A difficult balancing act : Informing breast cancer patients about adjuvant systemic therapy

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Part IV

Communicating the benefits and harms of adjuvant systemic therapy for early-stage breast cancer during patient consultations

Chapter 6

Information provision about the benefits and side-effects of adjuvant systemic therapy for breast cancer in clinical practice: *does the use of Adjuvant! facilitate communication?*

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Abstract

Background

Adjuvant systemic therapy for early-stage breast cancer may improve survival, but has side-effects impacting patients' quality of life. Knowing the magnitude of treatment benefits can facilitate oncologists' and patients' decision-making. Prediction tools such as Adjuvant! may help, but little is known about their use and the implications thereof. We assessed a) the prevalence and determinants of Adjuvant! use, b) information provision about treatment benefits and side-effects overall and by Adjuvant! use, and c) whether Adjuvant! use is associated with the likelihood of reaching a decision.

Methods

We audiotaped consecutive patient consultations about adjuvant systemic therapy. We assessed prevalence of Adjuvant! use in the whole sample (N=287), and determinants of use in N=217, excluding consultations by oncologists who *always* or *never* used Adjuvant!. We assessed differences in information provision and decision-making in a random subset of consultations with and without Adjuvant! (N=211).

Findings

The oncologists used Adjuvant! *prior* to 70% of consultations, and also or only *during* 67% of consultations. Use was less likely the higher the disease stage (P=0.002) and the older the oncologist (P=0.03). Relapse reduction probabilities were the most frequently communicated treatment benefit (96%). In 39/214 (18%) consultations it was unclear to what outcome communicated probabilities related. Generally, fewer side-effects were communicated for endocrine therapy (Md.=4 (range: 0-9) than for chemotherapy (Md.=7 (range: 1-13), irrespective of Adjuvant! use. Communication about side-effects was generally inconsistent. Decision-making was more often postponed if Adjuvant! was used (P=0.005).

Conclusion

Adjuvant! was frequently used during consultations with patients, however, its probabilities were not always clearly communicated. Also, there was great disparity in information provision about side-effects. Critical assessment of prediction model use in risk communication and guidance on information provision about side-effects are needed to ensure clear and balanced information in treatment decision making.

Introduction

Decisions about adjuvant systemic treatment for stage I-III breast cancer are often not straightforward given the impact that side-effects (e.g., alopecia, nausea, loss of appetite, fatigue and neuropathy) can have on patients' short- and long-term quality of life (1-4). Current clinical guidelines generally endorse discussing adjuvant systemic treatment with early-stage breast cancer patients if the expected absolute survival gain is minimally 3-5% (5-7). This also implies that roughly 9 out of 10 patients treated either undergo treatment without gain or die in spite of treatment. There generally is no 'best' treatment option in this setting, thus, treatment decisions need to be guided by patients' informed preferences.

When weighing the benefits of treatment against its harms, it is helpful to know the magnitude of the expected treatment benefit. Prediction tools have been developed for this purpose, such as Adjuvant! and PREDICT. Adjuvant! was the most often used tool in the Netherlands before being taken offline by the end of 2015 for updates (8). It quantifies 10-year recurrence and mortality probabilities with and without adjuvant systemic treatment (9,10). Clinical guidelines recommend using Adjuvant! to support clinicians in obtaining personalized prognostic information for their patients (5-7). Small self-report surveys amongst oncologists suggest that Adjuvant! is regularly used during consultations with patients (8,11,12). Three-quarters of oncologists indicated in a survey that they felt that using Adjuvant! during consultations helps patients to better understand their prognosis (8). Available studies reported though that fewer than half of the patients provided with prognostic estimates from Adjuvant! were able to comprehensibly articulate their prognosis after the consultation (13,14).

Unfortunately, evidence on whether and how Adjuvant! use influences information provision during real-time consultations is lacking. Yet, the use of Adjuvant! may have several important implications. For example, Adjuvant! only provides probabilities of the potential benefits of treatment, it does not incorporate information about nor probabilities of the potential side-effects. Adjuvant! use during consultations could therefore shift the focus of the consultation towards discussing prognosis with and without treatment, at the expense of discussing treatment side-effects. Effective communication about side-effects may be further complicated by a lack of guidance as to which side-effects of adjuvant systemic therapy for breast cancer minimally need to be communicated to patients. Available evidence suggests that Adjuvant! not only influences oncologists' treatment recommendations, but also patients' treatment preferences (15,16). If the information provision about benefits and side-effects is unbalanced, the potential treatment benefits (i.e., relapse probability reduction and mortality reduction) may primarily drive patients' treatment preferences and ultimately decision-making, rather than a trade-off between the benefits and side-effects (17).

This may simplify decision-making, but it calls into question the informed nature of the decision. Receiving information about treatment benefit and harms might make patients aware that there is no obvious choice, and that undergoing therapy does not guarantee a good outcome.

The aim of the current study was to provide insight in information provision about the benefits and harms of adjuvant systemic therapy for breast cancer during patient consultations, and the impact of Adjuvant! use on information provision and decision-making during these consultations. We specifically investigated 1) the prevalence, and 2) determinants of Adjuvant! use in clinical practice, 3) information provision about treatment benefits and side-effects overall and by Adjuvant! use, and 4) whether Adjuvant! use influenced the likelihood of reaching a decision.

Methods

Design

Patient sample

Breast cancer patients with stage I-III disease from 7 outpatient clinics were invited to participate if they a) did not have a prior history of cancer for which they had received systemic therapy, b) were eligible to receive adjuvant systemic chemotherapy and/or endocrine therapy, and c) were fluent in Dutch. Patients were recruited between July 2012 and February 2015. Medical ethics boards of the participating hospitals approved the study protocol.

Procedures and measures

The procedure was as follows: (1) consultations were audiotaped after obtaining informed consent from patients, (2) after each consultation oncologists completed a checklist, and (3) patients completed a survey, (4) after the recruitment ended oncologists completed a survey, and (5) additional tumor and treatment characteristics were collected from the medical charts, with patients' consent.

Half of the consultations were transcribed verbatim, the remaining were coded directly from audio. Due to time constraints, it proved impossible to transcribe all consultations. To ensure the reliability of coding directly from audio, each coder coded a sample of consultations (N=13-16) that had already been coded from transcript, minimally three months after the original coding. The agreement between coding from audio and transcripts was high (81% and 83%, respectively; kappa for all items ≥0.6). Consultations were double-coded by 2 trained research assistants until an inter-rater kappa of minimally 0.6 was reached for all items, then one research assistant performed final coding.

Below we describe per research question (RQ) in detail which data was collected in each of the steps described above.

RQ1: Frequency and mode of use of Adjuvant!

After each consultation, oncologists indicated whether Adjuvant! had been used during the consultation (no/yes), and if so, when (prior to/during the consultation/both prior and during). Further, if oncologists had used Adjuvant! during the consultation, we asked *how* they had used the model (only providing the prognostic information orally/orally and visually (via the computer screen and/or a printout of Adjuvant!'s output)).

Table 1 Characteristics of whole study population and subsets used in analyses (N (%))

		Subset	
	Whole population N= 287 (100%)	determinants sample* N= 217 (76%)	information provision sample# N= 211 (74%)
Patients characteristics			
Average age in years (range)	59 (32-90)	58 (33-90)	59 (35-90)
Education level			
Low	44 (19.5)	27 (15.7)	31 (18.2)
Intermediate	114 (50.4)	92 (53.5)	83 (48.8)
High	68 (30.1)	53 (30.8)	56 (32.9)
Unknown	61	45	41
Numeracy level			
Low	51 (22.4)	35 (20.1)	39 (22.7)
Intermediate	59 (25.9)	45 (25.9)	45 (26.2)
High	118 (51.8)	94 (54.0)	88 (51.2)
Unknown	59	43	39
Tumor characteristics			
TNM stage			
Stage I	127 (44.6)	96 (44.4)	92 (44.0)
Stage II	141 (49.5)	107 (49.5)	104 (49.8)
Stage III	17 (6.0)	13 (6.0)	13 (6.2)
Unknown	2	1	2
Consultation characteristics			
Median duration in minutes (range)	27 (6-80)	26 (6-80)	28 (6-80)
Treatment discussed			
Chemotherapy only	35 (12.2)	24 (11.1)	28 (13.3)
Endocrine therapy only	35 (12.2)	23 (10.6)	23 (10.9)
Chemotherapy & endocrine therapy	217 (75.6)	170 (78.3)	160 (75.8)
Use of Adjuvant! during consultation			
Not used	96 (33.4)	57 (26.3)	92 (43.6)
Used	191 (66.6)	160 (73.7)	119 (56.4)

* In the determinants sample we only included consultations by oncologists who: a) had included at least five patients to the study population, and b) did not *always* or *never* use Adjuvant! during the consultation.
# In the information provision sample we included a random sample of all consultations consisting of approximately an equal number of consultations with and without Adjuvant!.

Table 1 continued Characteristics of whole study population and subsets used in analyses (N (%))			
Oncologist characteristics			
Number of oncologists	30	24	28
Median number of patients included	6 (1-40)	5 (1-39)	4 (1-30)
Average age in years (range)	46 (30-66)	41 (30-66)	41 (30-66)
Gender			
Male	13 (43.3)	10 (41.7)	12 (42.9)
Female	17 (56.7)	14 (58.3)	16 (57.1)
Experience treating breast cancer			
Less than 5 years	11 (50.0)	9 (47.4)	10 (47.6)
Between 5-10 years	2 (9.1)	2 (10.5)	2 (9.5)
More than 10 years	9 (40.9)	8 (42.1)	9 (42.9)
Unknown	9	5	7
Type of hospital			
Academic	16 (53.3)	12 (50.0)	14 (50.0)
General teaching	14 (46.7)	12 (50.0)	14 (50.0)

[*] In the determinants sample we only included consultations by oncologists who: a) had included at least five patients to the study population, and b) did not *always* or *never* use Adjuvant! during the consultation.
[#] In the information provision sample we included a random sample of all consultations consisting of approximately an equal number of consultations with and without Adjuvant!.

If the checklist was missing, we used the audiotapes of the consultation to determine use of Adjuvant! (yes/no/unclear). Use of Adjuvant! was coded as 'Yes' if: a) prognostic probabilities from Adjuvant! were discussed during the consultation irrespective of whether Adjuvant!'s output was shown to patients, or b) Adjuvant!'s output was used to graphically illustrate the potential treatment effect, irrespective of whether the oncologist mentioned the probabilities.

RQ2: Determinants of Adjuvant! use

The potential determinants assessed were characteristics of a) the patient (age, education level, numeracy, and preference to receive prognostic probabilities), b) the disease (TNM stage, grade, estrogen receptor (ER) status, triple negative disease and/or Her2 status), and c) the oncologist (age, level of experience, type of hospital). If oncologists asked patients whether they wanted to receive prognostic probabilities, we coded patients' response to this question (yes/no/patient did not respond). If only a companion indicated an opinion, this was taken as the patients' opinion if she did not contradict it. After the consultation patients completed a survey covering, first, their education level (low (i.e., up to lower vocational education)/medium (i.e., up to secondary vocational education)/high (i.e., university of applied sciences and higher)). Secondly, their objective numeracy, i.e., their ability to understand and use numbers, was assessed using

the seven expanded numeracy items proposed by Lipkus *et al*.(18) Scores (range: 0-7) were divided into three categories (low numeracy= 0-2; intermediate numeracy= 3-5; high numeracy= 6-7). We assessed oncologists' socio-demographic characteristics in a short survey disseminated after the patient recruitment period closed (age, number of years of experience with treating breast cancer patients (<5 years/6-10 years/ >10 years) and type of hospital (general teaching/academic medical center)). Patient charts were examined to obtain tumor size (in cm), number of axillary lymph nodes, ER status and tumor grade. Tumor size and nodal status were used to determine TNM stage according to the American Joint Committee on Cancer definition, 7th edition (19).

RQ3: Communication of benefits and side-effects of treatment overall and by use of Adjuvant!
From the consultations we extracted data on: a) which disease outcomes (mortality/ relapse probability reduction) were discussed, b) whether benefit discussion included explicit disclosure of probabilities (yes/no), c) whether side-effects were communicated (yes/no), d) which side-effects were communicated, and e) comprehensiveness of the description of the side-effects (side-effect only mentioned (basic)/side-effect mentioned including information on the course of the symptoms/side-effect mentioned including the probability of occurrence).

RQ4: Association between use of Adjuvant! and decision-making
From all consultations, we extracted data on whether a treatment decision was made (made/postponed/made for only one of the treatments discussed in case both chemotherapy and endocrine therapy had been discussed), and what was decided (forego/ undergo/treatment postponed).

Statistical analyses
The participation rate was 358 out of 500 (72%) patients. Patient consultations were excluded if the audiotaping had failed (N=71/358 (20%)). This resulted in a sample of 287 consultations for analysis (see Figure 1 for a flowchart). Descriptive analyses were performed and we assessed the prevalence of Adjuvant! use in the whole sample (N=287) (RQ1). To determine whether and which patient, oncologist and disease characteristics influenced the use of Adjuvant! during consultations, we selected consultations by oncologists who had included minimally five patients into the study population and who did not *always* or *never* use Adjuvant! during the consultation (N=217) (RQ2). The association between the use of Adjuvant! and the determinants was assessed using χ^2 tests or Fisher's Exact Test, as appropriate.

The assessment of information provision about treatment benefits and side-effects (RQ3), and of whether a decision had been reached during the consultation (RQ4) required more extensive content analyses of the consultations. For reasons of feasibility

we used a random subset of approximately equal number of consultations with (N= 92) and without (N= 119) Adjuvant!. Differences in information provision are depicted graphically. The association between use of Adjuvant! and decision-making was assessed using a χ^2 test or Fisher's Exact Test as appropriate. Analyses were performed in SPSS 20. Significance testing was done two-sided at α=0.05.

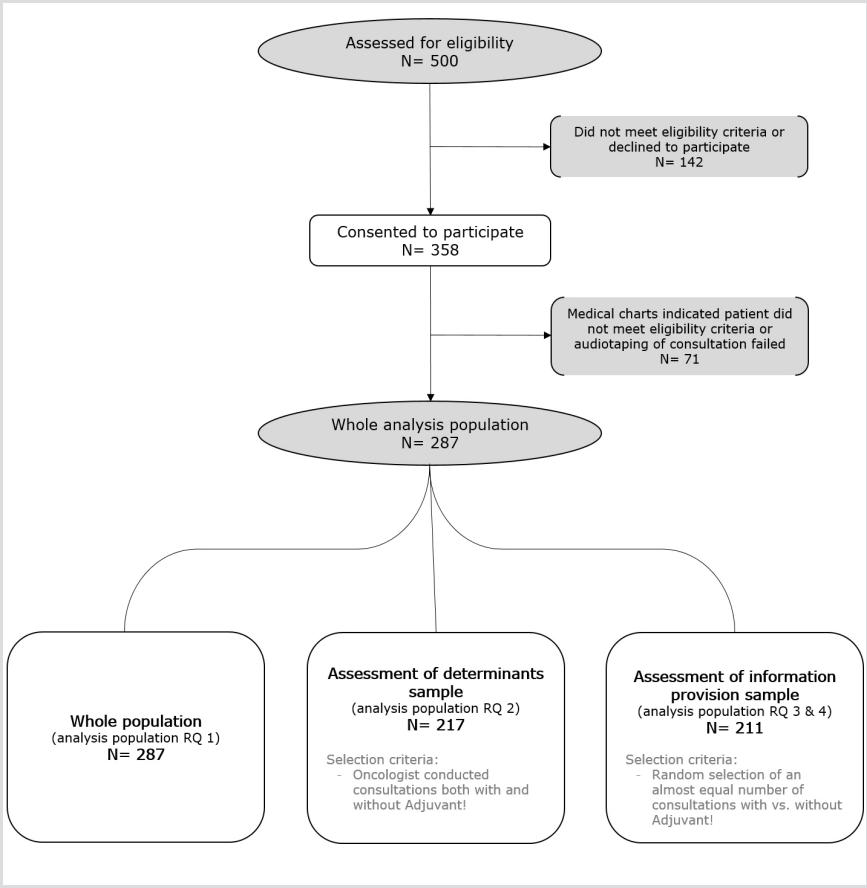


Figure 1 Flowchart of selection and analysis population

Results

Thirty oncologists (mean age: 46 years (range: 30-66 years)) included a median of 6 (range: 1-40) patients (Table 1). Patients (n= 287) were on average 59 years (range: 32-90 years), and they mostly had stage I (45%) or stage II (50%) disease. In three-quarters of the consultations both chemotherapy and endocrine therapy were discussed.

RQ1: Frequency and mode of use of Adjuvant!

Oncologists indicated in 70% of consultations that they had consulted Adjuvant! *prior* to the consultation. Oncologists with >10 years experience consulted Adjuvant! significantly less often prior to the consultation than those with ≤10 years experience (53% vs. 96% (P<0.001)). Adjuvant! was used *during* 191 (67%) of the patient consultations. In 74% of these 191 consultations, Adjuvant! was also reported to have been visually displayed either on the computer screen and/or using a printout of its output. If Adjuvant! was consulted prior to the consultation, it was subsequently used in 84% of those consultations.

RQ2: Determinants of Adjuvant! use during the consultation

Experienced oncologists used the model less frequently in the consultation than their less experienced counterparts (P= 0.03, (Table 2)). The higher the patient's TNM stage, the less frequently Adjuvant! was used during the consultation (P= 0.002). No other patient, oncologist, or disease characteristics were associated with Adjuvant! use.

RQ3: Information provision about treatment benefits and side-effects of treatment by use of Adjuvant! and by treatment

Communication about benefits

Figure 2 shows which benefits were presented during the consultations, by use of Adjuvant! and by treatment. In 183 of the 188 (97%) consultations in which chemotherapy was discussed, at least one benefit of chemotherapy was mentioned. In the remaining 3% of chemotherapy consultations patients could only assume a treatment benefit. In 96% of chemotherapy consultations relapse probability reduction was presented, and in 26% mortality reduction was (also) presented. If Adjuvant! was used, mortality reduction was discussed more often than if Adjuvant! was not used (P<0.001).

Table 2 Use of Adjuvant! by patient, disease, consultation and oncologist characteristics (col%)

	Adjuvant! Online *not* used* N= 57	Adjuvant! Online used* N= 160	P#
Patients characteristics			
Age			
younger than 50 years	17 (30)	29 (18)	0.10
50-70 years	29 (51)	105 (66)	
older than 70	11 (19)	25 (16)	
Education level			
Low	7 (16)	20 (16)	0.97
Intermediate	25 (56)	67 (53)	
High	13 (29)	40 (32)	
Numeracy level			
Low	11 (24)	24 (19)	0.62
Intermediate	12 (27)	33 (26)	
High	22 (49)	72 (56)	
Preference for hearing survival probabilities			
does not want probabilities	20 (91)	4 (8)	**<0.001**
wants probabilities	2 (9)	49 (93)	
Disease characteristics			
TNM stage			
Stage I	15 (26)	81 (51)	**0.002**
Stage II/III	42 (74)	78 (49)	
Grade			
Grade 1	6 (11)	17 (11)	0.97
Grade 2	30 (55)	83 (53)	
Grade 3	19 (35)	57 (36)	
ER status			
ER negative	5 (9)	22 (14)	0.48
ER positive	52 (91)	137 (86)	
Triple negative			
Not triple negative	53 (95)	147 (93)	0.76
Triple negative	3 (5)	12 (8)	

*Numbers do not always add up to column totals due to missing data.
#P-values from χ^2 tests or Fisher's Exact Tests (as appropriate).

Table 2 continued Use of Adjuvant! by patient, disease, consultation and oncologist characteristics (col%)			
	Adjuvant! Online *not* used* N= 57	Adjuvant! Online used* N= 160	P#
Her2neu status			
Negative	46 (84)	138 (87)	0.65
Positive	9 (16)	21 (13)	
Consultation characteristics			
Treatment discussed			
Chemotherapy only	4 (7)	20 (13)	0.11
Endocrine therapy only	10 (18)	13 (8)	
Chemotherapy & endocrine therapy	43 (75)	127 (79)	
Oncologist characteristics			
Gender			
Male	23 (40)	84 (53)	0.13
Female	34 (60)	76 (48)	
Experience treating breast cancer			
Less than 5 years	12 (22)	58 (38)	**0.03**
5-10 years	2 (4)	13 (9)	
More than 10 years	41 (75)	81 (53)	
Type of hospital			
Academic	44 (77)	117 (73)	0.60
General teaching	13 (23)	43 (27)	

*Numbers do not always add up to column totals due to missing data.
#P-values from χ^2 tests or Fisher's Exact Tests (as appropriate).

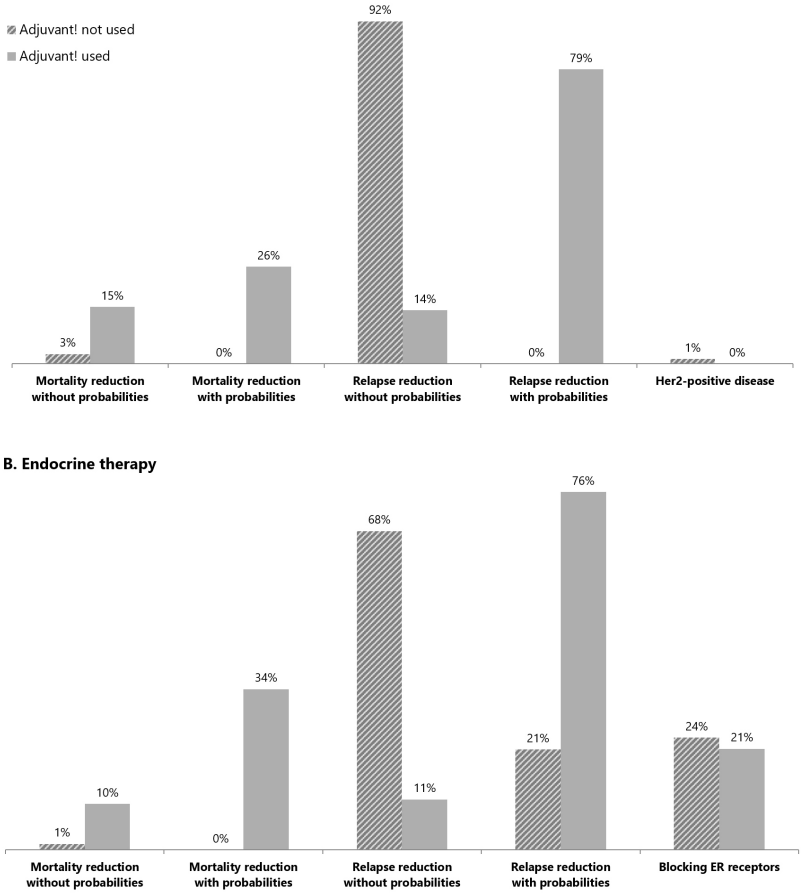
In 173 of the 183 (95%) endocrine therapy consultations, the treatment benefit was discussed. In the remaining 5% patients could only assume a treatment benefit. In 92% of consultations in which endocrine therapy was discussed, relapse reduction was mentioned, and in 26% mortality reduction was (also) mentioned. Mortality reduction was also discussed more often if Adjuvant! was used than if not (P<0.001).

Probabilities regarding benefits were discussed in 189/191 (99%) consultations in which Adjuvant! was used and in 25/92 (27%) consultations in which Adjuvant! was not used. In two consultations Adjuvant! was only used as a '*visual aid*' to indicate that relapse-free or breast cancer-specific survival improved with treatment. On average 4.6 (range: 0-12) probabilities were discussed when Adjuvant! was used, compared to 0.6 (range: 0-5) when Adjuvant! was not used. In 18% (39/214) of all consultations in

which probabilities were discussed (irrespective of Adjuvant! use) we were unable to classify the probabilities communicated. The oncologists' explanation –or lack thereof– made it impossible to determine whether the probabilities mentioned were survival or disease-free survival estimates.

Communication about treatment side-effects

Overall, 59 different chemotherapy and 43 different endocrine therapy side-effects were communicated during the consultations. Of these side-effects 66% (chemotherapy) and 79% (endocrine therapy) respectively were mentioned in fewer than five consultations. In Figures 3 and 4 we provide an overview of the side-effects that were communicated in at least ten consultations. There was no difference in the overall number of side-effects communicated by Adjuvant! use (Adjuvant! used, Md=6.0 (range: 1-13) vs. Adjuvant! not used, Md=6.5 (range: 1-15); P= 0.76). The overall number of side-effects communicated depended mostly on which treatment was discussed. If only chemotherapy was discussed, a median of 7 (range: 1-13) side-effects were mentioned, if only endocrine therapy was discussed a median of 4 (range: 0-9) side-effects were mentioned. If both treatments were discussed, a median of 6 (range: 1-12) chemotherapy and 1 (range: 0-9) endocrine therapy side-effects were discussed.

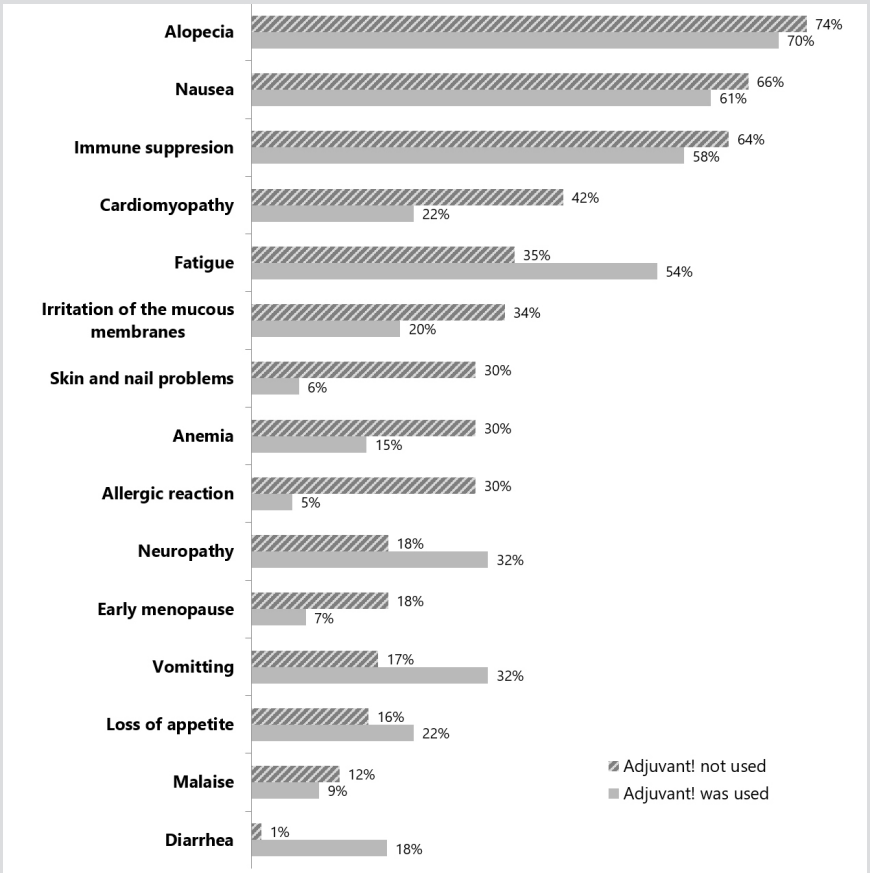


Percentages if Adjuvant! was notused are based on N= 77 chemotherapy and N= 80 endocrine therapy consultations.
Percentages if Adjuvant! was used are based on N= 111 chemotherapy and N= 103 endocrine therapy consultations.

Figure 2 Frequency with which the various treatment benefits are discussed by Adjuvant! use

There also was a wide variation within and between oncologists in the number of side-effects they communicated (Figure 5). The frequency with which specific side-effects were communicated differed by Adjuvant! use (Figures 3 and 4). There was no discernable pattern to the difference in which side-effects were communicated by Adjuvant! use. The comprehensiveness of the description of chemotherapy and endocrine therapy side-effects was basic in the majority of consultations, irrespective

of Adjuvant! use, and consisted only of mentioning the side effect. The probability of developing a side-effect was rarely discussed.



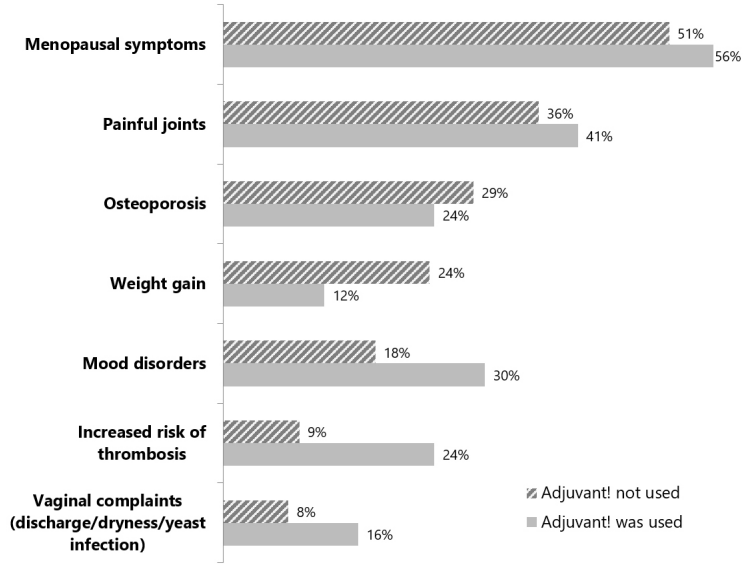
Percentages based on N=77 consultations without Adjuvant! and N=111 consultations with Adjuvant!.
Only side-effects communicated in ≥10 consultations were incorporated in the figure.

Figure 3 Overview of chemotherapy side-effects communicated by Adjuvant! use

RQ4: Association between use of Adjuvant! and decision-making

A decision was made for all treatments discussed in 162 out of 211 (77%) consultations, the decision was postponed in 21 (10%) consultations, and in 26 (12%) consultations a decision was made concerning only one of the treatment options discussed. For two consultations, it was unclear whether or not a decision had been made.

When Adjuvant! was used, decisions were postponed more often (36/118 (31%); Adjuvant! not used= 11/91 (12%); P= 0.005). For chemotherapy, overall the decision was postponed in 39/187 (21%) consultations, and in 30 out of those 39 (70%) consultations, Adjuvant! had been used (P<0.001). Also, in 48/187 (26%) consultations the decision was made to forego chemotherapy, and in 34 (71%) of those 48 consultations Adjuvant! had been used. For endocrine therapy, overall the decision was postponed in 21/178 (12%) consultations, and in 17 (81%) of those 21 consultations Adjuvant! had been used (P= 0.01). Also, in 6/178 (3%) consultations the decision was made to forego endocrine therapy, and in 5 of those 6 consultations Adjuvant! was used.



Percentages based on N=80 consultations without Adjuvant! and N=103 consultations with Adjuvant!.
Only side-effects communicated in ≥10 consultations were incorporated in the figure.

Figure 4 Overview of endocrine therapy side-effects communicated by Adjuvant! use

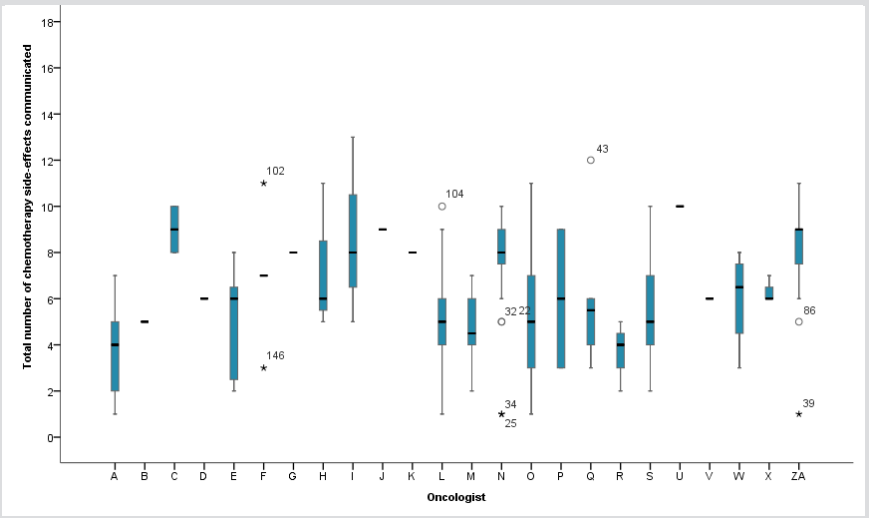
Discussion

In the current study we evaluated the frequency and determinants of use of Adjuvant!. We also assessed information provision about the benefits and side-effects of adjuvant systemic treatment, and whether information provision and the likelihood of reaching a decision during the consultation differed by the use of Adjuvant!.

The oncologists in the current study consulted Adjuvant! prior to 7 out of 10 consultations, and Adjuvant!'s estimates were discussed during 2 out of 3 consultations. This is in line with findings from surveys amongst oncologists about how often they use Adjuvant! (8), and suggests that communicating survival probabilities during consultations with patients is becoming the norm. Less experienced oncologists were more likely to use Adjuvant! both prior to and during consultations. This is likely a generation effect, with younger oncologists being more computer-savvy, but also more open to discussing prognosis than older oncologists. Not surprisingly, the higher the disease stage, the less likely it was that Adjuvant! would be used during the consultation. Oncologists might be hesitant to cause anxiety in patients, to demotivate them for treatment, or cause them to lose hope by communicating modest survival probabilities. Communicating good survival, on the other hand, might be seen by oncologists as a way to comfort and reassure their patients that no matter what they choose to do, their prospects are good. In a recent survey, three out of four oncologists indicated that they used Adjuvant! to convince patients that chemotherapy is not necessary (8), especially so for patients with stage I disease. This could also partly explain why Adjuvant! is used more often when prognosis is better. We found that chemotherapy was waived more often than endocrine therapy, especially if Adjuvant! had been used.

Interestingly, we found that regardless of Adjuvant! use, the reduction in relapse probability was the treatment benefit that oncologists most often discussed (>90%); mortality probabilities were rarely discussed (<5%), although more so if Adjuvant! was used during the consultation. The high frequency of discussing reduction in relapse probability contradicts the findings of an earlier study showing that oncologists valued Adjuvant!'s mortality probabilities more, because they had concerns about the robustness of the relapse estimates (8). Indeed, Adjuvant!'s relapse estimates have been shown to be less sound than its mortality estimates (20-22). Perhaps our oncologists were not aware of this limitation of Adjuvant!, but it seems more likely that they chose to discuss the relapse probabilities because the effect of treatment on relapse is larger than that on mortality. If treatment is an obvious 'best' choice from a medical perspective, such implicit persuasion need not be harmful. However, given that for the majority (>90%) of patients in this study there is no 'best' option, such steering could have unwanted effects (17). Remarkable was that in about one in five consultations we were unable to determine whether the probabilities communicated were overall or disease-free sur-

vival probabilities. Unclear risk communication undermines oncologists' intent to help patients to better understand their prognosis (8). These are disconcerting findings that require further in-depth investigation. If confirmed, it underlines the need for increased attention for risk communication in pre- and post-graduate curricula to provide clinicians with the tools to better convey prognosis to their patients.



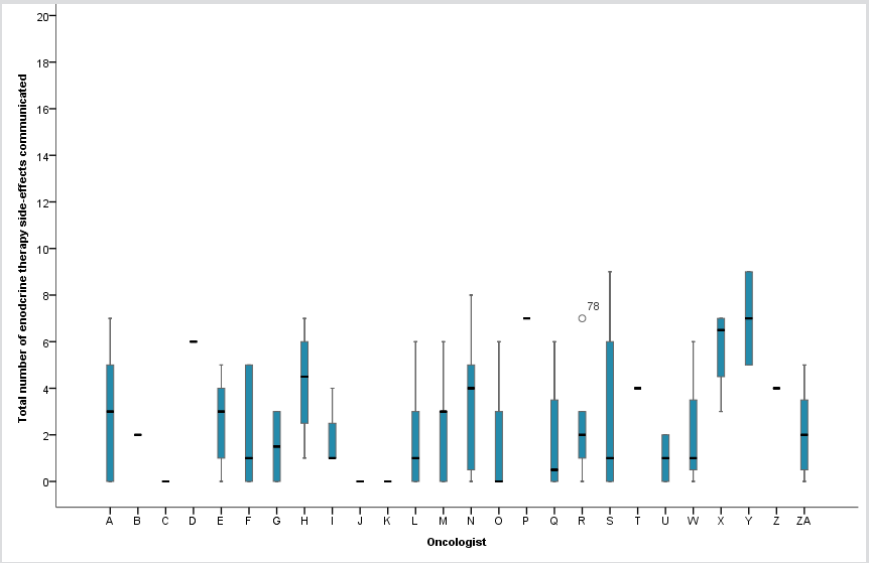


Figure 5 Frequency with which the various treatment benefits are discussed by Adjuvant! use

The use of Adjuvant! does not seem to drive the overall number of side-effects communicated during consultations, but we did find that the specific side-effects communicated varied by Adjuvant! use. One could perhaps think that if Adjuvant! is used to convince patients not to undergo chemotherapy, oncologists might be more inclined to communicate the more severe treatment side-effects, and if the aim is to convince patients about the merits of treatment the more severe side-effects would be omitted. However, such pattern was not identified. No single side-effect of either chemotherapy or endocrine therapy was communicated in all consultations. Apparently, there is no consensus with regards to which side-effects minimally need to be communicated to patients. Indeed, current clinical guidelines do not provide guidance about which side-effects must be communicated (5-7). Moreover, oncologists mostly only *mentioned* the side-effect, without further information on the probability of experiencing the side-effect, its implications for daily life, or its course over time. These findings are worrying, as patients also need to be appropriately informed about what the side-effects of treatment entail to be able to decide whether or not the benefits outweigh the side-effects. In our sample, oncologists regularly indicated that the breast cancer nurse or nurse practitioner would elaborate further on the side-effects (data not shown). This is not a mitigating factor, since in three out of four consultations the treatment decision was made during the consultation. Patients should be informed at that point in time about both the benefits and the side-effects of treatment. Remarkably, in five chemotherapy and nine endocrine therapy consultations, no treatment benefit was explicitly communicated, it had to be inferred. Nonetheless, in all but two of these 14 consultations, it was decided to initiate therapy. If patients are ill-informed about the potential benefits and side-effects their expectations might be unrealistic, which can lead to decisional regret and greater treatment discontinuation rates. For endocrine therapy, high discontinuation rates have been reported (23). Also, patients may receive treatment they might not have chosen had they been able to appropriately weigh side-effects and benefits, in a process of shared decision making.

Interestingly, decision-making was postponed more often when Adjuvant! was used, particularly in patients with stage I disease (data not shown). Perhaps hearing the survival probabilities from Adjuvant! makes patients realize that the treatment benefits are only modest. Patients might therefore need more time to consider whether they feel the benefits outweigh the side-effects.

A limitation of our study is its descriptive nature. Oncologists were not randomized to the use of Adjuvant! and therefore results may have been confounded by specifics of the oncologists or the particular patient. It is important to keep in mind that although we explicitly instructed oncologists to conduct their consultations as they normally would, the study might have influenced their use of Adjuvant!. We therefore asked oncologists in the post-study survey whether their use of Adjuvant! had changed during

the study period. Only two oncologists indicated to have used Adjuvant! more often than before our study.

This is the first study to assess the use of Adjuvant! during real-time patient consultations, its influence on information provision about the benefits and side-effects of treatment, and decision-making. Although Adjuvant! is currently offline due to updates and it is unclear when it will become available again, this study serves as a model for clinical usage of other prediction tools in oncology (e.g., PREDICT(24) or CancerMath(25)). Our findings underscore the importance of obtaining more insights into the use of these tools in clinical practice. Their use during consultations seems to have become commonplace, yet, there is limited knowledge of how well their estimates are communicated, whether patients understand this information, and whether this type of information influences decision-making (26). The findings from this study suggest that there is room for improvement in how probabilities are communicated, as well as in which information about the side-effects of treatment are communicated and how. Adequate information provision is key if oncologists want to enable their patients to participate in decision-making.

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