Preferred and Perceived Participation of Younger and Older Patients in Decision Making About Treatment for Early Breast Cancer: A Prospective Study

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Abstract

Older patients are believed to prefer a more passive role in decision making. This prospective study surveyed younger and older patients undergoing treatment for early breast cancer. Older patients most frequently preferred to decide with their clinician, although they often felt they had a passive role. It is important to elicit the preferred role of all patients, regardless of their age.

Background: 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. **Patients and Methods:** A prospective multicenter study was conducted in Leiden, The Hague, and Tilburg over a 2-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 vs. 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 favoring 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 having 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.

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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

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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. 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 adjuvant 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 adverse effects and the inconveniences associated with treatment. Research has shown that large differences exist in preferences for adjuvant systemic therapy among 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, nonclinical challenges (eg, less social support) may affect the 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 after 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 3 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, as well as the concordance between preferred and perceived roles.

Materials and Methods

Participants

This study was conducted at 1 academic and 2 nonacademic teaching hospitals in The Netherlands from January 2012 to December 2013. Eligible patients were aged $\geq$ 40 years, had a primary ductal carcinoma-in-situ or an invasive tumor (clinical T1-2), and were candidates for both BCS (with radiotherapy) and mastectomy. Exclusion criteria were bilateral BC, *BRCA1/2* mutation, previous diagnosis of (non)invasive BC, other malignancies within the past 5 years (except nonmelanoma skin cancer or cervical carcinoma-in-situ), poor comprehension of the Dutch language, mental or cognitive problems, intention to undergo neoadjuvant 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 reoperation due to tumor-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 tumors 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 $\geq$ 70 years were only included in the aCT analysis if they presented with highly unfavorable prognostic features (ie, positive nodes and/or HR-negative tumors, or an intermediate- or high-grade, HR-positive tumor $\geq$ 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 mastectomy. 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 1 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 2 questions to determine their preferred role in decision making about these treatments. They had to complete the questionnaire after surgery but before the postsurgical 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 5 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 5 roles (presented in the past tense).

Participant Characteristics. Self-report data on sociodemographic details were collected in the presurgery questionnaire. Medical charts were reviewed for information on tumor 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 $\geq$ 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 2 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 chi-square or Fisher exact tests. Data were analyzed by SPSS 22 (IBM SPSS, Chicago, IL). $P < .05$ 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). Because 3 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 days; 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 ($P < .001$) and less often had children living at home ($P = .05$). Further, older patients more often experienced one specific geriatric health condition: severe sensory impairment ($P = .02$). Although a greater proportion of the older patients had one or more comorbid conditions than younger patients, there were no significant differences among the 3 most common types (cardiovascular, endocrine, and musculoskeletal diseases).

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 postsurgical 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 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 days; Table 1) and the aHT questionnaire on average 31 days (range, 8-58 days) after consultation. In the aCT analysis, 11 patients (26%) were aged $\geq$ 65 years, and in the aHT analysis, 12 patients (31%) were aged $\geq$ 65 years.

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 ($P = .62$ and $P = .94$, 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

Table 1 Patient Characteristics by Age Group and Decision Type

Variable	Total	40-64 y	≥65 y
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 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
Retired	22 (30)	6 (12)	16 (64)
Have 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)
No. 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)
Difficulty walking (yes)	6 (24)	2 (15)	4 (33)
Tumor Characteristics			
Preoperative Tumor Morphology			
DCIS	11 (15)	7 (14)	4 (16)
Invasive	63 (85)	42 (86)	21 (84)
Treatment Characteristics			
Type of Surgery Performed			
BCS	53 (72)	38 (78)	15 (60)
Mastectomy	21 (28)	11 (22)	10 (40)
Adjuvant Chemotherapy[a]	(n = 43)	(n = 32, 74%)	(n = 11, 26%)
Patient Characteristics			

Table 1 Continued

Variable	Total	40-64 y	≥65 y
Age (y)	60 (42-76)	55 (42-63)	70 (65-76)
Time from medical oncologist consultation to filling in follow-up questionnaire (d)	29 (9-89)[g]	30 (9-58)[g]	24 (18-89)
Treatment Characteristics			
Received chemotherapy			
No	19 (44)	11 (34)	8 (73)
Yes	24 (56)	21 (66)	3 (27)
Had initiated therapy at time of filling in 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 follow-up questionnaire (d)	31 (8-58)[g]	31 (9-58)[g]	28 (8-53)
Treatment Characteristics			
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 follow-up questionnaire			
No	18 (51)	18 (72)	0
Yes	17 (49)	7 (28)	10 (100)

Data are presented as n (%) or median (range).
Abbreviations: BCS = breast-conserving surgery; DCIS = ductal carcinoma-in-situ; ICD = International Classification of Disease.
[a]Three patient groups because of 3 different inclusion criteria.
[b]Two participants did not fill in date of completion.
[c]Levels of education were categorized as follows: low = completed no/primary school; intermediate = completed lower general secondary education/vocational training; 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.

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 ($P = .77$).

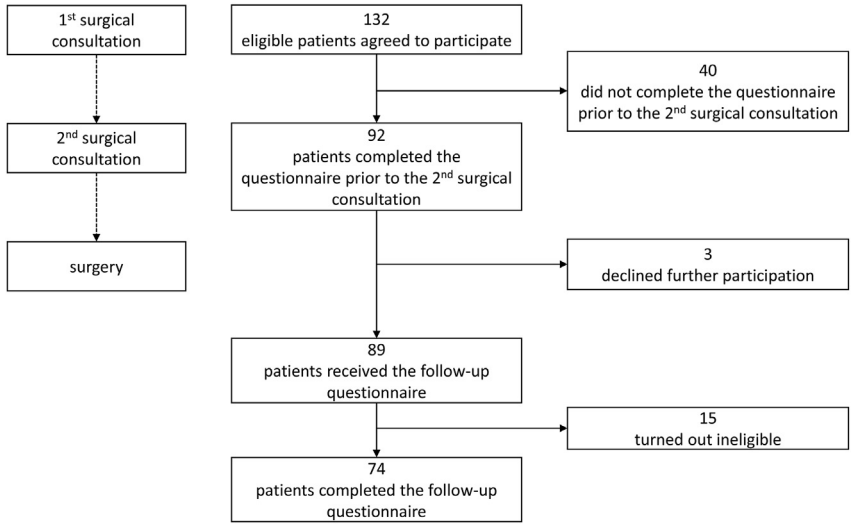
Adjuvant Chemotherapy. Again, both preferred and perceived roles varied between the age groups, but the differences were not significant ($P = .41$ and $P = .82$, respectively). Younger and older participants most frequently indicated a preference for a shared role (47% and 73%, respectively), followed 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% vs. 36%), and older participants more often indicated to have perceived a passive role (36% vs. 25%). In 50% of the younger and 54% of the older participants, their perceived role matched their preferred role ($P = .80$). 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 ($P = .43$ and $P = .52$, 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 ($P = .45$). 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%).

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.

Figure 1 Flowchart of Selection of Patients Included in Analysis for Decision Making About Type of Surgery



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 3 in 5 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 mastectomy.[25] In contrast, a retrospective study found that preferring a passive role was

Figure 2 Flowchart of Selection of Patients Included in Analysis for Decision Making About Adjuvant Chemotherapy (aCT) and Adjuvant Hormonal Therapy (aHT)

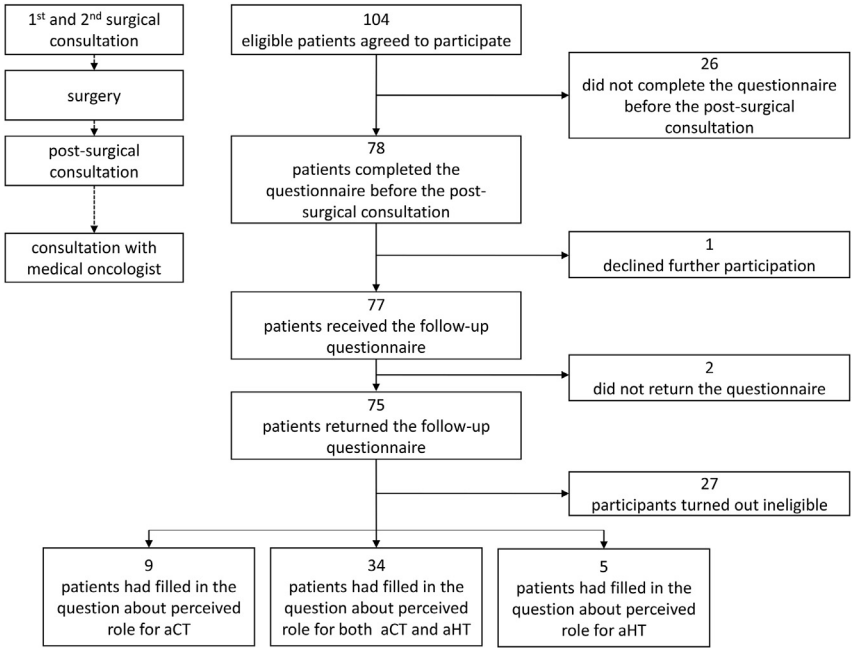


Table 2 Preferred (Preconsultation) and Perceived (Postconsultation) Roles and Concordance Between Roles by Decision Type

A. Type of Surgery (BCS vs. Mastectomy)

Preferred Role	40-64 y (N = 49)				≥65 y (N = 25)			
	Perceived Role				Perceived Role			
	Active	Shared	Passive	Total	Active	Shared	Passive	Total
Active	**8 (16)**	5 (10)	4 (8)	17 (35)	**5 (20)**	3 (12)	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**	8 (16)	1 (4)	1 (4)	**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)

Preferred Role	40-64 y (N = 32)				≥65 y (N = 11)			
	Perceived Role				Perceived Role			
	Active	Shared	Passive	Total	Active	Shared	Passive	Total
Active	**6 (19)**	2 (6)	3 (9)	11 (34)	**2 (18)**	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	**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)

Preferred Role	40-64 y (N = 27)				≥65 y (N = 12)			
	Perceived Role				Perceived Role			
	Active	Shared	Passive	Total	Active	Shared	Passive	Total
Active	**5 (19)**	2 (7)	5 (19)	12 (44)	**2 (17)**	1 (8)	0	3 (25)
Shared	6 (22)	**3 (11)**	1 (4)	10 (37)	0	**3 (25)**	4 (33)	7 (58)
Passive	1 (4)	2 (7)	**2 (7)**	5 (19)	1 (8)	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 diagonal bold line add up to numbers and proportion of participants who experienced a greater role than initially preferred. Numbers and proportions above diagonal bold line add up to numbers and proportions of participants who experienced a lesser role than initially preferred.
Abbreviation: BCS = breast-conserving surgery.

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 adverse 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 mastectomy 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 2 surgical options. It is therefore unsurprising 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 tumors, 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 affect 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 patient preferences regarding decisional roles for 3 common BC 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 (eg, 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 (eg, 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 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 (http://www.cardiffandvaleuhb.wales.nhs.uk/ask3).

Conclusion

Older patients, like younger patients, often favored 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 SDM, 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 favored participation in decision making. However, older patients more often than younger patients perceived that 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.

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Disclosure

The authors have stated that they have no conflict of interest.

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