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

Hamelinck, V.C.

CHAPTER 5

Preferred and Perceived Participation of Younger and Older Patients in Decision-Making about Treatment for Early Breast Cancer: a Prospective Study

Victoria C. Hamelinck
Esther Bastiaannet
Arwen H. Pieterse
Cornelis J.H. van de Velde
Gerrit-Jan Liefers
Anne M. Stiggelbout

Clinical Breast Cancer 2018;18(2):245-253

ABSTRACT

Purpose | Older patients are believed to prefer a more passive role in treatment decision-making, but studies reporting this relation were conducted over a decade ago or were retrospective. We prospectively compared younger (40-64 years) versus older (≥65 years) breast cancer patients' preferences for decision-making roles and their perceived actual roles.

Methods | A prospective multicenter study was conducted in Leiden, The Hague and Tilburg over a two-year period. Early-stage breast cancer patients were surveyed about their preferred and perceived decision-making roles (active, shared, or passive) concerning surgery type (breast-conserving versus mastectomy) (n=74); adjuvant chemotherapy (aCT, n=43); and adjuvant hormonal therapy (aHT, n=39).

Results | For all decisions, both age groups most frequently preferred a shared role before consultation, except for decisions about aHT, for which younger patients more commonly preferred an active role. The proportion of patients favouring an active or passive role in each decision was lower for the older than the younger patients, but none of the differences was significant. Regarding perceived actual roles, both groups most frequently reported an active role in the surgical decision after consultation. In deciding about both aCT and aHT, a larger proportion of older patients perceived having had a passive role compared to younger patients, and a greater proportion of younger patients perceived to have been active. Again, differences were not statistically significant.

Conclusion | Most older patients preferred to decide together with their clinician, but preferences varied widely. Older patients more often than younger patients perceived they had not been involved in decisions about systemic therapy. Clinicians should invite all patients to participate in decision-making and elicit their preferred role.

INTRODUCTION

Over the last years, patient decisional role preferences in treatment decisions and shared decision-making (SDM) have been of central interest.[1] SDM entails clinicians helping patients to understand the potential benefits and risks of different treatment options, based on the best available medical evidence, and encouraging them to consider what matters most to them and to communicate their preferences. These preferences are then integrated with the clinical evidence to select the treatment option that best fits the patient.[2,3] SDM is strongly advocated in situations in which more than one option is medically appropriate and the choice strongly depends on patient preferences.[4] This is particularly true in early-stage breast cancer (BC). Primary treatment often involves a choice between breast-conserving surgery (BCS) and mastectomy (MAST). Both surgical options are equally effective in terms of survival,[5] but they have different consequences that may be valued differently by individual patients.[6,7] The importance of SDM has also been emphasized in the decisions about adjuvant systemic therapy in early-stage BC.[8] Adjuvant chemotherapy (aCT) or hormonal therapy (aHT) can improve disease-free survival,[9] but the benefits sometimes are only marginal and must be balanced against the large probability of side effects and inconveniences associated with treatment. Research has shown that large differences exist in preferences for adjuvant systemic therapy between individuals.[6] In these decisions, treatment choice therefore relies on a subjective weighing of the considerations.

Decision-making about treatment is complex for all patients, but it may be even more challenging when it comes to older patients. There is more uncertainty about the most appropriate treatment in this patient group, as clinical trials have frequently excluded older patients because of age or comorbid conditions,[10] and as shorter life expectancy decreases the benefit from treatment. Additionally, older patients often use multiple medications which may interact with treatment.[11] Further, a large heterogeneity exists among older patients in terms of general health status, physical and cognitive functioning, and tolerance to treatment toxicity.[12] Finally, non-clinical challenges (e.g., less social support) may affect treatment preferences of older patients differently compared to younger patients.[13] These reasons underscore the need to involve older patients in the decision-making process.[14,15]

A commonly reported argument against SDM with older patients is that they do not want a role in which they share the responsibility for the decision with the clinician, and that they would rather just receive information about their disease and treatment.[16-19] Studies that examined the preferred role of older patients in deciding about BC treatment have yielded inconsistent findings. Some found that a majority of older patients preferred a passive role like younger patients,[20] while others reported that a majority of the elderly wished a shared role[21-23] like younger patients.[24-27] It is noteworthy that most studies reporting a relation between older age and a passive decisional role preference were conducted over a decade ago.[20,28-31]

In the current era, in which patients are encouraged to be involved in treatment decision-making, it is conceivable that older patients have different decisional role preferences than older patients from previous generations.[32] It therefore remains unclear if and to what extent older patients prefer to be involved in decision-making, and how their preferences compare to that of younger patients. Furthermore, most studies assessed preferences following decision-making, whereby the patients' perceived role in the consultation could have strongly influenced their preferences, and whereby older patients in particular most likely had experienced passive roles.[16,33] Little is known about patients' decision-making preferences as assessed prospectively.

This prospective study aimed to compare the preferences of younger versus older patients for decision-making roles concerning three decisions (type of surgery, aCT, and aHT) in early BC. We also explored, for each decision, whether younger versus older patients differed in their perceived roles, and the concordance between preferred and perceived roles.

METHODS

Participants

This study was conducted at one academic and two non-academic teaching hospitals in the Netherlands, from January 2012 to December 2013. Eligible patients were aged ≥40 years, had a primary ductal carcinoma in situ or an invasive tumour (clinical T_{1-2}), and were candidates for both BCS (with radiotherapy) and MAST. Exclusion criteria were bilateral BC, *BRCA* 1/2 mutation, previous diagnosis of (non)invasive BC, other malignancies within the past five years (except non-melanoma skin cancer or cervical carcinoma in situ), poor comprehension of the Dutch language, mental/cognitive problems, intention to undergo neo-adjuvant therapy, any concurrent malignancy, and evidence of metastatic disease. Approval of the study protocol was obtained from the Medical Ethical Committee of the Leiden University Medical Center and the review boards of the other participating hospitals. Written informed consent was obtained from all participants.

Additional criteria were applied to each treatment decision. For surgery, patients who underwent a re-operation due to tumour positive surgical margins were excluded. For adjuvant systemic therapy, only patients eligible to receive aCT, aHT, or both were included. We first selected the patients who were referred to a medical oncologist. Subsequently, patients with hormone receptor (HR)-negative tumours were excluded from the aHT-related analysis, as they are ineligible to be treated with aHT. Finally, based on the national treatment guidelines,[34] patients aged ≥70 years were only included in the aCT analysis if they presented with highly unfavourable prognostic features (i.e., positive nodes and/or HR-negative tumours, or an intermediate- or a high-grade, HR-positive tumour ≥2.0 cm in size).

Procedure

Eligible patients were informed about the study during the first surgical consultation, after having been informed about the diagnosis and their eligibility for both BCS and MAST. Those who were interested received a questionnaire that contained a short comparative overview of the surgical options (see Hamelinck et al.[35] for more details), and one question to determine the participant's role preference in decision-making. They were instructed to complete the questionnaire before the second surgical consultation, in which the surgical options are usually discussed more in detail, a treatment recommendation is given, and a decision is made.

Before surgery, only the participants with invasive disease received another questionnaire. This questionnaire contained information on aCT and aHT (see Hamelinck et al.[13] for more details) and two questions to determine their preferred role in decision-making about these treatments. They had to complete the questionnaire after surgery but before the post-surgical consultation. During that consultation, patients are informed whether adjuvant systemic therapy is recommended based on pathology results, and that in case of eligibility, a consultation with the medical oncologist follows to discuss the systemic therapy options. We purposively asked participants to complete the questionnaire about surgery before the second surgical consultation, and the questionnaire about adjuvant systemic therapy before the post-surgical consultation, to prevent the surgeon's recommendation for type of surgery and for referral to the medical oncologist, respectively, from influencing the participant's decisional role preference. Six weeks after surgery, all participants received a mailed follow-up questionnaire containing questions regarding participants' perceptions of their role during decision-making about surgery, and if applicable, about aCT and/or aHT. By then, it was expected that patients with an indication for adjuvant systemic therapy had been referred to the medical oncologist and that a treatment plan had been determined.

Measures

Preferred and perceived role in decision-making

A modified version of the Control Preferences Scale[36] was used to assess decisional role preferences. For each treatment decision, participants were asked to indicate their preferred role for involvement in decision-making from the following five roles: (1) the patient decides, (2) the patient decides after considering the clinician's opinion, (3) the patient decides jointly with the clinician, (4) the clinician decides after considering the patient's opinion, and (5) the clinician decides. Perceived role in decision-making was assessed by asking participants to indicate the role they had played in each decision, by choosing from the same five roles (presented in the past tense).

Participants' characteristics

Self-report data on socio-demographic details were collected in the pre-surgery questionnaire.

Medical charts were reviewed for information on tumour and treatment characteristics, date of first medical oncology visit (in which a decision about systemic therapy is usually made), and geriatric conditions.[37] Comorbid conditions were also registered using the 10th revision of the International Classification of Diseases.[38]

Statistical analyses

Participants were divided into younger (aged 40-64 years) and older (aged ≥65 years) patients. For each decision, only participants who filled in both their preferred and perceived role were included. Responses regarding preferred and perceived roles were categorized as active (responses of 1-2), shared (3), and passive (4-5). Each participant's preferred role was compared to her perceived role, resulting into two categories: concordance (preferred and perceived role were similar) and discordance (preferred role differed from perceived role). In case of discordance, we noted whether more (from passive to shared/active; from shared to active) or less (from active to shared/passive; from shared to passive) involvement was perceived than preferred. Descriptive statistics were used to present participants' characteristics, preferred and perceived roles, and concordance. Differences in characteristics, roles, and concordance among the age groups were assessed by the χ^2 or Fisher Exact tests. Data were analysed using SPSS version 22. A p-value <0.05 was considered statistically significant.

RESULTS

Participants

Type of surgery

Overall, 132 eligible patients agreed to participate (75% response). Of them, 92 answered the question about preferred role in surgical decision-making before the second surgical consultation. No significant differences were found between characteristics of participants who did versus who did not return the questionnaire before the consultation (data not shown). As three patients subsequently withdrew from the study, 89 were sent the follow-up questionnaire and 83 of these returned it. Nine of them were excluded for the following reasons: underwent a reoperation (n=7), had a concurrent malignancy discovered after surgery (n=1), or did not answer the question about perceived role (n=1). In total, 74 participants completed the questionnaire at a median of 60 days after the consultation (range, 45-115; Table 1 and Figure 1). A majority had invasive disease (85%) and underwent BCS (72%). The sample included 49 younger (66%) and 25 older (34%) patients. Younger and older patients did not differ on most variables, with the exception that older versus younger participants were less often employed (p<0.001) and had less often children living at home (p=0.05). Further, older patients more often experienced one specific geriatric health condition: severe sensory impairment (p=0.02). Although a greater proportion of the older patients had one or more comorbid conditions than younger patients, there were no significant differences between the three most common types (cardiovascular, endocrine, and musculoskeletal diseases).

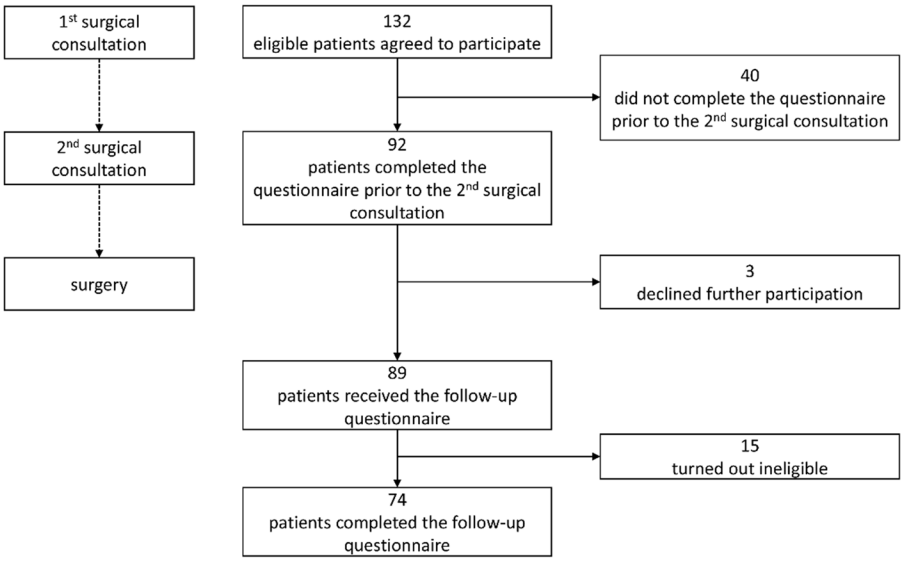

Figure 1. Flow chart of selection of patients included in analysis for decision-making about type of surgery

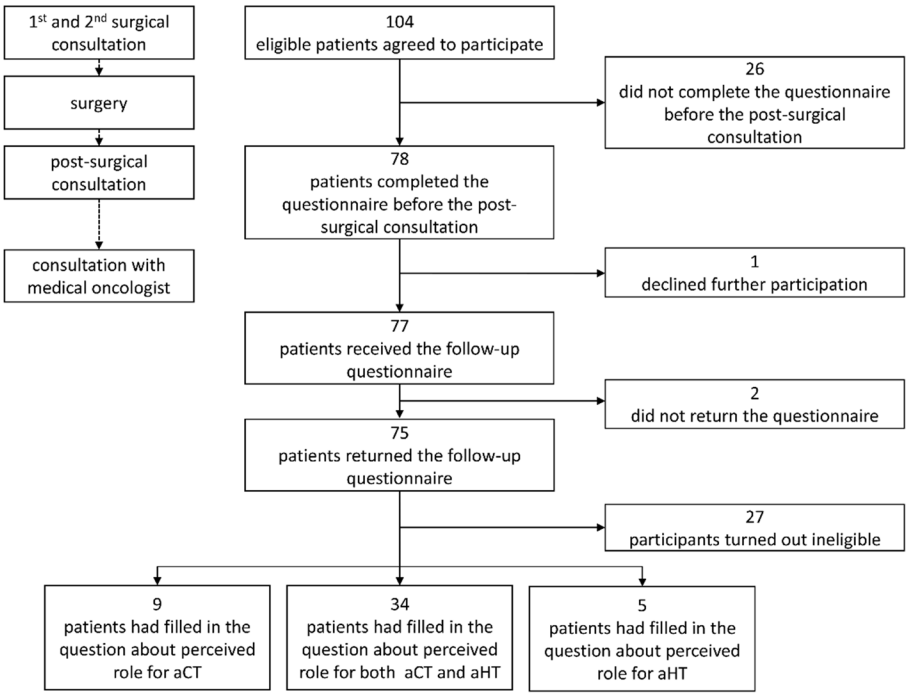

Figure 2. Flow chart of selection of patients included in analysis for decision-making about adjuvant chemotherapy (aCT) and adjuvant hormonal therapy (aHT)

Adjuvant systemic therapy

In total, 104 participants received the questionnaire about preferred roles in aCT and aHT decision-making, and 78 completed the questions before the post-surgical consultation. No significant differences were found for patients' age between those who did versus did not return the questionnaire before the consultation. One participant dropped out after filling out the questionnaire, and 77 received the follow-up questionnaire. Of the 75 who returned it, 52 had visited a medical oncologist. Participants were excluded if they had a concurrent malignancy (n=1), if the perceived role question was answered before their medical oncology visit (n=2), or if the question was not answered (n=1). Of the remaining 48 patients, 34 had an indication for both aCT and aHT, 9 had an indication for only aCT and 5 for only aHT. Thus, 43 participants were included in the aCT analysis and 39 in the aHT analysis (Figure 2). Participants completed the aCT questionnaire on average 29 days after consultation (range, 9-89, Table 1) and the aHT questionnaire on average 31 days (range, 8-58) after consultation. In the aCT analysis, 11 patients (26%) were aged ≥65 years, and in the aHT analysis, 12 patients (31%) were aged ≥65 years.

Table 1. Patient characteristics by age group and decision type

	Total		40-64 y		≥65 y	
Variables	n	%	n	%	n	%
Surgery[a]	(n=74)		(n=49, 66%)		(n=25, 34%)	
Patient characteristics						
Age (y)	60 (42-80)		55 (42-64)		70 (65-80)	
Time from second surgical consultation to filling in the follow-up questionnaire (d)	60 (45-115)[b]		60 (46-105)[b]		61 (45-115)	
Marital status						
married/living together	50	68	33	67	17	68
single/divorced/widowed	24	32	16	33	8	32
Educational level[c]						
low	19	26	11	22	8	32
intermediate	34	46	20	41	14	56
high	21	28	18	37	3	12
Employment status						
full/part-time	36	49	34	69	2	8
housekeeper	9	12	2	4	7	28
unemployed/long-term sick leave	7	10	7	14	0	0
retired	22	30	6	12	16	64
Having children						
no children	16	22	10	20	6	24
yes, children not living at home	40	54	23	47	17	68
yes, children living at home	18	24	16	33	2	8
Number of comorbid conditions						
0	25	34	21	43	4	16
1	16	22	9	18	7	28
2 or more	33	45	19	39	14	56
Type of comorbid conditions						
cardiovascular diseases (ICD10-9; yes)	30	41	16	33	14	56

endocrine diseases (ICD10-4; yes)	18	24	10	20	8	32
musculoskeletal diseases (ICD10-13; yes)	15	20	8	16	7	28
other diseases (yes)[d]	30	41	19	39	11	44
Geriatric health condition[e]						
no	49	66	36	73	13	52
yes	25	34	13	27	12	48
Specific geriatric health condition[f]						
incontinence (yes)	3	12	1	8	2	17
severe sensory impairment (yes)	10	40	2	15	8	67
depression (yes)	4	16	3	23	1	8
polypharmacy (yes)	17	68	11	85	6	50
difficulties with walking (yes)	6	24	2	15	4	33
Preoperative tumor morphology						
DCIS	11	15	7	14	4	16
invasive	63	85	42	86	21	84
Type of surgery performed						
BCS	53	72	38	78	15	60
MAST	21	28	11	22	10	40
Adjuvant chemotherapy[a]	(n=43)		(n=32, 74%)		(n=11, 26%)	
Patient characteristics						
Age (y)	60 (42-76)		55 (42-63)		70 (65-76)	
Time from medical oncologist consultation to filling in the follow-up questionnaire (d)	29 (9-89)[g]		30 (9-58)[g]		24 (18-89)	
Received chemotherapy						
no	19	44	11	34	8	73
yes	24	56	21	66	3	27
Had initiated therapy at time of filling in the follow-up questionnaire						
no	12	50	10	48	2	67
yes	12	50	11	52	1	33
Adjuvant hormonal therapy[a]	(n=39)		(n=27, 69%)		(n=12, 31%)	
Patient characteristics						
Age (y)	60 (42-86)		55 (42-63)		73 (65-86)	
Time from medical oncologist consultation to filling in the follow-up questionnaire (d)	31 (8-58)[g]		31 (9-58)[g]		28 (8-53)	
Received hormonal therapy						
no	4	10	2	7	2	17
yes	35	90	25	93	10	83
Had initiated therapy at time of filling in the follow-up questionnaire						
no	18	51	18	72	0	0
yes	17	49	7	28	10	100

Data are presented as n (n%) or median (ranges)
DCIS= Ductal carcinoma in situ; BCS= Breast-conserving surgery; MAST= Mastectomy; ICD= International Classification of Disease; y = years; d=days

[a] Three patient groups because of three different inclusion criteria
[b] Two participants did not fill in date of completion
[c] 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
[d] Other comorbid diseases included respiratory diseases (ICD10-10), neurologic diseases (ICD10-6), psychiatric diseases (ICD10-5), digestive diseases (ICD10-11), genitourinary diseases (ICD10-14) and blood diseases (ICD10-3)
[e] 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; difficulty walking
[f] No participant had difficulties carrying out daily activities
[g] One participant did not fill in date of completion

Preferred and perceived roles in decision-making

Type of surgery

Differences in both preferred and perceived roles between the age groups were found, but the differences were not significant (p=0.62 and p=0.94, respectively). Both younger and older participants most often preferred a shared role (49% and 60%, respectively) before consultation (Table 2A). Fewer members of both groups wished an active role (35% and 32%, respectively), and only 16% of younger and 8% of older participants preferred a passive role. After consultation, both younger and older participants most frequently reported to have perceived they had had an active role (49% and 56%, respectively), followed by shared (37% and 32%) and passive (14% and 12%) roles. Comparison of preferred and perceived roles showed that 32% of the younger and 36% of the older participants had participated to their preferred extent, 43% of the younger and 40% of the older participants had played a greater role in the decision than initially preferred, and 25% of the younger and 24% of the older participants had been less involved than preferred. The differences in concordance between the groups did not significantly differ (p=0.77).

Adjuvant chemotherapy

Again, both preferred and perceived roles varied between the age groups, but the differences were not significant (p=0.41 and p=0.82, respectively). Younger and older participants most frequently indicated a preference for a shared role (47% and 73%, respectively), followed by a preference for an active (34% and 18%) or a passive (19% and 9%) role (Table 2B). After consultation, younger participants more often perceived to have had an active role than older participants (41% versus 36%), and older participants more often indicated to have perceived a passive role (36% versus 25%). In 50% of the younger and 54% of the older participants, their perceived role matched their preferred role (p=0.80). The remainder of the younger participants were most often more involved than initially desired (28%), whereas older participants were most often less involved (27%).

Adjuvant hormonal therapy

As earlier, differences in preferred and perceived roles between the age groups were not significant (p=0.43 and p=0.52, respectively). Younger participants often preferred an active role (44%), whereas older participants more often had a preference for a shared role (58%) (Table 2C). Younger participants most often perceived to have had an active role (44%) and older participants most often a passive role (42%). Fifty percent of the older participants had their preferred role match their perceived role, compared to 37% of the younger participants, but this difference was not significant (p=0.45). Also in this decision, younger participants were most often more involved than initially desired (33%) and older participants most often less involved than desired (41%).

Table 2. Preferred (pre-consultation) and perceived (post-consultation) roles and concordance between the roles by decision type

A. Type of surgery (breast-conserving surgery vs. mastectomy)								
	40-64 y (n=49)				**≥65 y** (n=25)			
	Perceived role				**Perceived role**			
Preferred role	active	shared	passive	total	active	shared	passive	total
active	**8 (16)**	5 (10)	4 (8)	17 (35)	**5 (20)**	3 (12)	0 (0)	8 (32)
shared	13 (27)	**8 (16)**	3 (6)	24 (49)	8 (32)	**4 (16)**	3 (12)	15 (60)
passive	3 (6)	5 (10)	**0 (0)**	8 (16)	1 (4)	1 (4)	**0 (0)**	2 (8)
total	24 (49)	18 (37)	7 (14)	49 (100)	14 (56)	8 (32)	3 (12)	25 (100)
B. Adjuvant chemotherapy (yes/no)								
	40-64 y (n=32)				**≥65 y** (n=11)			
	Perceived role				**Perceived role**			
Preferred role	active	shared	passive	total	active	shared	passive	total
active	**6 (19)**	2 (6)	3 (9)	11 (34)	**2 (18)**	0 (0)	0 (0)	2 (18)
shared	6 (19)	**7 (22)**	2 (6)	15 (47)	2 (18)	**3 (27)**	3 (27)	8 (73)
passive	1 (3)	2 (6)	**3 (9)**	6 (19)	0 (0)	0 (0)	**1 (9)**	1 (9)
total	13 (41)	11 (34)	8 (25)	32 (100)	4 (36)	3 (27)	4 (36)	11 (100)
C. Adjuvant hormonal therapy (yes/no)								
	40-64 y (n=27)				**≥65 y** (n=12)			
	Perceived role				**Perceived role**			
Preferred role	active	shared	passive	total	active	shared	passive	total
active	**5 (19)**	2 (7)	5 (19)	12 (44)	**2 (17)**	1 (8)	0 (0)	3 (25)
shared	6 (22)	**3 (11)**	1 (4)	10 (37)	0 (0)	**3 (25)**	4 (33)	7 (58)
passive	1 (4)	2 (7)	**2 (7)**	5 (19)	1 (8)	0 (0)	**1 (8)**	2 (17)
total	12 (44)	7 (26)	8 (30)	27 (100)	3 (25)	4 (33)	5 (42)	12 (100)

Data are presented as n (%)

Numbers and proportions in bold add up to numbers and proportions of concordance between preferred and perceived role; Numbers and proportions below the diagonal bold line add up to numbers and proportion of participants who experienced a greater role than initially preferred; Numbers and proportions above the diagonal bold line add up to numbers and proportions of participants who experienced a lesser role than initially preferred

DISCUSSION

In this prospective study of patients with early BC, we compared the preferred and perceived roles of younger and older patients in decisions about type of surgery, aCT and aHT, as well as the concordance between their preferred versus perceived decision-making roles.

Our findings challenge the belief that older patients often prefer to leave treatment decisions to their clinician. Only few older patients wished a passive role, and most preferred to make

the decision themselves or together with their oncologist, in line with another recent study[39] showing that most older patients preferred a shared or active role over a passive role. In our study, about three in five older patients preferred to make the decision together with their clinician. Our finding that both younger and older patients most often preferred to be involved in making the decision about type of surgery is in line with one of the few other prospective studies among newly-diagnosed patients with early-stage disease eligible for BCS and MAST.[25] In contrast, a retrospective study found that preferring a passive role was related to being older.[40] Patients' experiences of the decision-making process may possibly have influenced their reported preferences in the latter study. Our results suggest that patients of all ages prefer to be involved in decision-making and thus that one should not automatically assume that older patients wish to defer the decision to the clinician. This is particularly important because clinicians often underestimate patients' decisional role preferences[41] and rarely ask patients for their preferences.[42]

Although decisional role preferences did not significantly differ between age groups, preferred roles in deciding whether to undergo aHT stand out, with relatively more younger than older patients preferring to make the decision themselves. Premenopausal patients may perceive aHT as having a greater impact on their daily lives than older patients, given that aHT can cause menopausal symptoms. We found in our previous study[13] that both age groups, but more so in younger patients, frequently reported that concern about the short- and long-term side-effects was an important factor in their preferences for aHT (of 74 patients in our previous study, 35 participated in the present study).

We also found that older patients' perceived roles varied from those of younger patients and varied across the different decisions. Because BCS and MAST are equivalent options in terms of survival, and are presented as such in national guidelines,[34] we may expect that clinicians offer patients a choice between these two surgical options. It is, not surprising then, that both older and younger patients frequently perceived to have had an active role in making the decision. In contrast, older patients more often than younger patients felt that they had not been involved in making the decision concerning aCT. The treatment guidelines indeed state that aCT may not be a reasonable treatment option for patients over 70 years of age.[34] Similarly, older patients more often perceived to have had a passive role in deciding about aHT. In clinical practice, patients with HR-positive tumours, irrespective of their age, are rarely offered a choice about aHT.[43] Younger patients may ask more questions after being informed about aHT, which could result in more communication about treatment characteristics. As a result, younger patients may have felt more involved in decision-making,[44] thereby explaining why they more frequently perceived an active role. More research is needed to better explain these findings.

For each decision, we found an overall difference between patients' preferred versus perceived decisional roles in 40% of the younger patients and 47% of the older patients. For both age groups, the largest difference was observed with respect to the decision about surgery. Differences in these gaps between the age groups were minimal, except for the decision about aHT. Discordance can negatively impact patients' treatment outcomes and experiences of care[45,46] and it is therefore important that future studies examine how the occurrence of discordant roles can be minimized.

To our knowledge, our study is the first to prospectively explore patients' preferences regarding decisional roles for three common breast cancer treatment decisions with a specific focus on age-differences. A strength is that data were prospectively collected from patients. A potential limitation is that the decisional role preferences were regarded as if these remained stable; however, a patient's preference can change during or between consultations (e.g., a more active decisional role preference after receiving information about treatment options than before the consultation[47]). Also, recall bias could have affected participants' perception of their role during the consultation. Another limitation is the small number of older participants. We did not find significant differences between the age groups, as the sample size may not have been large enough to detect these. We believe it to be worthwhile to examine whether our findings also hold with a larger sample of older patients. Regardless of this limitation, this study provides valuable insights into the decision-making roles of this growing patient group.

It is important for clinicians to know that most older patients are willing to be involved in decision-making. However, we also want to stress the variation in role preferences among older patients and across the different decisions. As clinicians set the agenda for the consultation, it is reasonable to expect that the responsibility for inviting patients to participate in decision-making lies with clinicians. They should explicitly inform patients that a decision needs to be made and explain why patient involvement is relevant.[2,48] Older patients who feel they are not (yet) ready or able to engage in deliberation about different treatment options should be offered more time and support (e.g., an appointment with a nurse specialist, patient decision aids[49,50] or other support tools if available). This approach could improve their participation in decision-making. In the end, of course, at the patient's wish, the clinician can make the final decision, as long as he/she has elicited the patient's concerns and goals.[2] In addition, health care as a whole should empower older patients to become more involved in the decision-making process. The use of interventions that guide older patients through topics that are important to ask can help them better prepare for the consultation and may give them encouragement to be involved,[51] such as campaigns like 'Ask3' (e.g.. http://www.cardiffandvaleuhb.wales.nhs.uk/ask3).

Conclusion

Older patients, like younger patients, often favoured participation in decision-making about treatments for early BC. Also, both age groups mostly perceived more involvement than they preferred in the decision about surgery. Some older patients perceived less involvement than they preferred in aCT and aHT decision-making, and these patients may therefore need more encouragement to participate. Our results underscore the need for clinicians to invite all patients to participate in decision-making for each decision, and to retrieve to what extent patients want to be involved in making the final decision.

CLINICAL PRACTICE POINTS

- Older patients are believed to prefer a more passive role in treatment decision-making than younger patients. However, studies showing this relation were conducted over a decade ago, or were retrospective. In this era of increased attention to shared decision-making, it is conceivable that older patients have different decisional role preferences than older patients from previous generations.
- This prospective study found that older patients, like younger patients, often favoured to participate in decision-making. However, older patients more often than younger patients perceived they had not been involved in decisions about systemic therapy.
- Clinicians need to know that most older patients are willing to be involved in making treatment decisions, although role preferences varied within older – as in younger – patients and across decisions. It is therefore important that clinicians invite all patients to participate in decision-making, regardless of their age. Aside from the clinician's role, it is also important to stimulate older patients themselves to become more involved in decisions about their treatment, for example by directing patients to key questions to help them prepare better for the consultation.

Acknowledgements

We would like to thank all patients who shared their time and insights, and the health care professionals at the Leiden University Medical Center (Leiden), Haga Hospital (The Hague) and TweeSteden Hospital (Tilburg), for their help in patient recruitment, monitoring the study, and for their participation in data collection. This study is part of the FOCUS study (Female breast cancer in the elderly; optimizing clinical guidelines using clinico-pathological and molecular data; Dutch Cancer Society, grant number 2007-3968).

Funding

This study was supported by a grant from Pink Ribbon, the Netherlands (grant number 2011. WO06.C107). The funding source had no involvement in the study design, in the collection, analysis and interpretation of data, in the writing of the manuscript, or in the decision to submit the manuscript for publication.

Reference List

1. Patiëntenfederatie Nederland. Samen beslissen. Accessed on 29 June 2016. Available from: https://www.npcf.nl/themas/samen-beslissen/
2. Stiggelbout AM, Pieterse AH, De Haes JC. Shared decision making: Concepts, evidence, and practice. *Patient Educ Couns* 2015;98:1172-1179.
3. Elwyn G, Frosch D, Thomson R et al. Shared decision making: a model for clinical practice. *J Gen Intern Med* 2012;27:1361-1367.
4. Muller-Engelmann M, Donner-Banzhoff N, Keller H et al. When decisions should be shared: a study of social norms in medical decision making using a factorial survey approach. *Med Decis Making* 2013;33:37-47.
5. Veronesi U, Cascinelli N, Mariani L et al. Twenty-year follow-up of a randomized study comparing breast-conserving surgery with radical mastectomy for early breast cancer. *N Engl J Med* 2002;347:1227-1232.
6. Hamelinck VC, Bastiaannet E, Pieterse AH et al. Patients' preferences for surgical and adjuvant systemic treatment in early breast cancer: a systematic review. *Cancer Treat Rev* 2014;40:1005-1018.
7. Sivell S, Edwards A, Elwyn G et al. Understanding surgery choices for breast cancer: how might the Theory of Planned Behaviour and the Common Sense Model contribute to decision support interventions? *Health Expect* 2011;14 Suppl 1:6-19.
8. Andrews J, Guyatt G, Oxman AD et al. GRADE guidelines: 14. Going from evidence to recommendations: the significance and presentation of recommendations. *J Clin Epidemiol* 2013;66:719-725.
9. Early Breast Cancer Trialists' Collaborative Group. Effects of chemotherapy and hormonal therapy for early breast cancer on recurrence and 15-year survival: an overview of the randomised trials. *Lancet* 2005;365:1687-1717.
10. Biganzoli L, Wildiers H, Oakman C et al. Management of elderly patients with breast cancer: updated recommendations of the International Society of Geriatric Oncology (SIOG) and European Society of Breast Cancer Specialists (EUSOMA). *Lancet Oncol* 2012;13:e148-160.
11. Aapro M, Bernard-Marty C, Brain EG et al. Anthracycline cardiotoxicity in the elderly cancer patient: a SIOG expert position paper. *Ann Oncol* 2011;22:257-267.
12. Braithwaite D, Satariano WA, Sternfeld B et al. Long-term prognostic role of functional limitations among women with breast cancer. *J Natl Cancer Inst* 2010;102:1468-1477.
13. Hamelinck VC, Bastiaannet E, Pieterse AH et al. A prospective comparison of younger and older patients' preferences for adjuvant chemotherapy and hormonal therapy in early breast cancer. *Clin Breast Cancer* 2016;16:379-388.
14. Hawley ST and Morrison R. Achieving high-quality surgical treatment decisions: the perspective of older breast cancer patients. *Aging Health* 2012;8:589-599.
15. Politi MC, Lewis CL, Frosch DL. Supporting shared decisions when clinical evidence is low. *Med Care Res Rev* 2013;70:113S-128S.
16. Brom L, Hopmans W, Pasman HR et al. Congruence between patients' preferred and perceived participation in medical decision-making: a review of the literature. *BMC Med Inform Decis Mak* 2014;14:25.
17. Maly RC, Umezawa Y, Leake B et al. Determinants of participation in treatment decision-making by older breast cancer patients. *Breast Cancer Res Treat* 2004;85:201-209.
18. Shepherd HL, Butow PN, Tattersall MH. Factors which motivate cancer doctors to involve their patients in reaching treatment decisions. *Patient Educ Couns* 2011;84:229-235.
19. Wetzels R, Geest TA, Wensing M et al. GPs' views on involvement of older patients: an European qualitative study. *Patient Educ Couns* 2004;53:183-188.
20. Wallberg B, Michelson H, Nystedt M et al. Information needs and preferences for participation in treatment decisions among Swedish breast cancer patients. *Acta Oncol* 2000;39:467-476.
21. Harder H, Ballinger R, Langridge C et al. Adjuvant chemotherapy in elderly women with breast cancer: patients' perspectives on information giving and decision making. *Psychooncology* 2013;22:2729-2735.
22. Mandelblatt JS, Faul LA, Luta G et al. Patient and physician decision styles and breast cancer

chemotherapy use in older women: Cancer and Leukemia Group B protocol 369901. *J Clin Oncol* 2012;30:2609-2614.

23. Morgan JL, Burton M, Collins K et al. The balance of clinician and patient input into treatment decision-making in older women with operable breast cancer. *Psychooncology* 2015;24:1761-1766.
24. Hack TF, Degner LF, Dyck DG. Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis. *Soc Sci Med* 1994;39:279-289.
25. Janz NK, Wren PA, Copeland LA et al. Patient-physician concordance: preferences, perceptions, and factors influencing the breast cancer surgical decision. *J Clin Oncol* 2004;22:3091-3098.
26. Nakashima M, Kuroki S, Shinkoda H et al. Information-seeking experiences and decision-making roles of Japanese women with breast cancer. *Fukuoka Igaku Zasshi* 2012;103:120-130.
27. Shelton RC, Clarke Hillyer G, Hershman DL et al. Interpersonal influences and attitudes about adjuvant therapy treatment decisions among non-metastatic breast cancer patients: an examination of differences by age and race/ethnicity in the BQUAL study. *Breast Cancer Res Treat* 2013;137:817-828.
28. Degner LF, Kristjanson LJ, Bowman D et al. Information needs and decisional preferences in women with breast cancer. *JAMA* 1997;277:1485-1492.
29. Lam W, Fielding R, Chan M et al. Participation and satisfaction with surgical treatment decision-making in breast cancer among Chinese women. *Breast Cancer Res Treat* 2003;80:171-180.
30. Lobb EA, Kenny DT, Butow PN et al. Women's preferences for discussion of prognosis in early breast cancer. *Health Expect* 2001;4:48-57.
31. Petrisek AC, Laliberte LL, Allen SM et al. The treatment decision-making process: age differences in a sample of women recently diagnosed with nonrecurrent, early-stage breast cancer. *Gerontologist* 1997;37:598-608.
32. Busari JO. The discourse of generational segmentation and the implications for postgraduate medical education. *Perspect Med Educ* 2013;2:340-348.
33. Jansen SJ, Kievit J, Nooij MA et al. Patients' preferences for adjuvant chemotherapy in early-stage breast cancer: is treatment worthwhile? *Br J Cancer* 2001;84:1577-1585.
34. Nationaal Borstkanker Overleg Nederland. Breast Cancer Guideline. Accessed on 1 November 2014. Available from: http://www.oncoline.nl/uploaded/docs/mammacarcinoom/Dutch%20Breast%20Cancer%20Guideline%202012.pdf
35. Hamelinck VC, Bastiaannet E, Pieterse AH et al. A prospective comparison of younger and older patients' preferences for breast-conserving surgery versus mastectomy in early breast cancer. *J Geriatr Oncol* 2018;9(2):170-173.
36. Degner LF, Sloan JA, Venkatesh P. The Control Preferences Scale. *Can J Nurs Res* 1997;29:21-43.
37. Wildiers H, Heeren P, Puts M et al. International Society of Geriatric Oncology consensus on geriatric assessment in older patients with cancer. *J Clin Oncol* 2014;32:2595-2603.
38. World Health Organization. International Statistical Classification of Diseases and Related Health Problems 10th Revision. Accessed on 6 November 2014. Available from: http://apps.who.int/classifications/icd10/browse/2010/en
39. Pauillaud E, Canou-Poitrine F, Varnier G et al. Preferences about information and decision-making among older patients with and without cancer. *Age and Ageing.* 2017:46:665-671.
40. Caldon LJ, Walters SJ, Reed MW. Changing trends in the decision-making preferences of women with early breast cancer. *Br J Surg* 2008;95:312-318.
41. Stalmeier PF, van Tol-Geerdink JJ, van Lin EN et al. Doctors' and patients' preferences for participation and treatment in curative prostate cancer radiotherapy. *J Clin Oncol* 2007;25:3096-3100.
42. Pieterse AH, Kunneman M, Engelhardt EG et al. Oncologist, patient, and companion questions during pretreatment consultations about adjuvant cancer treatment: a shared decision-making perspective. *Psycho-oncology* 2017:26(7): 943-950.
43. Engelhardt EG, Pieterse AH, van der Hout A et al. Use of implicit persuasion in decision-making about adjuvant cancer treatment: a potential barrier to shared decision-making. *Med Decis Making* 2016;66:55-66.

44. Pieterse AH, Baas-Thijssen MC, Marijnen CA et al. Clinician and cancer patient views on patient participation in treatment decision-making: a quantitative and qualitative exploration. *Br J Cancer* 2008;99:875-882.
45. Keating NL, Guadagnoli E, Landrum MB et al. Treatment decision making in early-stage breast cancer: should surgeons match patients' desired level of involvement? *J Clin Oncol* 2002;20:1473-1479.
46. Lantz PM, Janz NK, Fagerlin A et al. Satisfaction with surgery outcomes and the decision process in a population-based sample of women with breast cancer. *Health Serv Res* 2005;40:745-767.
47. van Tol-Geerdink JJ, Leer JW, van Lin EN et al. Offering a treatment choice in the irradiation of prostate cancer leads to better informed and more active patients, without harm to well-being. *Int J Radiat Oncol Biol Phys* 2008;70:442-448.
48. Stiggelbout AM, Gärtner FR, Pieterse AH. Gedeelde besluitvorming met ouderen. Accessed on 25 April 2017. Available from: http://www.verensotijdschrift.nl/om2015/november-2015-licht-op-oranje/praktijk/gedeelde-besluitvorming-met-ouderen/#.WtJ_Ic4UmmQ
49. Van Weert JC, van Munster BC, Sanders R et al. Decision aids to help older people make health decisions: a systematic review and meta-analysis. *BMC Med Inform Decis Mak* 2016;16:45.
50. Wong J, D'Alimonte L, Angus J et al. Development of patients' decision aid for older women with stage I breast cancer considering radiotherapy after lumpectomy. *Int J Radiat Oncol Biol Phys* 2012;84:30-38.
51. Shepherd HL, Barratt A, Trevena LJ et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: a cross-over trial. *Patient Educ Couns* 2011;84:379-385.