

# 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 ( $\geq 65$  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.<sup>1</sup> 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

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## Treatment Decision Making Roles of Younger and Older Patients

integrated with the clinical evidence to select the treatment option that best fits the patient.<sup>2,3</sup> SDM is strongly advocated in situations in which more than one option is medically appropriate, and the choice strongly depends on patient preferences.<sup>4</sup> 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,<sup>5</sup> but they have different consequences that may be valued differently by individual patients.<sup>6,7</sup> The importance of SDM has also been emphasized in the decisions about adjuvant systemic therapy in early-stage BC.<sup>8</sup> Adjuvant chemotherapy (aCT) or adjuvant hormonal therapy (aHT) can improve disease-free survival,<sup>9</sup> 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.<sup>6</sup> 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,<sup>10</sup> and as shorter life expectancy decreases the benefit from treatment. Additionally, older patients often use multiple medications, which may interact with treatment.<sup>11</sup> Further, a large heterogeneity exists among older patients in terms of general health status, physical and cognitive functioning, and tolerance to treatment toxicity.<sup>12</sup> Finally, nonclinical challenges (eg, less social support) may affect the treatment preferences of older patients differently compared to younger patients.<sup>13</sup> These reasons underscore the need to involve older patients in the decision-making process.<sup>14,15</sup>

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.<sup>16-19</sup> 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,<sup>20</sup> while others reported that a majority of the elderly wished a shared role<sup>21-23</sup> like younger patients.<sup>24-27</sup> It is noteworthy that most studies reporting a relation between older age and a passive decisional role preference were conducted over a decade ago.<sup>20,28-31</sup> 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.<sup>32</sup> 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.<sup>16,33</sup> 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,<sup>34</sup> 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<sup>35</sup> 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<sup>13</sup> 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

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