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

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CHAPTER 3

A Prospective Comparison of Younger and Older Patients' Preferences for Breast-Conserving Surgery versus Mastectomy in Early Breast Cancer

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To the Editor,

Older women with breast cancer (BC) currently comprise about 40% of all new cases, and this percentage will increase in coming decades.[1] Most early BC patients are eligible for either mastectomy (MAST) or breast conserving-surgery (BCS). These treatments are equivalent in terms of survival rates,[2] but differ in cosmetic outcome, use of additional surgery or radiotherapy, and local recurrence. Patient age is not a contraindication for BCS,[3] but older patients less frequently undergo BCS than younger patients.[4] This variation by age remains after accounting for clinical and nonclinical factors (e.g., tumour stage, comorbidities).[4] An explanation may be different patient preferences. Given older patients' higher occurrence of medical and nonmedical challenges (e.g., limited transportation access),[3] their preferences may differ from those of younger patients. They may also value the impact of treatment (on e.g., body image) differently.

Older patients also less often undergo breast reconstruction following MAST.[5] Although the procedure is suggested to be safe for older patients with comparable complication rates and quality of life improvements as in younger patients,[5] older patients are thought to more often decline reconstruction.[5] However, little is known about their preferences.

Age-differences in treatment decision-making have received little attention.[6] Most studies identified which factors influenced patients' choice for type of surgery. Other studies were restricted to older patients, thereby making it difficult to determine whether the decisive factors count only in older patients. A shortcoming of most studies is that they assessed preferences after surgery, or after the treatment decision had been made.[6] Consequently, cognitive justification may account for patients' strong preference in these studies for the treatment they received or were recommended.[7] The findings may therefore not reflect the preferences of patients facing the decision.

We prospectively compared younger versus older patients' surgical treatment preferences, influencing factors and preferences for breast reconstruction.

METHODS

Participants

Eligible patients had a first primary ductal carcinoma in situ or T_{1-2} invasive disease and were candidates for both BCS with radiotherapy and MAST. Exclusion criteria were bilateral tumour, *BRCA 1/2* mutation, malignancy within the past five years, poor proficiency in Dutch, mental/cognitive problems, neo-adjuvant therapy, and metastatic disease. Participants were

recruited in three (academic and non-academic) hospitals from January 2012-December 2013. The Medical Ethical Committee of the Leiden University Medical Center and the review boards of the participating hospitals approved the study. All patients provided informed consent.

Patients were approached after having been informed about their diagnosis in the first surgical consultation. The surgeons were instructed to discuss the benefits and risks of each option in their usual fashion, but were asked to explicitly mention that the patient had a choice between BCS and MAST, and to not direct the patient towards one or the other option. At the end of the consultation, the surgeon handed out a questionnaire and asked the patient to complete it shortly after the consultation. During the second surgical consultation, the surgeon discusses the options again and gives a recommendation for either surgical option. To prevent the surgeon's recommendation from influencing the participant's preference, participants were asked to complete the questionnaire before the second consultation.

Measures and analyses

The questionnaire included a one-page overview of the differences in the main features of BCS and MAST (Appendix A.1). Except that both options have equivalent survival rates, similarities were not presented (e.g., indication for systemic therapy), to limit the amount of information and because we expected that this information would not influence the participant's choice. Participants were then asked: *'Imagine that both BCS (with radiotherapy) and MAST were available options, which type of surgery would you prefer?'* The response scale ranged from (1) *definitely prefer BCS with radiotherapy*, to (3) *no preference for either option*, to (5) *definitely prefer MAST*. Subsequently, they rated a list of factors (e.g., the surgeon's recommendation) based on literature.[8]

After a short description of breast reconstruction (Appendix A.2), all participants were also asked: *'Imagine that you would undergo a MAST, which option would you prefer (probably would choose reconstruction/probably would not choose reconstruction/do not know)?'.*

Participants were categorized into 'younger' (40-64 years) and 'older' (≥65 years) patients. Response categories were recoded into preference for BCS with radiotherapy; preference for MAST; and no/unknown preference ('no preference for either option' and the participants not answering the question). Mean scores were calculated for each factor and compared between the younger and older participants indicating a preference for either BCS or MAST.

RESULTS

One hundred and seventeen patients agreed to participate (72%). Participants were excluded

if they completed the questionnaire after the second consultation (n=20) or if, for logistic reasons, the decision had been made in the first consultation (n=18). The median age of the remaining 79 participants was 61 years (range, 42-80); 34% (n=27) were aged ≥65 years (Table 1).

Table 1. Characteristics of the study population overall and by age category

	Total (n=79)		**40-64 years** (n=52, 66%)		**≥65 years** (n=27, 34%)		
Variables	n	%	n	%	n	%	*p*
Patient characteristics							
Median age in years (range)	61 (42-80)		56 (42-64)		70 (65-80)		-
Marital status							
married/living together	54	68	37	71	17	63	0.46
single/divorced/widowed	25	32	15	29	10	37	
Educational level[a]							
low	24	30	15	29	9	33	0.50
intermediate	34	43	21	40	13	48	
high	21	27	16	31	5	19	
Employment status							
full/part-time	39	49	37	71	2	7	**<0.001**
housekeeper	10	13	3	6	7	26	
unemployed/long-term sick leave	5	6	5	10	0	0	
retired	25	32	7	13	18	67	
Having children							
no children	16	20	9	17	7	26	0.05
yes, children not living at home	45	57	27	52	18	67	
yes, children living at home	18	23	16	31	2	7	
Number of comorbid conditions							
0	22	28	18	35	4	15	0.14
1	20	25	13	25	7	26	
2 or more	37	47	21	40	16	59	
Geriatric health condition[b]							
no	49	62	37	71	12	44	**0.02**
yes	30	38	15	29	15	56	
Tumour characteristics							
Morphology							
DCIS	16	20	10	19	6	22	0.75
invasive T_{1-2}	63	80	42	81	21	78	

DCIS= Ductal carcinoma in situ; BCS= Breast-conserving surgery; MAST= Mastectomy; T_{1-2}= Tumour size not larger than 5 cm

A p-value in bold means a significant difference between younger and older participants with respect to that variable

[a] Levels of education were categorized as low=completed no/primary school; intermediate=completed lower general secondary education/ vocational training; or high=completed pre-university education/high vocational training/university

[b] Presence of a geriatric health condition was defined as having one or more of the following characteristics: not able to carry out daily activities, incontinence, severe sensory impairment, depression, polypharmacy; difficulties with walking

Type of surgery

BCS (with radiotherapy) was most frequently preferred; by 69% (36/52) of the younger and 56% (15/27) of the older participants respectively. Nineteen percent (10/52) of the younger and 40% (11/27) of the older participants preferred MAST, and 12% (6/52) of the younger and 4% (1/27) of the older participants expressed no preference, or the preference was unknown. These differences were not significant (p=0.11).

Both age groups assigned the highest importance to the surgeon's treatment recommendation (Figure 1). Two factors significantly differed between the groups: younger participants rated the possibility of breast reconstruction as more important than older participants (2.6 versus 1.9, p=0.01), whereas older participants were more concerned about possible additional surgery (3.2 versus 2.7, p=0.04). Further, older participants tended to be more concerned about the side effects of radiotherapy (2.8 versus 2.4, p=0.07) and the frequent hospital visits for radiotherapy (2.6 versus 2.0, p=0.06).

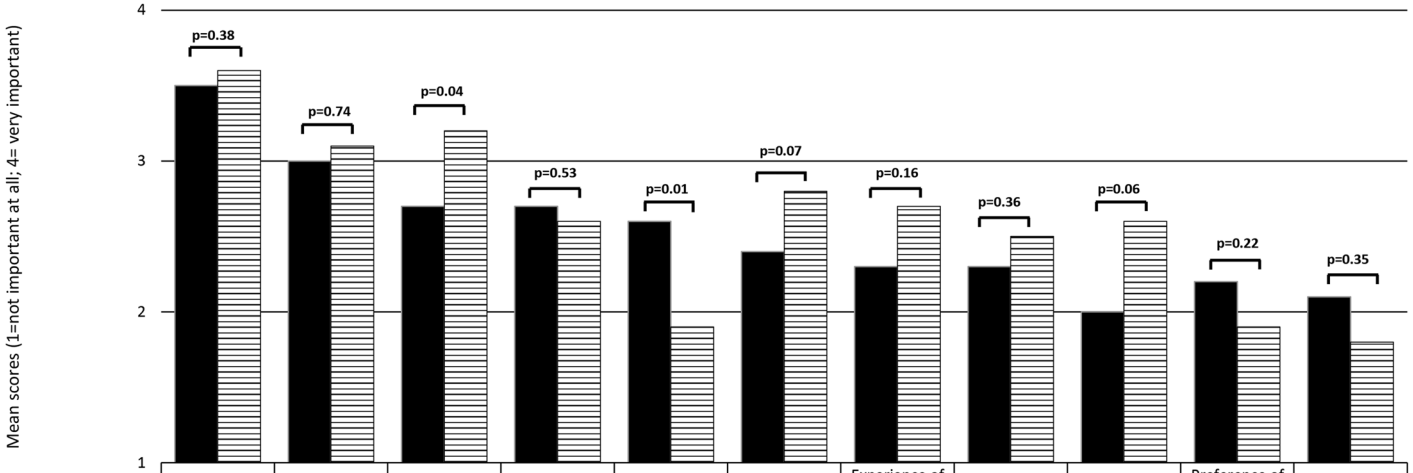
Breast reconstruction

Thirty-five percent (18/52) of the younger versus 26% (7/27) of the older participants did not know whether they would opt for post-MAST breast reconstruction or did not answer the question. Of those reporting a preference, significantly fewer older (40%; 8/20) than younger (77%; 26/34) participants would probably choose to have a reconstruction (p=0.01).

DISCUSSION

The current study is the first to prospectively compare younger and older patients' surgical treatment preferences. It is often assumed that MAST is the preferred choice among older women who are thought to be less interested in their physical appearance than younger women.[4] Indeed, our study showed that treatment preferences differed between the age groups, but not significantly so. Like the younger women, older participants also frequently preferred BCS to MAST, and both groups did not differ in their views on loss of a breast. A retrospective study[9] among patients aged ≥67 years found that body image was stated to be an important factor when deciding about treatment. These findings illustrate that older women require as much information as younger women about breast appearance after surgery when discussing each option.

Our findings suggest that treatment-related factors appear to play a larger role in decision-making. Older patients may want to avoid the extra daily hospital visits for radiotherapy that are needed to complete breast-conserving therapy.[9] Getting to radiotherapy appointments can be a larger burden at older age, as patients are more likely to experience mobility limitations and/or to rely on others. This may explain why older women may not choose BCS. Our findings indeed show a trend that frequent hospital visits for radiotherapy as



	The treatment recommendation of the surgeon	Fear of disease recurrence	Being reluctant to the possible need of undergoing an extra surgery	The possibility that I might lose a breast	Possibility of breast reconstruction	Side effects of radiation therapy	Experience of others who underwent a breast-conserving surgery	Experience of others who underwent a mastectomy	Frequent hospital visits for radiation therapy	Preference of significant others (partner, child[ren], environment)	Fear of radiotherapy
■ 40-64 years (n=46)	3.5 [b,c]	3.0	2.7	2.7	2.6 [b]	2.4 [b]	2.3 [b]	2.3	2.0	2.2	2.1
⊟ ≥65 years (n=26)[a]	3.6 [c]	3.1	3.2	2.6	1.9 [b]	2.8 [c]	2.7 [b]	2.5 [b]	2.6	1.9	1.8

Figure 1. Importance of factors for treatment preference among the participants preferring either breast-conserving surgery (with radiotherapy) or mastectomy

Differences in mean scores between younger and older participants were tested using Independent Samples t-test

[a] One out of 26 did not fill in any of these questions, and was excluded from all analyses

[b] One person did not answer this question

[c] For this item, participants' lowest score was 2 and the highest score was 4. For the remaining items, the scores ranged between 1 and 4

well as radiotherapy side effects are contributing factors to older patients' preference for MAST over BCS. Thus, the benefit of breast preservation may not outweigh the treatment inconvenience and the possible side effects. Another treatment-related factor that seemed relevant to older women is the wish to avoid the risk of having a second surgery.[9] The risk of undergoing another surgery after MAST is generally smaller than after BCS. In our study, older participants were indeed more concerned about the possible need of having to undergo additional surgery than younger participants.

Both age groups stated the surgeon's treatment recommendation to be the most important factor. Since the clinician's recommendation may possibly overrule other factors that patients also consider important,[10] this stresses the imperative for clinicians to avoid providing a recommendation before having assessed patients' concerns. Especially when deciding between BCS and MAST, patient preferences become increasingly relevant.

Unfortunately, the sample of older participants was small. Some differences that can be seen as relevant were therefore not statistically significant. Nonetheless, our findings demonstrate the need to discuss both surgical options, not just with younger patients. Similarly, although not all older patients may want a reconstructive surgery, before making a decision patients should know about the option of post-MAST reconstruction. Whether they consider having reconstruction and when (during/after MAST) should be preferably elicited in the first surgical consultation, as it may influence the choice between MAST and BCS. A visit to a plastic surgeon can then be scheduled before a surgical decision is reached.

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APPENDIX A. Preferences for type of surgery and for breast reconstruction following mastectomy

A.1 Breast-conserving surgery versus mastectomy

The content in the overview was based on patient education brochures[1] and on information provided on the website[2] of the Dutch Breast Cancer Association. The information about 10-year loco-regional recurrence risks after breast-conserving surgery with radiotherapy and mastectomy was based on data of the Early Breast Cancer Trialists' Collaborative Group.[3] Drawings of the breast after breast-conserving surgery and mastectomy were reprinted by permission of the American Society of Clinical Oncology.[4]

The content was checked after discussion with two surgical oncologists, one radiation oncologist, three research nurses/nurse specialists and one plastic surgeon. A pilot test was carried out among three healthy women and seven breast cancer patients to check for problems in understanding. During this process, the researcher encouraged them to think aloud as they answered the question, and to vocalize any thoughts, including difficulties, distress and suggestions for improvement. Based on their feedback, we rephrased the question and clarified the instruction.

In most situations there is a choice between:

- breast-conserving surgery
- mastectomy

The choice depends, amongst others, on the size and location of the tumour in the breast. A breast-conserving surgery is always followed by radiotherapy.

The chances of surviving breast cancer are the same for both breast-conserving surgery with radiotherapy and mastectomy.

On the next page you will find an overview with general information about both surgical options. The information is based on education material of the Dutch Cancer Society and Dutch Breast Cancer Association.

Please carefully read the overview and scan the differences between both surgical types. Then answer the question: **Imagine that both breast-conserving surgery (followed by radiotherapy) and mastectomy were available treatment options, which type of surgery would you prefer?**

1	2	3	4	5
Definitely prefer breast-conserving surgery followed by radiotherapy	Prefer breast-conserving surgery followed by radiotherapy	No preference between the two options	Prefer mastectomy	Definitely prefer mastectomy

	Breast-conserving surgery	Mastectomy
Surgical procedure *Length of time in hospital*	Only the cancer lump is removed. The remaining of the breast is preserved. Most patients are home within 24 hours of surgery or the next day.	The whole breast is removed. Most patients stay overnight at the hospital.
Complications after surgery	*Possible* complications include: • Bleeding • Wound infection • Pain and discomfort • Small collection of fluid under the wound	*Possible* complications include: • Bleeding • Wound infection • Pain and discomfort • Collection of fluid under the wound
A second surgery (more than one operation)	If there are still cancer cells after the surgery, another operation on the breast may be needed. The second surgical procedure may be a breast-conserving surgery or a mastectomy.	After a mastectomy, another operation is seldom to never required.
Radiotherapy	A breast-conserving surgery is *always* followed by radiotherapy to the breast. A course of radiotherapy can take 3 to 5 weeks. Most patients undergo radiotherapy 4 or 5 days a week. Radiotherapy usually begins within a few weeks after surgery and takes place at the hospital. You can go home after each session of radiotherapy.	After a mastectomy, radiotherapy is usually *not* given. Whether or not radiotherapy is given depends on the results of the surgery; 1 out of 10 women still need radiotherapy. In case radiotherapy is needed after a mastectomy, the procedure is the same as with a breast-conserving surgery (see left).
Side effects of radiotherapy	*Possible* side effects of radiation to the breast: • Redness of the skin. This is a temporary reaction. • Painful and/or tender breast. This is a temporary reaction. • A slight discoloration of the skin. This is irreversible and occurs rarely. • The breast tissue may feel permanently firmer. • Most patients experience fatigue during radiotherapy and in the first weeks afterwards.	In case radiotherapy is given after mastectomy, side effects can occur similar as to those of radiotherapy after breast-conserving surgery (see left).

The chances of cancer coming back in the breast	About 14.4 out of 100 women will develop a recurrence in the breast and/or armpit in the 10 years after a breast-conserving surgery.	About 13.8 out of 100 women will develop a recurrence in the chest region and/or armpit in the 10 years after a mastectomy.
Cosmetic results (what will my breast look like after surgery?)	The effect of the surgery on the appearance of the breast is minimal, but the breast can look different. The shape and size of the breast after surgery may differ somewhat from the other breast. 	The whole breast is removed and a large scar remains. There are options to undergo breast reconstruction or to wear an external prosthesis. 
Breast reconstruction (creating a 'new breast')	After a breast-conserving surgery, a breast reconstruction is usually not performed.	After a mastectomy, there are options for a breast reconstruction. In some cases a breast reconstruction can be carried out at the same time as the mastectomy. In some cases, in another operation, sometime later.
page 2 of 2		

A.2 Breast reconstruction

The information below was based on patient education brochures,[1] information of the Dutch Breast Cancer Association,[5] and expertise of two surgical oncologists and one plastic surgeon. A pilot study was conducted among three healthy women and seven breast cancer patients. Minor revisions were made based on their feedback.

It is possible to undergo a breast reconstruction following a mastectomy. This is an operation to create a new breast that matches the shape and size of the other breast as closely as possible. For this procedure the surgeon will refer you to a plastic surgeon.

The procedure differs from patient to patient. In some cases the reconstruction can be performed immediately after the mastectomy (during the same operation). In some cases the surgery is performed at a later time after the mastectomy. A breast reconstruction does not affect the chance of the cancer coming back or the ability to check for recurrence.

Breast reconstructive surgery usually requires a hospital stay of a few days. It will take a few weeks to heal fully.

As with any (breast) surgery, complications may occur after breast reconstruction.

After a reconstruction the new breast looks natural. However, the reconstructed breast feels different and the shape and size may differ from the original breast.

Imagine that you would undergo a mastectomy, which option would you prefer?

☐ After a mastectomy, I would probably choose to have a breast reconstruction

☐ After a mastectomy, I would probably not choose to have a breast reconstruction

☐ I do not know

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