

ORIGINAL PAPER

Exploring women's experiences with a decision aid for neoadjuvant systemic therapy for operable breast cancer

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Abstract

Background: Some women with operable breast cancer have a choice between receiving upfront surgery followed by chemotherapy or neoadjuvant systemic therapy (NAST) prior to receiving surgery. While survival outcomes are equivalent for both options, the decision about treatment sequence can be difficult due to its complexity and perceived urgency. A decision aid has been developed to help patients decide on whether to receive NAST.

Aims: To explore, qualitatively, women's use and perceived benefit of a decision aid to help with their decision on NAST.

Methods: A framework analysis process was conducted on a purposeful sample of 20, one-on-one, semistructured phone interviews with early-stage breast cancer patients eligible for NAST. Participants had recently decided on whether or not to have NAST.

Results: Patients perceived the decision aid as useful to becoming more informed and involved in making a decision as to whether they receive NAST. They described the information provided in the decision aid as reliable, relevant, sufficient in terms of amount, and tailored to their needs. Reading and rereading the decision aid at home in-between the consultations with their surgeon and their medical oncologist allowed women to better understand their treatment options and easily integrate the decision aid into their care. The decision aid seemed to confirm but not change women's decisions on NAST.

Conclusion: The decision aid appears to help breast cancer patients support their decision about whether to receive NAST. Patients' ability to review the decision aid in-between two consultations seems to be an acceptable and feasible way of integrating the decision aid into patients' care.

KEYWORDS

breast cancer, decision aid, decision making, qualitative research

1 | INTRODUCTION

1.1 | Breast cancer treatment decisions can be challenging

To maximise their outcomes, patients should be involved in their treatment decisions, to the extent they desire.¹ This can decrease patients' distress and anxiety, and increase their satisfaction with the consultation and overall quality of life.² However, breast cancer patients can be

overwhelmed by the number of treatment options available to them.³ In addition to the large number of treatment options available, the complexity of each treatment choice can further complicate the decision-making process. For instance, treatment choices are increasingly involving differing outcomes, such as efficacy and toxicity, which may be valued differently by different patients. Such decisions are called "preference-sensitive."^{4,5} They can be very difficult for patients, as the "best choice" cannot be predefined; it depends on patients' preferences and involves each individual patient weighing up the risks against benefits of the

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options available to them. It is essential that patients are adequately supported by the health care system when deciding on their treatment.⁶

1.2 | Deciding on neoadjuvant systemic therapy can be particularly difficult for patients

Some early-stage breast cancer patients with larger operable or highly proliferative disease may be offered a choice about whether to have neoadjuvant systemic therapy (NAST), ie. chemotherapy or endocrine therapy before surgery. This is a particularly difficult decision to make, as the concept of NAST adds complexity and uncertainty at a time when patients are likely to be distressed from the initial diagnosis of cancer. However, patients may value the neoadjuvant approach due to a higher chance of breast conserving surgery rather than mastectomy.⁷ Neoadjuvant systemic therapy also allows a better understanding of tumour response and biology, which can facilitate prognostication.⁸ Improved prognostication can decrease patients' anxiety and depression associated with their cancer and potential treatment outcomes.^{9,10} Survival and recurrence rates are equivalent for NAST followed by surgery compared to receiving surgery first.⁸ However, some patients fear that their cancer could get worse while receiving NAST and thus prefer to have the tumour surgically removed as soon as possible.¹¹ Therefore, for women with operable breast cancer, the decision for or against NAST relies heavily on patients' preferences.¹² To allow these patients to make informed treatment decisions, they need to be provided with adequate, evidence-based information.

1.3 | Decision aids can improve patient outcomes

Decision aids provide patients with evidence-based information regarding the health care options available to them. Decision aids aim to assist patients with clarifying and communicating the value they associate with each option.¹³ They are designed to engage patients in the decision-making process and to guide them towards making deliberated decisions that align with their preferences.¹⁴ A number of Cochrane reviews have shown that decision aids are effective in improving certain patient outcomes, including increased knowledge and understanding of the options available, and reduced decisional conflict, when compared to usual care.¹⁵ Although decision aids have been developed for numerous health conditions, one was not available for the decision on NAST before this study commenced.¹⁶ To fill this current gap, our group designed a decision aid to help women become more informed and more involved in decisions about NAST. The decision aid is being evaluated in a prospective, single-arm pre-post trial. Here, we report on the qualitative analysis of phone interviews included in the larger trial to assess women's use of, and perceived benefit from, the decision aid. This substudy aims to provide in-depth insights into women's perspective on the effectiveness of the decision aid and helps explore whether it might be a valuable tool to facilitate decision making on NAST in clinical practice.

1.4 | AIMS

The aim of this study was to explore, qualitatively, in a sample of early-stage breast cancer patients eligible for NAST, the use and perceived

benefit of a decision aid that was designed to provide women with relevant information to assist their decision on NAST.

2 | METHODS

2.1 | Development and testing of a decision aid on NAST

The development of the decision aid was informed by (1) a qualitative study conducted to examine the information needs of patients receiving NAST;¹¹ (2) a literature review to define treatment options and the positive and negative outcomes associated with those options; and (3) identification of relevant issues important to the decision on NAST by an expert consensus panel. The structure of the decision aid was based on the International Patient Decision Aid Standards Collaboration (IPDAS) statement to include a balanced description of adjuvant and neoadjuvant therapy. The decision aid includes an introduction that helps newly diagnosed breast cancer patients understand basic concepts about their treatment modalities. This was important, as these patients may not have received other written general information at the time when NAST was discussed. The decision aid further includes brief general information about breast cancer and the treatments commonly used, an explanation of the options for the timing of chemotherapy and surgery, the advantages and disadvantages of neoadjuvant and adjuvant therapy, a values clarification exercise (ie. a worksheet to help patients consider how they value key aspects of the decision on NAST), a page for notes, a glossary, and information about where to find additional resources. To improve patients' risk perception and lead to better informed decision making, key components of risk are presented in visual, numeric, and narrative formats using appropriate labelling. The decision aid is designed to be compatible with online and paper delivery. The IPDAS criteria for judging the quality of decision aids have been adhered to (please see Appendix S1 for a completed IPDAS checklist).¹⁷⁻¹⁹ Consumers and members of a breast cancer support organisation (Breast Cancer Network Australia) reviewed and helped refine the content and comprehensibility of the decision aid. Care was taken to make use of the shortest word and simplest sentence structure possible. Word and sentence length had to be balanced against the overall length of the decision aid. An excessively long decision aid was not considered likely to be approachable by those with low literacy. To avoid duplication of information, the decision aid refers to other information sources, which are routinely made available by breast care nurses to women who have been diagnosed with breast cancer.

2.2 | Setting and sample

A purposeful sample of 20 patients attending breast cancer treatment centres in New South Wales and Victoria were interviewed one-on-one via telephone. Recruitment continued until data saturation (no new themes in 3 consecutive interviews) was achieved.

2.3 | Inclusion and exclusion criteria

Patients were eligible for this study if, at the time of enrolment, they (1) were female; (2) were aged ≥ 18 years; (3) had a histological diagnosis

of operable invasive breast cancer; (4) were considered for neoadjuvant systemic (chemo or endocrine) therapy (NAST) as a treatment option with curative intent; and (5) were willing and able to access the trial information and the decision aid via the Internet and complete the telephone interview. Patients were excluded if (1) < 3-month duration of NAST was planned; (2) they had hearing or other impairment that would preclude a phone interview; (3) they had insufficient English language skills for participation in a phone interview; (4) they had inflammatory, metastatic, or inoperable breast cancer; (5) they were considered by the treating investigator to have a medical or psychiatric condition precluding informed consent; and (6) they were unable to be contacted via telephone. We excluded those patients who were going to receive less than three months of chemotherapy because the outcome probabilities presented do not apply to those patients. The intent was to include patients who were going to receive a full course of neoadjuvant chemotherapy, which is typically three months or more. This duration is required for maximal benefit from neoadjuvant chemotherapy.

2.4 | Recruitment

The treating clinician identified eligible patients attending their clinic for a consultation, introduced the trial, and obtained written consent to be contacted by the Australia and New Zealand Breast Cancer Trials Group (ANZBCTG) for study registration. The clinician then completed a screening form and faxed it to ANZBCTG. The screening form contained an eligibility checklist, investigator assessment of information needs and distress at that time, consent for release of information to the ANZBCTG, and patient email address and phone number for further contact. Patients who consented to further study contact were emailed a link with access to the trial information letter and online consent form, which patients could access after the consultation with their treating clinician. The consent form asked patients to provide consent to take part in the larger intervention trial and gave participants the option to opt out of a follow-up telephone interview. Once patients had consented to participate in the trial they entered their demographic details and completed a series of patient reported outcome measures in an online survey. Patients were then provided with access to the decision aid, which they could read online or print out. Patients who consented to a telephone interview were contacted via phone by a member of the research team (AH) to schedule the interview. Most interviews took place two to three months after study consent (median time between study consent and interview: 93 d). Women were not asked to have the decision aid on hand during the interview.

2.5 | Data collection

All interviews were conducted by a single researcher (AH) who has been trained in qualitative research methods. Participants were informed that the interviews would be audio-recorded and transcribed but that their information would remain confidential and de-identified. They were then asked to tell the interviewer how they made their decision to have chemotherapy before or after surgery. Participants were encouraged to tell their story in the way

they preferred, without interruption from the interviewer. This narrative was followed by semistructured open-ended questions that included asking patients about the information provided to them, their information seeking behaviour, the decision-making process, psychological concerns, and experiences with the decision aid. The question guide is described in Appendix S2. At the end of the interview, patients were given the option to provide additional comments. The questions were informed by a previous study and discussions amongst the research team.^{11,19} Participants were asked as many questions as needed to gain the required information, with prompting used to elicit topics not spontaneously spoken about by patients.

2.6 | Data analysis

Interviews were transcribed verbatim. Transcripts were checked for accuracy by one researcher (AH) and analysed using a framework analysis process. Transcripts and conclusions drawn from the data were double-checked by another member of the research team (NZ). Disagreement was resolved by discussions between AH and NZ. The framework method was considered appropriate to develop a profound understanding of patients' experiences with the decision aid, as it provides a systematic model for managing and mapping the interview data and for generating themes by making comparisons within and between cases.²⁰ After familiarising ourselves with the data, AH examined, compared, and categorised segments of content to assign codes and to start the development of categories. A category in this sense was a group of codes that share a commonality.²¹ After identifying initial codes and categories, AH developed a coding matrix and assigned data to the codes and categories in the coding matrix.²² This coding matrix was then discussed and refined with one member of the research team (NZ). Throughout the coding process, an iterative approach was applied. Newly developed categories and existing ones were constantly compared with each other and revised if necessary. To do this, the interviews were analysed individually and then compared with each other.^{23,24} The coding process was accompanied by writing analytical memos. This helped document the research process and preliminary findings. These techniques contributed to the intersubjectivity of the procedure and allow to reconstruct or repeat the analysis.²⁵ Demographics are presented using appropriate summary statistics.

3 | ETHICS

This study was developed and conducted in accordance with the tenets of the Declaration of Helsinki and principles of Good Clinical Practice. All participants provided voluntary informed consent. The study was approved by a recognised Human Research Ethics Committee and conducted according to local site governance processes. The parent intervention trial was prospectively registered on the Australia and New Zealand Clinical Trials Registry (www.anzctr.org.au, ACTRN12614001267640).

4 | RESULTS

4.1 | Demographics

Patients were interviewed via phone between February and September 2016 by one researcher (AH). Of 59 patients who consented to the larger trial, 42 consented to be interviewed and 20 were interviewed, by which time saturation was achieved. Interviews lasted between 15 and 37 minutes. Participants' median age was 52 (SD = 6.9); median time since diagnosis was 82 days (IQR = 49–141). The majority of patients decided for NAST (85%), while the remaining 15% underwent upfront surgery. Most patients were married or living with a partner (85%) and had a university-level degree (75%, see Table 1).

4.2 | The use and perceived benefit of the decision aid

The following themes emerged from the data: (1) integration of the decision aid into care, (2) improved knowledge and understanding of treatment options, (3) providing customised, reliable information, and (4) facilitating involvement in decision making. Our data suggest that by providing customised and reliable information to patients, the decision aid helped women better understand their options and thus facilitated the decision-making process. Most women used the decision aid in-between the consultations with their doctors. As such, the decision aid could be easily integrated into women's care pathway. The themes are described in detail below.

4.3 | Integration of the decision aid into care

Most women used the decision aid just after the initial consultation with their surgeon about their treatment options, prior to their consultation

with the medical oncologist, and perceived this as the right timing. A mean of 5 days (SD = 2.3) elapsed between study consent and treatment decision. Reading and rereading the decision aid at home in-between the two consultations allowed women to easily integrate the decision aid into their care. They appreciated the opportunity to reconsider their options at their own pace after consulting their surgeon. This was particularly important for those women who thought that the initial consultation with their surgeon did not provide sufficient time to answer all the questions they had. Many women felt that the decision on NAST needed to be made quickly and welcomed using the time in-between the consultation with their surgeon and their medical oncologist to think about their options with the help of the decision aid.

I think it was important to speak to the surgeon and get his view on it all, but I think it was also very helpful to have the written information that was in the decision aid so I could sit and read that at my own pace. [...] When you are in a surgeon appointment, it's only a limited amount of time. Like it's specific to, boom, boom, boom, the things that have to be dealt with. It felt like it [=the decision aid] was more information than what I'd had from him [=the surgeon]. It was also that I was able to absorb it better because I could sit down and take the time to read it. [patient ID: 13010041]

While most women received the decision aid after the initial consultation with their surgeon, many women made the decision during or just after this initial discussion and some wished they had the decision aid "right from the start" [patient ID: 13010035], ie. just after their diagnosis. Although using the decision aid in-between two consultations seemed appropriate, some patients reported they would have liked to receive the decision aid during rather than after the initial consultation with their surgeon.

The book that I was sent after I did that survey, I would have loved to have had access to that book from the get go. [patient ID: 13010034]

Some patients did not use the decision aid as they felt that they (or their doctors) had already made the decision. However, most women read the entire decision aid at least once and then reread the passages they perceived to be most relevant to them. The amount of information provided was seen to be appropriate. Patients appreciated that they could read the decision aid from beginning to end or only focus on those parts they were most interested in.

You could read more into it if you wanted, but for me, I read bits and pieces of the bits that weren't relevant to me – and all of what was relevant to me but I think it was enough information that if you weren't quite sure you could always go and get more if you wanted [...] for me it was the right amount of information. [patient ID: 13010033]

4.4 | Improved knowledge and understanding of treatment options

The decision aid enhanced patients' knowledge and understanding of the treatment options available to them by summarising and extending

TABLE 1 Patient characteristics

	Patients (n = 20)
Age in years, mean (SD)	52 (6.9)
Marital status	
De facto	15% (3)
Married	70% (14)
Single	15% (3)
Education	
Secondary school	15% (3)
Vocational	10% (2)
University	75% (15)
Lymph nodes involved	
Yes	45% (9)
No	55% (11)
Treatment decision	
Neoadjuvant	85% (17)
Adjuvant	15% (3)
Surgery	
Mastectomy only	45% (9)
Breast conserving surgery only	50% (10)
Both	5% (1)

the information provided by their doctors. It helped women comprehend and make sense of their cancer and treatment options. Many women reported that the decision aid made up for their perceived lack of medical expertise by providing structured, objective information and by answering questions patients had after the consultation with their doctor.

Sometimes you just need it clearly laid out in front of you, this is your options, without having different people who had their own agendas telling you what is right and what is wrong, or what you should do. [patient ID: 13010033]

It enhanced what my surgeon had told me and allowed me to process it and understand it at a greater depth than I would have been able to if I hadn't had the decision aid. [patient ID: 13010034]

It was very simply written and also to-the-point. I suppose there were some questions that I might have been asking myself and they were being answered in that booklet. [patient ID: 13010035]

Some women indicated that the included graphs and statistics were particularly helpful to understand the potential risks and benefits of their treatment options. Others found that the explanation of different types of breast cancer helped them better understand why different patients received different treatments. Some participants with a medical background felt that the decision aid could have provided them with more detailed information, for example, on potentials risks and benefits of NAST and upfront surgery according to different age groups. However, they thought that the decision aid provided the right depth and breadth of information to suit the needs of the heterogeneous group of breast cancer patients, which includes patients with very different educational backgrounds and literacy levels.

It did give figures for chances of it [=the cancer] disappearing altogether and chances of it coming back, the different types of cancer and yeah, I became a bit more of an expert about breast cancers and the different types that I had been before. [patient ID: 13010048]

I found it interesting to read a little bit about the other cancers and make the decision on me and my situation rather than everyone's situation. [patient ID: 13010033]

I think that the particularly relevant bit was understanding the different types of cancer and the explanation of the HER2 and the other types of cancer, and how they are all slightly different, because I didn't know any of that before I got cancer. [...] so yes the relevant thing, I think, was understanding all the different types of cancer and how one size doesn't fit all. Not everyone should have the same approach. [patient ID: 13010041]

The decision aid also helped women deal with the fears associated with their treatment options and assisted them in making an informed, rational decision based on their individual circumstances and preferences.

I felt after reading it [=the decision aid] that my fears about the tumour remaining there were abated really. [...] my cancer was triple negative and I understood that it had potentially grown quite fast. Once I understood the rationale for why I might have chemotherapy first, I actually felt it was a better option for me to start the chemotherapy sooner rather than later, given that it also had spread to my lymph nodes. [patient ID: 13010033]

4.5 | Providing customised, reliable information

Women appreciated that information was provided in both face-to-face and written format. Many women preferred the printed decision aid over the online version due to ease of access, viewing, portability, and ability to make notations. Also, patients preferred using the decision aid instead of information they found by searching online. They perceived the information provided in the decision aid to be more trustworthy and targeted to their needs, compared with sources that they identified on the Internet.

I just found that the information that I was Googling on the internet, it was too much, it was too airy fairy. Whereas this [=the decision aid] was just straight to the point, it was just in great user friendly language and that's what I really loved about the book. [patient ID: 13010035]

I was a little bit overwhelmed and I wanted reliable information, so I chose not to Google, not to do a Google doctor. [patient ID: 13010034]

All patients who used the decision aid described the information provided in the decision aid as reliable and tailored to their needs. They liked how the decision aid was organised, including the use of graphics, tables, and sufficient white space that reduced the crowding of text. Most patients found the decision aid easy to understand and balanced (not in favour of NAST or upfront surgery). Some patients perceived it to be in favour of NAST and wished it contained more information on upfront surgery.

The way it's laid out, it's quite spacious on the pages and there are lots of diagrams and stuff. So it's not, you know, it's quite intimidating if it was all heavy text closely together. [patient ID: 13010015]

I think it was more slightly biased in terms of chemotherapy first but it could have just been my reading of it because I was already in that frame of mind. [patient ID: 13010041]

4.6 | Facilitating involvement in decision making

The decision aid not only enabled patients to make an informed decision on NAST but also helped them become more involved in the decision-making process, for example, by prompting additional questions to ask their doctors during the consultation. Some women took parts of the decision aid to the next consultation with their

specialist. This served as a platform for further discussion about their preferences and concerns and helped women remember the questions they wanted to ask their doctor. One patient found the step-by-step approach for how to arrive at a treatment decision particularly helpful. This section of the decision aid included guidance to patients to understand, review, prioritise, and discuss the information provided (see Appendix S3).

I felt like I was more involved in the decision and I was making the decision in a more informed way that I maybe would have been able to if I'd just relied on the surgeon's information, if that makes sense. [patient ID: 13010033]

It [=the decision aid] was opening up other questions for me to think about, to help me think about. [patient ID: 13010024]

I actually then just pulled out pages that I thought were more towards what I was thinking. [...] I took that with me to the oncologist appointment. Just so I had things that reminded me of what I wanted to ask. [patient ID: 13010026]

Some women reported that their family members used the decision aid as well and thus became more informed and involved in the decision-making process. This saved patients from spending time and effort educating their support persons about the risks and benefits of the different treatment options available to them.

My husband went through the decision aid as well, and also my two adult daughters. I think it was quite helpful for them. I saved my breath, if you know what I mean, in terms of having to explain and justify why one option might be a better choice than another. [patient ID: 13010034]

All patients received a treatment recommendation from their doctor and chose the recommended option. The decision-making process was guided by their doctors' opinion and based on patients' trust in their doctors' medical expertise and experience. Although the decision aid helped patients understand their options, confirm their decision, and increase their involvement in the decision-making process, it did not change women's decisions on NAST. Women who felt they made an informed decision on NAST and were involved in the decision-making process seemed to be more satisfied and certain about their decision.

It [=the decision aid] just kind of clarified and confirmed to me what I was doing, and the decision I made. [patient ID: 13010032]

I felt that having chemo first was the right decision - and the information in there [=the decision aid] helped me confirm that that was the right decision. I just think it's something that should be out there for all women in this situation [...] It's such an important tool to have to make sure that you're making the decision that's right for you. [patient ID: 13010033]

5 | DISCUSSION

5.1 | Fitting decision aids into the clinic workflow: a feasible prospect

These results suggest that the decision aid was a useful tool to support breast cancer patients in deciding on whether to have NAST. The themes that emerged from the data were of integration of the decision aid into care, increased knowledge and understanding of treatment options, providing customised, reliable information, and involvement in the decision-making process. The decision aid supported women's comprehension of their cancer and the treatment options available to them. It facilitated their participation in deciding on NAST and helped women confirm that they made the right decision. This is in line with current evidence supporting the effectiveness of decision aids in improving patient outcomes.^{15,26} The degree of patients' engagement with this decision aid demonstrates the feasibility of patient involvement in decision making in the context of a confronting diagnosis accompanied by a variety of decisions, rather than expecting clinician-led decision making.

Although decision aids have been shown to be effective in improving patient outcomes, widespread clinical use is not yet commonplace.²⁷ More efforts need to be made to explore how to best integrate decision aids into routine doctor-patient communication. Depending on the format and the decision being made, individual decision aids may be better suited to use either during the consultation or afterwards.¹⁵ The breast cancer patients in our sample appreciated reading the decision aid in-between having a consultation with their surgeon and their follow-up consultation with their medical oncologist. Patients received the decision aid after the initial consultation with their surgeon, while waiting to see their medical oncologist. This allowed the decision aid to be easily integrated into their care pathway. It also gave women the opportunity to reconsider their options and feel more certain about choosing a treatment. This is in line with previous studies reporting reduces in patients' decisional conflict, decisional regret, and depression after the use of decision aids, which had been delivered as a post consultation supplement.^{15,28,29} Further studies have suggested that using a decision aid prior to the consultation during which a health care decision is made might increase patients' feeling of being informed about their options, as well as patients' ability and willingness to participate in the decision-making process at hand.³⁰⁻³²

Although using the decision aid in between patients' consultation with their surgeon and their consultation with their medical oncologist seems to be appropriate, some women said that the intervention should be introduced and endorsed during the initial consultation with their surgeon. Such an approach may be possible with sufficient resources, however might be difficult to broadly incorporate into routine practice given many clinicians' reluctance regarding the provision of decision aids during the consultation.^{33,34} For example, it has been suggested that clinicians might fear that the use of decisions aids could increase their time pressure.^{35,36} Further barriers include clinicians' lack of awareness of decision aids or their belief that decisions aids are not applicable to the circumstances of each individual patient.³⁷ The study processes precluded investigators from

providing participants with the decision aid at the initial consultation with their surgeon, because pre-decision aid questionnaires were required for the larger intervention trial in which this qualitative study was embedded. However, investigators were given a card showing key images and graphs from the decision aid to demonstrate within the consultation. In routine clinical practice, the decision aid could be briefly introduced during the initial consultation with the surgeon. Face-to-face communication between doctor and patient might be best suited to introduce and explain the preference-sensitive nature of the decision on NAST and the potential benefits of the decision aid.³⁸ This is in line with previous studies that suggest that patients might value having important treatment decisions discussed with their clinician first and having decision aids delivered during the consultation.^{39,40} Patients could then use and engage with the decision aid after the consultation to broaden and deepen their understanding of the conveyed information and prior to making a final treatment decision.

5.2 | Exploring the benefits of the decision aid on NAST

The women included in our sample were well educated and had high health literacy levels, which may have contributed to positive feedback about comprehensibility. We do not know whether women with lower health literacy levels would perceive the same benefits from using the decision aid. However, there is evidence to suggest that if patients with lower literacy levels are provided with appropriate decision support, they participate equally well and benefit by becoming more aware of their health care options.⁴¹ It would be beneficial to administer the decision aid to a more representative sample of breast cancer patients to investigate whether our findings are generalisable.

The decision aid reassured women that they made the right decision on NAST but did not change their decision. Other decision aid studies have demonstrated a variable effect on treatment choice¹⁵; however, the intent is to inform and involve rather than to change people's mind. All women trusted and followed their doctors' treatment recommendation. Many patients felt that their treatment decision needed to be made quickly and felt overwhelmed by their cancer diagnosis and treatment options. Decision aids, such as the one provided within this study, might be an opportunity to counteract this "rushed" decision making by allowing patients to reconsider and confirm their treatment decision.^{42,43} Because all patients in our study received a treatment recommendation, this decision aid could be used to educate women on the preference-sensitive nature of the decision on NAST and to highlight the benefits of involving patients' preferences in this decision.^{44,45} As such, the endorsement by clinicians influenced the decision aid's success. Also, the decision aid gave patients' support persons specific information about the options available and enabled their participation in the decision-making process. This mirrors previous studies that reported that decision aids can increase families' knowledge of the options available to patients and their involvement in decision making.^{46,47}

5.3 | The influence of the decision aid on the decision about NAST

Although most women felt that the decision aid provided unbiased, balanced information, some women perceived that the decision aid was in favour of NAST. When probed to explain why they felt this way, women reported that they decided for NAST and felt that they might have read the decision aid according to what they had already decided. One could assume that to obtain or maintain cognitive consonance, women who chose NAST read the decision aid to confirm their decision and thus got the impression that NAST was recommended by the decision aid.⁴⁸ However, it might be that the decision aid is in fact biased. Further examination is needed to answer this question.

A number of women indicated a preference for more detailed information. Although the decision aid includes links to further information sources, it might be worthwhile to provide an optional supplement to the decision aid for those patients who would like to receive more information on the decision on NAST. Such a supplement could include potential risks and benefits of NAST and upfront surgery according to different age groups. This would be more amenable to an online format, which incorporates links and additional pages for those who want more information. Similar approaches have been shown to be valued by patients.^{49,50}

6 | LIMITATIONS

Our findings are not intended to be numerically representative. They rather provide much needed in-depth insights into patients' use and perceived benefit of this decision aid, and decision aids in general. As such, we avoided potentially misleading numerical description of our results. A quantitative analysis of the decision aid that includes a larger sample size will be reported elsewhere. Most study participants (85%) chose NAST over upfront surgery. Thus, women's perceptions of the decision aid may have been influenced by their treatment decision. Also, some women used the decision aid months prior to the interview, introducing the possibility of recall bias that could potentially lead to inaccurate narratives.⁵¹ Some patients noted that the shock over their cancer diagnosis and the plethora of information to consider added further difficulty with remembering the decision aid's content.

That is a really, really shady period of my life. I can't remember much. You probably know that people do not remember much when they first hear the diagnosis.
[patient ID: 13010023]

We do not have recordings of the consultations during which the decision aid was introduced. As such, we do not know how the communication skills and styles of the doctors who were involved in the delivery of the decision aid might have influenced patients' use and perceived benefit of the decision aid.

7 | CONCLUSIONS

Our results suggest that the decision aid is a valuable tool for supporting women with their decision on NAST. It seemed to increase

women's knowledge and understanding of the options available to them and helped them feel more involved in the decision-making process. The decision aid assisted women with confirming that they made the right decision. For most women, using the decision aid in-between the consultation with their surgeon and the consultation with their medical oncologist appeared to be an acceptable and feasible way of integrating the decision aid into patient care.

COMPETING INTERESTS

The authors declare that they have no competing interests.

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AUTHORS' CONTRIBUTIONS

AH and NZ conceived of this paper together. AH conducted data collection and analysis. The results of the data analysis were double-checked by NZ. All authors reviewed and approved the final manuscript.

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SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

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