of importance from most to least important. Write down the letter of the most important reason in the box behind 1, the second most important reason in the box behind 2, and so on until you used all the reasons you chose in question 2. If you chose less than five reasons in question 2 not all boxes will be filled.

1		Most important
2		
3		
4		
5		Least important

Question 4:

Please check the boxes before the letters of reasons why you follow the suggestion of the clinician not to undergo radiotherapy. Try to choose as many reasons that are relevant for you, with a maximum of five reasons.

"I follow the suggestion of the clinician to not undergo radiotherapy..."

	L	"..because that is the advice of the clinician and I trust the clinician."
	M	"..because this is also recommended by the breast care nurse."
	N	"..because the clinician takes the time to explain everything."
	O	"..because I trust the scientific evidence."
	P	"..because I feel too old to undergo radiotherapy."
	Q	"..because I think it is important that new insights are tested in clinical practice."
	R	"..due to the risk of complications from the radiotherapy such as a thinning of the skin and poor wound healing."
	S	"..because I am scared for the (unknown) long term adverse effects due to irradiation of the heart and lungs."
	T	"..to avoid the direct inconvenience of radiotherapy that I have to lie and hold still in an uncomfortable position."
	U	"..because I am familiar with a person who has had a negative experience with radiotherapy."
	V	"..because the people around me support me in this."
	W	"..to avoid the frequent visits to the hospital (16-20 times) that are needed for the radiotherapy."
	X	"..to avoid being dependent on others for the frequent hospital visits (16-20 times)."
	Y	Other reason:

Question 5:

Please arrange the reasons that you just chose in order of importance from most to least important. Write down the letter of the most important reason in the box behind 1, the second most important reason in the box behind 2, and so on until you used all the reasons you chose in question 4. If you chose less than five reasons in question 4 not all boxes will be filled.

1		Most important
2		
3		
4		
5		Least important