

Original article

A novel patient decision aid for aftercare in breast cancer patients: A promising tool to reduce costs by individualizing aftercare



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ABSTRACT

Objective: A patient decision aid (PtDA), was developed to support breast cancer patients making choices about their aftercare. The aim of this pilot was to test the effects of the PtDA on Shared Decision Making (SDM), Decision Evaluation (DES) in patients, consultation time, choice of aftercare and hospital costs.

Methods: A prospective before-and-after study including a control (no PtDA-usage) and experimental group (PtDA-usage during consultation) was conducted in six hospitals. Patients were offered a choice between intensive (face-to-face consultations) and less intensive (telephonic or on demand consultations) aftercare. All patients filled out three validated questionnaires (baseline (T0), directly after the consultation (T1), three months later (T2)), assessing demographics (T0), SDM(T1) and DES (T1, T2). Hospital costs and choice of aftercare were assessed from the patients' files (T2). Effect sizes (η^2 : 0.01 = small; 0.06 = medium; 0.14 = large; ϕ : 0.1 = small, 0.3 = medium, 0.5 = large) and p-values were calculated using both univariate and multivariate GLMs, a repeated measures GLM and chi-square-tests. **Results:** A small improvement in SDM ($\eta^2 = 0.02$) and an effect ($\eta^2 = 0.10$) on DES was found in the experimental group. Significantly more PtDA-users (51% vs. 29%, $\phi = 0.22$) chose less intensive aftercare, leading to a small reduction of hospital costs (122 vs. 92 Euro, $\eta^2 = 0.01$), and a large increase in average consultation time (12.5 min; $\eta^2 = 0.29$).

Conclusion: This pilot study showed promising effects of the PtDA on SDM and hospital costs. The PtDA can be developed further to potentially reduce the increased consultation time.

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Background

Breast cancer is the most prevalent type of cancer among women in the Netherlands; a ten year calculation was 131,563 cases in 2016 [1]. Due to improved screening methods and treatment, a growing number of patients have survived [2]. Consequently, the number of patients requiring follow-up and aftercare [3] after

primary treatment is increasing.

Since 2012, Dutch treatment guidelines [4] advise health professionals (HPs) to offer patients annual follow-up with mammography, to monitor for recurrences [5]. Also, aftercare during that period, to help patients cope with psychosocial consequences of the disease, its treatment and side-effects is recommended. The aftercare content is however not specified, which leaves room for personalized care. Previous research has shown that less intensive aftercare options are a cost-effective alternative to traditional, face-to-face consultations and can be offered to create more options for patients [6,7]. Simulations show that incorporating individual patient preferences regarding aftercare

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would increase patient satisfaction, which is the main objective of the PtDA, and lower hospital costs [8,9]. As the majority of breast cancer patients want to engage in their own health decisions [10], incorporating patient preferences in aftercare is desirable from both an ethical and cost perspective.

Patient Decision Aids (PtDAs) are tools to help patients choose healthcare options based on an assessment of their preferences [11]. PtDAs are used to support an active role for the patients in the decision-making process [12], and have been shown to improve shared decision making (SDM) [12–14], by improving knowledge of available options, higher patient satisfaction, more patient involvement in decision-making and a stronger sense of control [15–17]. Patient preferences regarding health care characteristics are often assessed using a Value Clarification Method (VCM) (e.g. preferred frequency, setting or health professional involved) [18]. These preferences are then matched to treatment options available in the facility. However, no PtDA is currently available for any patient group making choices about their aftercare.

PtDAs commonly identify individual preferences in an analytical matter only, often by means of weighing characteristics of the options [18]. However, individuals also make use of intuitive processes to make healthcare decisions [18] and adding this intuitive component to a PtDA is thought to positively influence the effectiveness [18].

Therefore, we developed a PtDA for breast cancer patients to support them in making decisions about their personal aftercare trajectory, combining both analytical and intuitive preference identification exercises. The aim of the current study was to test the PtDA's effect on patient-perceived SDM, patient decision evaluation (choice satisfaction-uncertainty, choice information and choice control) [19], aftercare choice and hospital costs in a pilot test with a control group. Based on previous research [6–9], it was expected that using the PtDA during a consultation would increase consultation time but lower hospital care costs, due to a proportion of patients opting for less intensive aftercare. Furthermore, use of the PtDA was expected to result in more patient perceived SDM and more positive decision evaluation.

Patients and methods

Development of the PtDA

The PtDA was developed using IPDAS guidelines [20,21], a format used to standardize the development process (see appendix B for a description on how the IPDAS criteria were used to develop the PtDA). To inform the content and design of the PtDA, three focus groups with eleven patients and seven individual interviews with health professionals (HPs) were conducted [22]. The resulting digital PtDA (appendix A), consisted of four consecutive sections:

Introduction and generic information

This section contained information on late side-effects of primary treatment (surgery, radiotherapy, chemotherapy, immunotherapy and/or hormonal therapy) [23], since this information may influence preferences and subsequent aftercare decisions. Additionally, patients were informed of the follow-up as prescribed in the national guidelines (i.e. yearly mammography) and of the fact that choosing any of the aftercare options would not influence their survival rate [5,24,25]. It was emphasized that the PtDA solely focused on aftercare, whereas follow-up is standard for all patients.

Assessment of preferences and values

Patients stated their preference regarding nine related aftercare characteristics, derived from preliminary studies [22], by clicking on one of two options. For instance having their aftercare

consultation with either a nurse or medical specialist or starting aftercare right away or delayed. Thereafter, patients indicated the importance of each characteristic (1 = unimportant, 10 = highly important). Finally, patients identified and ranked their five most important characteristics.

Presentation of available aftercare options and intuitive preference assessment

All available aftercare options were presented. Hospitals offered at least two options; one intensive (scheduled consultations in the hospital) and one less intensive option (scheduled telephonic consultations and/or consultations in the hospital on demand). After reading the outline of the options, patients indicated their first intuitive reaction to them as positive, neutral or negative.

Overview of the (mis)match between aftercare options and individual preferences

Data on patient's preferences and intuitive response was combined into an overview resembling an option grid [26]. Option characteristics that matched the patient's intuitive response or preferences were highlighted on the grid (appendix A). Patients were encouraged to discuss the overview with their healthcare professional (HP) to make a decision.

Study design

A before-and-after design was applied; 50 patients recruited across six hospitals between June and August 2015 were assigned to the control group; 50 patients recruited between September 2015 and March 2016 to the experimental group. This design was chosen to prevent contamination between the study arms as the same nurses were involved in both the control and experimental group consultation. Also, the before-and-after design allowed final adjustments to the PtDA to be made and pretesting parallel to inclusion of patients in the before arm (i.e. control arm) of the study, which was an effective approach for this pilot study.

Identical aftercare options and the aftercare decision consultations were offered to all patients; however, only patients in the experimental group used the PtDA. Due to the explorative nature of this pilot study, no power calculation has been done. This study was approved by the Medical Ethics Committee of the University Hospital in Maastricht (MEC 14-4-203) and registered in the Dutch Trial Registry (NTR5884).

Procedures and endpoints

A flowchart of the procedure is depicted in Fig. 1. Eligible breast cancer patients had to be female, > 18 years of age, fluent in Dutch and their primary treatment had to be completed. After recruitment by their HP following primary treatment, an information letter, consent form, and the baseline questionnaire (T0) were sent to the patient's home address with a return envelope. All outcomes with their time of measurement are shown in Table 1. The baseline questionnaire measured patient demographics in terms of age (in years), educational level patients indicated their highest education with specific categories (e.g. primary school, high school degree, college degree, university degree, etcetera) which were later combined into broader categories (1 = low, 2 = medium, 3 = high) and income (1 = low, 2 = medium, 3 = high) deducted from the patient's answers to more specific categories (e.g. 850–1150, <850 etc.). Patients in the experimental group received written PtDA instructions. Participation was voluntary and no monetary incentive was offered.

In order to make a decision with their HP, all patients attended a consultation with their HP < 3 months after completing primary

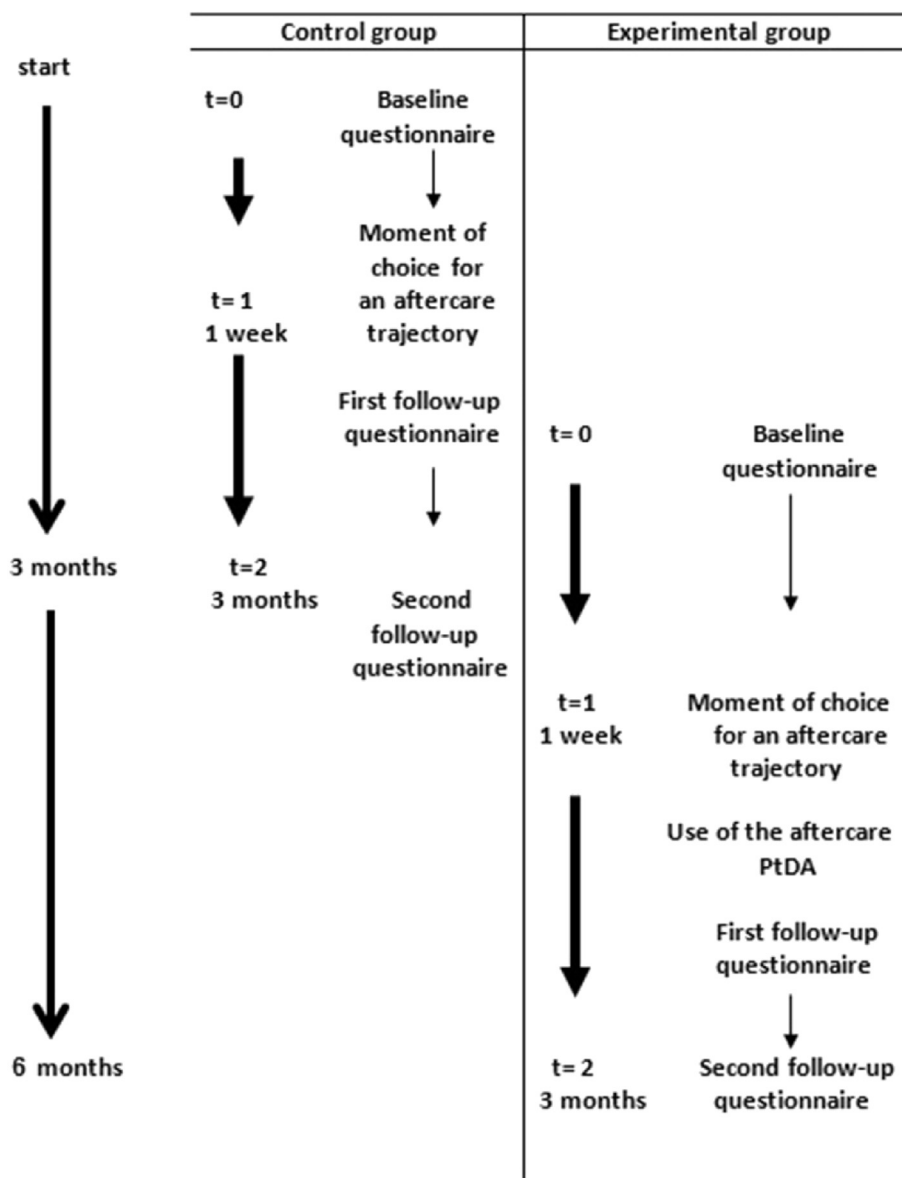


Fig. 1. Flowchart of the control and experimental group in the comparative study.

Table 1
Outcome measures and time of measurement.

Outcome measure	Time of measurement	T0	T1	T2
Patient characteristics	✓			
SDM-Q-9			✓	
DES			✓	✓
Choice of aftercare			✓	
Consultation time			✓	
Hospital costs				✓

T0 = one week before the consultation. T1 = directly after the consultation. T2 = three months after the consultation. DES = Decision Evaluation Scales, SDM-Q-9 = Shared Decision Making Questionnaire.

treatment and were offered the available aftercare options. Patients in the experimental group additionally used the PtDA during the consultation.

Directly after the consultation (T1), patients filled out the second questionnaire, which measured patient-perceived SDM using the validated questionnaire SDM-Q-9 [27]. Also, it contained

decision evaluation with the validated questionnaire decision evaluation scales (DES) (three subscales: satisfaction-uncertainty, choice information and choice control) [19]. Satisfaction-uncertainty measures a kind of decisional conflict, choice information measures the extent to which the patients are informed about the different options they are presented with and choice control measures the extent to which the patients feel they can exercise control over the decision they are faced with. HPs filled out a Case Report form (CRF) for each consultation to record the patient's primary treatment and length of the consultation (in minutes).

At three months after the consultation (T2), patients filled out the DES. In addition, breast cancer related hospital care (e.g. consultations or imaging) that patients had received over the previous three months, and choice of aftercare (intensive = 1 (face-to-face consultations in the hospital) or less intensive = 2 (telephonic consultations or on demand face-to-face consultations)), were extracted from medical records.

Hospital costs were calculated by multiplying hospital resource use with prices referenced from 2014 obtained from the Dutch

governmental manual for healthcare cost analysis [28]. Prices for telephonic consultations were not included in the manual. These were calculated by using the prices of telephonic consultations referenced in the article by Kimman, Dirksen et al. [7] and using the factor given in the governmental manual to bring the prices to the 2014 level.

Analysis

To analyse the data, SPSS version 23 was used. To test for potential confounding variables, differences in characteristics between the control and the experimental group were tested using t-tests and chi-square tests. Differences in SDM-Q-9 scores were tested using a univariate ANOVA. The data was logarithmically transformed, since they were negatively skewed. To compare scores on the subscales of DES (choice satisfaction-uncertainty, choice information and choice control) at T1 and T2 between the two groups multivariate General Linear Models (GLMs) and a repeated measures GLM was used. Missing values on the DES-subscales were imputed using linear regression and the GLM tests were repeated as a sensitivity analysis. To measure the effect of the PtDA on chosen aftercare, a chi-square test was performed. A t-test was used on the effect of the PtDA on consultation time. Univariate ANOVAs were performed to compare hospital costs between groups using bootstrapping with 1000 simulations.

Since effect sizes are less influenced by sample size effects than significance levels [29] and a relatively small sample was used in this pilot test, effect sizes (η_p^2) (0.01 = small; 0.06 = medium; 0.14 = large) [30] were calculated for all the analyses using SPSS version 23. Phi (ϕ) was used for the Chi-square test as effect size (0.1 = small, 0.3 = medium, 0.5 = large) [31]. Additionally, p-values are reported and deemed statistically significant if $p < .05$.

Results

Sample

No significant differences in baseline patient characteristics as age, educational level, income level or type of primary treatment were found between the groups (Table 2). Therefore, no confounding variables needed to be included in the analyses. The average age of the participants for the two groups was between 58 and 60 years and the most common primary treatments in both groups were surgery or surgery with radiotherapy but without systemic therapy.

Table 2

Baseline patient characteristics. No significant differences were found between the groups for any of the characteristics.

Characteristic	Control group (N = 44)	Experimental group (N = 43)	p-value
Age (years), mean (SD)	59.7 (8.6)	58.4 (11.0)	.55
Educational level, % (n)			
Low	40.9% (18)	30.2% (13)	.52
Medium	29.5% (13)	39.5% (17)	
High	29.5% (13)	30.2% (13)	
Income level, % (n)			
Low	13.6% (6)	14.0% (6)	.99
Medium	43.2% (19)	41.9% (18)	
High	20.5% (9)	20.9% (9)	
Undisclosed	22.7% (10)	23.3% (10)	
Primary treatment	N = 44	N = 37	
Surgery only (n (%))	16 (36.4%)	10 (27.0%)	.84
Surgery with radiotherapy without Systemic therapy (n (%))	16 (36.4%)	16 (43.2%)	
Surgery with systemic therapy without radiotherapy (n (%))	3 (6.8%)	3 (8.1%)	
Surgery with radiotherapy and systemic therapy (n (%))	9 (20.5%)	8 (21.6%)	

The effects of the PtDA

Somewhat higher scores on the SDM-Q-9 (Table 3) for patients in the experimental group were found with a small non-significant effect. On DES lower average scores were found for both groups on all subscales at T2 compared to those measured at T1 with a small to moderate (but not significant) effect between the two groups on this difference in scores. No significant effect on average scores on the subscales of DES between the two groups at T1 was seen, however a moderate to large (and significant) effect was found at T2 (Table 4). The same effects were observed when analyses were repeated after missing values were imputed.

A significantly larger percentage of patients in the experimental group (51%) chose less intensive aftercare than those in the control group (29%) (Table 4). However, application of the PtDA also lengthened consultation time significantly, by 12.5 min on average (the difference in consultation length between the control and the experimental group) (Table 3).

A small effect (not significant) was seen on hospital costs (Tables 5 and 6) with slightly lower costs for the experimental group. Limiting the analyses to the subgroup of patients who chose less intensive aftercare, lower costs in the experimental group were found with a medium effect (not significant). Limiting the analyses to the subgroup of patients who chose intensive aftercare, no significant effects on hospital costs were seen.

Discussion

Discussion: implications of the aftercare PtDA

This is the first study presenting the evaluation of a PtDA for aftercare for curatively treated breast cancer patients. Although most effects were small and non-significant, this pilot study does suggest a small improvement in SDM. In addition, the results showed significantly more patients choosing less intensive aftercare after using the PtDA. However, the resulting small reduction in hospital costs was counterbalanced by an increased consultation time with PtDA-usage during the consultation.

Based on previous research indicating that PtDAs can increase patient involvement [10,32], it was expected that use of the PtDA would increase SDM. Indeed some increase in perceived SDM was found, but the effect size was small. After using the PtDA, five patients were interviewed about the PtDA and the PtDA was discussed with the HPs involved in the study during a group meeting and in individual interviews. Patients indicated they felt included in the decision making process due to PtDA-usage. HPs mentioned that

Table 3

Effects of the PtDA on choice of aftercare option, SDM-Q-9 scores and consultation time all measured at T1 immediately after consultation.

	Control group	Experimental group	Test-value	Effect size	p-value
Choice of aftercare option: percentage of patients choosing less intensive aftercare (telephonic consultations or on demand consultations)	29%	51%	$\chi^2 = 4.67$	$\phi = .22$.04
SDM-Q-9 total scores (Mean (SD))	45 (10.70)	48 (5.88)	F = 1.04	$\eta_p^2 = -.02$.31
Consultation time in minutes (Mean (SD))	29.8 (7.72)	42.3 (12.13)	F = 29.93	$\eta_p^2 = .29$.00

Scores on the SDM-Q-9 range from 1 to 6 on each question. The total score range is thus 9–54, with 54 as the best score, and 9 as the poorest score.

Table 4

Scores on the decision evaluation scales measured at T1 (directly after consultation) and T2 (three months after the consultation).

Scores on the subscales of the decision evaluation scales	Control group (N = 38)	Experimental group (N = 33)	F	Effect Size η_p^2	p-value
Satisfaction – Uncertainty at T1 (Mean(SD))	4.24 (.76)	4.41 (.54)	1.22	.02	.27
Satisfaction – Uncertainty at T2 (Mean(SD))	3.66 (.22)	3.60 (.43)	.72	.01	.40
Choice Information at T1 (Mean(SD))	4.30 (.64)	4.32 (.60)	.05	.00	.83
Choice Information at T2 (Mean(SD))	3.29 (.35)	3.45 (.49)	2.61	.04	.11
Choice Control at T1	4.65 (.56)	4.62 (.50)	.03	.00	.86
Choice Control at T2	1.75 (.64)	2.37 (1.16)	8.07	.10	.01

Scores on all subscales of the DES range from 1–5, with 5 representing the best score and 1 representing the poorest score. The results of the repeated measures GLM for the control group (N=36) and the experimental group (N=29) was: F=2.63; $\eta_p^2 = 0.04$; p = .11. No between subject effect was found with the repeated measures GLM (F=2.34; $\eta_p^2 = 0.03$; p = .13).**Table 5**

Results of the analysis of hospital costs during the first 3 months of aftercare.

Costs in €	Mean (SD) Control group	Mean (SD) Experimental group	F	Effect size η_p^2	p-value	Bootstrapping 95% confidence interval control group Lower - Upper	Bootstrapping 95% confidence interval experimental group Lower - Upper
Total	122.72 (149.01) N = 37	92.13 (160.09) N = 44	.78	.01	.38	79.19–169.21	49.70–145.40
Less intensive aftercare	124.39 (181.41) N = 11	52.41 (100.58) N = 22	2.18	.07	.15	36.24–250.51	14.40–98.08
Intensive aftercare	122.01 (137.14) N = 26	131.85 (179.62) N = 22	.04	.00	.84	70.66–173.42	58.51–225.75

Less intensive aftercare: telephonic or on demand; intensive: face to face. Hospital costs are cost from care used by patients during the first three months after the aftercare consultation. Costs for the development of the PtDA or the extra cost from using the PtDA during the consultation are not taken into account.

Table 6

Hospital costs used in the control and experimental group by patients that opted for intensive aftercare or less intensive aftercare.

	Control group (n = 37)				Experimental group (n = 44)			
	Intensive aftercare (n = 26)		Less intensive aftercare (n = 11)		Intensive aftercare (n = 22)		Less intensive aftercare (n = 22)	
Units of resource use and cost prices:	Number of times used by patients	Mean costs (€)	Number of times used by patients	Mean costs (€)	Number of times used by patients	Mean costs (€)	Number of times used by patients	Mean costs (€)
Face-to-face consultation (€91 per consultation)	26	91.00	11	91.00	18	74.45	10	41.36
Telephonic consultation (€23,93 per consultation)	6	5.52	4	8.70	4	4.35	1	1.09
Blood tests (€10,61 per ordered test)	1	0.41	1	0.96	0	0	0	0
Imaging (€87 per mammography)	3	10.03	3	23.73	7	27.68	1	3.95
Hospitalisation (€476 per day)	0	0	0	0	0	0	0	0
Physiotherapy (€33 per session)	4	1.27	0	0	11	16.50	3	4.50
Social work (€65 per session)	0	0	0	0	3	8.86	0	0
Emergency room (€259 per visit)	1	9.96	0	0	0	0	0	0
Total Mean costs (€)		118.19		124.39		131.84		50.9

they thought patients to be more involved in consultations where the PtDA was used. These oral evaluations (anecdotal reports) support an effect of the PtDA on SDM. But further research on this point is necessary.

Furthermore, although PtDA-usage did not have an effect on choice control (one of the subscales of DES) immediately after the consultation, three months afterwards it seems to have led to a higher sense of choice control. Presumably, because the PtDA

increases patient involvement as does providing options without PtDA-usage; however the PtDA-effect lingers for a larger amount of time showing a significantly higher score after three months.

As theorized beforehand, a larger percentage of patients in the experimental group chose less intensive aftercare, which was a significant difference even in this pilot study. It was reasoned that patients who are informed on the absent value of aftercare concerning survival, would be encouraged to choose less intensive

aftercare [16,17]. However, no effect was found on choice information. Choice information is a subscale of DES and measures the extent to which the patient felt informed about their options. This absence of effect may be caused by the fact that this subscale was developed to test treatment-focused PtDAs, whereas we used it for an aftercare PtDA. However, no other scale is currently available specifically for aftercare PtDAs. Aftercare choices can be altered later on, unlike most treatment choices; i.e. surgery cannot be undone. For an aftercare choice a match between the patient's preferences and the choice is important. The choice can change over time, for example due to changes in a patient's personal circumstances or health state, a patient's preference for (characteristics of) aftercare, is not expected to change over time [33]. Preference stability could therefore be a better measure to comment on the effectiveness of the PtDA. However, the follow-up period of three months was too short to assess preference stability during the first year after treatment for which this PtDA was developed. Moreover, the absence of an effect can potentially be caused by the influence of the HP, seen as the choice was made during a consultation with the HP using SDM. However, the same HPs were involved in testing the control group patients as the experimental group patients; therefore the influence of the HP on choice information in the two groups is likely limited.

Total hospital costs were slightly lower in the experimental group, with a medium effect on hospital costs for less intensive aftercare in the experimental group compared to the control group.

Choosing less intensive aftercare after using the PtDA seems to lead to lower hospital costs. This was however counterbalanced by an increase in consultation time. In the current study the PtDA was used during the consultation as patients preferred this in our unpublished preliminary study. However, other PtDAs were offered pre-consultation did not generate any negative patient evaluations [34–36]. Offering the current PtDA before the consultation may therefore decrease consultation time and subsequently show a more favourable impact on costs.

Strengths and limitations

A strength of the current study is that a control and experimental group were included. Although recruited in succession, both groups were comparable concerning patient characteristics measured. Furthermore, the PtDA included both analytical and intuitive preference assessment, which has only been applied in a handful of PtDAs [18].

A limitation is that a follow-up period of three months was rather short. Especially to make inferences about preference stability and hospital cost for the traditional aftercare consisted of consultations once every three months. Still this follow-up period gave us an indication of the hospital costs made by patients after primary treatment is finished.

Another limitation is that the sample size was relatively small; however for a pilot study the sample size was considerably large. Because of the small sample size with analysing the results the main focus was put on effect sizes rather than significance levels, although these were reported as well, as effect sizes are less sensitive when small samples are used.

Conclusion and further research

The pilot study of the first aftercare PtDA showed promising effects on shared decision making, choice evaluation, aftercare choice and costs. However, the small reduction in hospital costs was counterbalanced by a significant increase in consultation time. Therefore, when implementing the PtDA in the clinic, making the PtDA available before the consultation can potentially compensate

for that use of time. As the results of the PtDA will still be discussed during the consultation the interaction between HP and patient will remain considerable. Further research to assess how this change in PtDA-usage will affect the consultation is warranted. Moreover, further barriers and facilitators to adopt the PtDA into clinical practice are currently assessed.

Declarations of interest

None.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.breast.2018.06.015>.

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