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Follow-up after treatment for breast cancer: One strategy fits all? An investigation of patient preferences using a discrete choice experiment

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Abstract

Clinical guidelines for the follow-up after breast cancer recommend frequent outpatient clinic visits to be examined for a possible recurrence or a second primary breast tumour, and to receive information and psychosocial support. However, needs and preferences for follow-up may differ between patients, raising the question whether the current 'one size fits all' approach is appropriate. This study explored patients' preferences for follow-up. *Patients and methods.* A discrete choice experiment survey with 16 choice tasks was filled out by 331 breast cancer patients. Each choice task consisted of two hypothetical follow-up scenarios for the first year after treatment, described by levels of the following characteristics; attendance at an educational group programme, frequency of visits, waiting time, contact mode, and type of healthcare provider. *Results.* The healthcare provider and contact mode were the most important characteristics of follow-up to patients. The medical specialist was the most preferred to perform the follow-up, but a combination of the medical specialist and breast care nurse alternating was also acceptable to patients. Face-to-face contact was strongly preferred to telephone contact. Follow-up visits every three months were preferred over visits every four, six, or 12 months. Heterogeneity in preference between patients was strong, especially for the healthcare provider and attendance at an educational group programme. Age, education, and previous experience with follow-up characteristics influenced preferences, but treatment modality did not. *Conclusion.* The results of this study show that overall patient satisfaction would not differ significantly if patients have follow-up by medical specialist and breast care nurse alternating compared to follow-up by a medical specialist only. Furthermore, we found heterogeneity in preferences for most attributes, indicating that one strategy does not fit all. Individualised follow-up seems to offer the potential for significant increases in patient satisfaction.

Clinical guidelines for follow-up after curative treatment for breast cancer recommend that women attend frequent follow-up clinic visits, to be examined for possible local or regional recurrence or a second primary breast tumour, and to receive information and psychosocial support [1]. However, clinical outcomes are not affected by frequency, intensity, and type of follow-up [2–5], and there is doubt whether short outpatient clinic visits are appropriate to provide psychosocial support [6,7]. Hence, a more individualised follow-up, in which patient preferences are taken into account, is being proposed [8]. Particularly in the first year after treatment, when scheduled follow-up visits are most frequent, a shared decision making process and more flexible follow-up may increase patient satisfaction, adherence to the strategy, and ultimately quality of life [9].

Several studies have investigated patient preferences regarding breast cancer follow-up using cross-sectional surveys [10–12]. De Bock and colleagues

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analysed the needs of women who participated in a routine follow-up programme (n=116). More than half of the patients preferred lifetime follow-up, twice a year, performed by the medical specialist. Furthermore, younger age was related to a greater need for information during follow-up [10]. Montgomery and colleagues found that women (n=79) expected some form of follow-up, but there was no consistency regarding the frequency [11]. Renton and colleagues concluded that, although women were generally satisfied with current hospital follow-up, they would accept changes. Results of the study suggest that if services were reorganised, women would prefer involvement of specialist nurses in follow-up to that of their general practitioner [12]. Hence, women do expect to receive some form of follow-up after breast cancer, but preferences for patient education, length, frequency, and provider of follow-up can vary considerably.

Additionally, results from several clinical trials show that patients who have experienced alternative follow-up strategies, e.g. by a breast care nurse [5], by a general practitioner [4], less frequent follow-up [13], or follow-up by telephone [14] were equally satisfied as patients who received traditional hospital follow-up.

This paper deals with womens' preferences for the follow-up after breast cancer treatment, including most alternative strategies that have been proposed in the literature, using a discrete choice experiment (DCE). A DCE is a survey methodology capable of establishing preferences, which is grounded in economic theory [15,16], and has an advantage over traditional satisfaction questionnaires, in that it enables the researcher to measure strength of preferences for different characteristics of follow-up and the trade-offs made between them. DCEs are found to be a valid and reliable approach to elicit preferences in a health care context [17] and are recognised as a useful tool for medical decision making [18,19].

In a DCE respondents are asked to choose the preferred alternative from a set of two or more hypothetical scenarios. The scenarios are described by key characteristics ('attributes') of follow-up, such as the healthcare provider. The respondents' evaluation of a scenario depends on the levels of the attributes (for example, a nurse, medical specialist, or general practitioner). The relative importance of attributes and levels to respondents, and the trade-offs made between them, can be assessed by asking respondents to make choices in multiple scenarios with different levels of attributes. A detailed explanation of the methodology applied in healthcare has been described by Lanscar and Louviere [19], and Ryan and Gerard [18].

To our knowledge, this is the first study that aims to measure the strength of preferences for several characteristics of breast cancer follow-up using a discrete choice experiment. We also explore the variety in patient preferences (i.e. 'preference heterogeneity') which ultimately allows us to explore optimal ways of providing individual-level follow-up to patients.

Patients and methods

Patients

This study was performed among Dutch breast cancer patients who finished curative treatment between June 2006 and December 2007. Data collection took place between May and July 2008. Of 557 eligible patients from five participating hospitals, 359 agreed to participate and subsequently received a survey with the discrete choice experiment. Completed surveys from 331 patients were used for the analysis (response rate of 59%). Respondents' characteristics can be found in Table I. The average age was 58 years (range 34 to 83) and the mean time since finalising breast cancer treatment was 14 months (range 4 to 24 months). The study was approved by the Medical Ethical Committee of the Maastricht University Medical Centre.

Table I. Characteristics of the 331 respondents of the discrete choice experiment.

Category	No. respondents (%)
Age	
< 60 year	145 (43.8)
≥ 60 year	186 (56.2)
Living with a partner	
Living alone or single parent	79 (23.9)
Living with partner (and children)	247 (74.6)
Other	5 (1.5)
Education	
No education, primary school, lower education	111 (33.5)
Secondary education	134 (40.5)
Higher education	86 (25.0)
Treatment modality	
Surgery	48 (14.5)
Surgery and radiotherapy	128 (38.7)
Surgery and chemotherapy	58 (17.5)
Surgery and radiotherapy and chemotherapy	96 (29.0)
Unknown	1 (0.3)
Hormonal therapy	
Yes	126 (38.1)
No	204 (61.6)
Unknown	1 (0.3)
Experience with follow-up	
Follow-up by a breast care nurse	37 (11.2)
Follow-up by a medical specialist	220 (66.5)
Combination of breast care nurse and medical specialist	74 (22.3)
Participation in educational group programme	27 (8.2)
Experience with telephone follow-up	24 (7.3)

Methods

A discrete choice experiment survey was used. The survey comprised two sections: the DCE (16 hypothetical choice tasks) and a section with questions regarding background information of the respondent.

A crucial stage of DCE design is the identification of the key characteristics (attributes) that describe the scenarios in the choice tasks, and their levels [19,20]. The choice of these attributes and levels was based on a review of the literature [21], local policy initiatives [22], and expert opinion. Attributes were included if they represented common current practice in follow-up or relevant potential initiatives. Table II provides the attributes and levels used in the choice tasks.

The combination of attributes and levels in this study resulted in ($4^3 \times 2^2 =$) 256 possible scenarios (a 'full factorial design'). Since presenting all 256 scenarios to respondents would be too burdensome, only a subset of the scenarios, a fractional factorial design, was used. With a 32-profile fractional factorial design we were able to estimate main effects and two-way interactions between contact mode and all other attributes. Subsequently, to construct choice tasks, a fold-over of the design was created. A fold-over takes the original design, shifts the attribute levels (e.g. medical specialist becomes breast care nurse, every three months becomes every four months, etc), and adds this fold-over design as extra scenarios to the original design, creating choice tasks. The design ensured orthogonality (the absence of multicollinearity between attributes) and was balanced in terms of the number of times each level of an attribute was seen [23]. A maximum of 16 choice tasks per respondents was considered feasible, hence two surveys each with 16 choice tasks were created by blocking the design. This means that each respondent faces only a subset of choice situations from the fractional factorial design. Blocks were determined based on an additional orthogonal column to the design with two levels. Respondents were randomly assigned to one of the two blocks. An example of a choice task is shown in Figure 1.

The survey started with a short introduction on why the study was performed and an outline

Table II. Attributes and levels of the discrete choice experiment.

Attributes	Levels	Explanations	A priori expectations
Attendance at educational group programme	• Yes • No[a]	The educational group programme consists of two group meetings of two hours, led by a breast care nurse and healthcare psychologist, in which patients (and their partners) are informed of the physical and psychosocial consequences of the disease and its treatment, and possible signs of recurrence.	No a priori expectations about the direction of preferences.
Frequency of visits	• Every 3 months • Every 4 months • Every 6 months • Every 12 months	The frequency of visits determines whether a patient has scheduled follow-up visits every 3, 4, 6, or 12 months. Regardless of the frequency, patients can always make additional appointments whenever they feel the need.	In general, a positive preference for an increase in frequency is expected.
Waiting time in minutes	• 5 • 30 • 60 • 90	This is the time a patient has to wait after the set time of the appointment. This can thus be at the hospital or general practitioner's office (face-to-face contact) or at home (telephone contact).	In general, a negative preference for an increase in waiting time is expected.
Contact mode	• Face-to-face[a] • Telephone	A visit (face-to-face) to a healthcare provider consists of a short physical examination and open discussion about general wellbeing and the recovery process. A telephone follow-up consists of an open discussion about general wellbeing and the recovery process only. If the patient or healthcare provider feels the need, an additional appointment (face-to-face) can be made.	In general, a negative preference for telephone contact compared to face-to-face contact is expected.
Healthcare provider	• Medical specialist[a] • Breast care nurse/nurse practitioner • General practitioner • Breast care nurse and medical specialist	The medical specialist is (preferably) the patient's surgeon, oncologist or radiotherapist. They may alternate. The breast care nurse is a nurse specialised in breast cancer; a nurse practitioner is a nurse with advanced medical training (master's level). They are both referred to as breast care nurse in the survey.	In general, a positive preference for medical specialist compared to the other healthcare providers is expected.

[a]Reference group in modelling

of the purpose and effectiveness of follow-up after breast cancer. A comprehensive description of each attribute and its level to clarify their meaning and implications to respondents followed. Importantly, every choice task started with information on the effectiveness of follow-up, the annual mammography, and the possibility to make additional appointments (see Figure 1). To be able to investigate whether patients preferred what they themselves had experienced [24], respondents were asked to describe the follow-up strategy they had received in their first year after treatment. Additionally, background information on education level, living with a partner or alone, and received treatment modality was retrieved.

The survey was pilot tested (n=10) to check for any problems in interpretation and face validity, which led to minor changes to the text and layout.

Establishing preferences

All eligible patients were contacted by telephone by independent employees of the Centre for Data and Information Management of the Maastricht University to ask for participation. When informed consent was obtained, respondents received the postal survey. Respondents were asked to fill out the survey at home. Contact details of the researcher were given for any questions or clarification. At a later time, answers to the completed survey were collected by telephone and entered into a database. NLOGIT 3.0 software package (Econometric Software Inc.) was used to analyse the data.

Random parameter logit (RPL) modelling was used to estimate a choice model and specify a utility function [25,26]. All probabilistic choice models are characterised by the following equation:

$$U_{in} = V_{in} + \varepsilon_{in,}$$

where $V_{in} = g_n(X_i)$ is the systematic utility component that depends on the attributes of the alternative (X_i) and the individual's specific tastes, and ε_{in} is an error component. Assuming that a respondent can choose between two alternatives, i and j, then the probability that alternative i is chosen is given by:

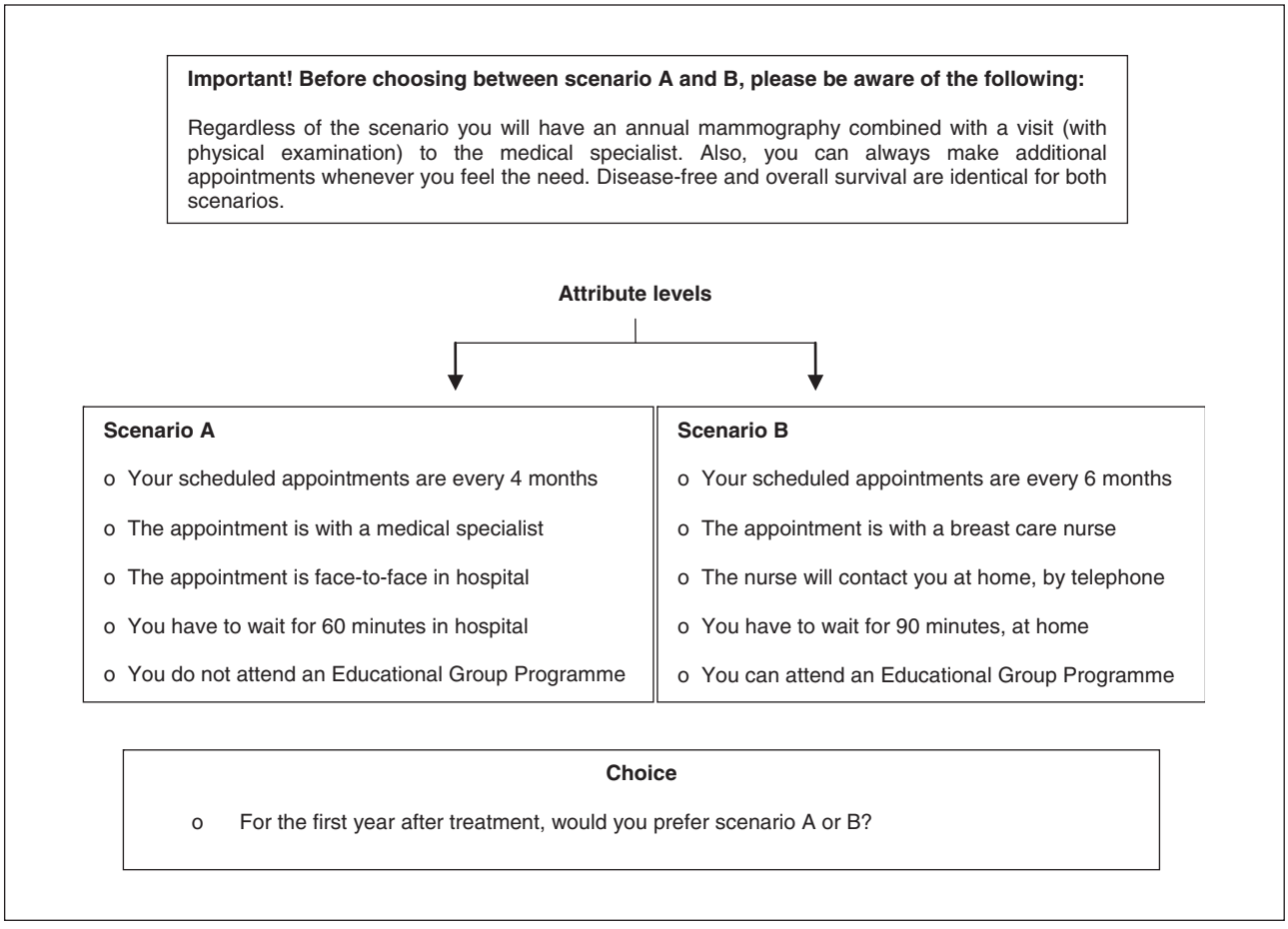

Figure 1. Structure of a discrete choice task. Scenarios varied systematically over 32 choice tasks.

$$P_{in} = \text{Prob}(U_{in} > U_{jn}) = \text{Prob}(V_{in} + \varepsilon_{in} > V_{jn} + \varepsilon_{jn}) = \text{Prob}(V_{in} - V_{jn} > \varepsilon_{jn} - \varepsilon_{in}) \text{ if i is not equal to j.}$$

This generates the well known standard logit specification if the error terms are assumed to follow independent and identical Gumbel distributions:

$$P_{in} = \exp(V_{in})/(\exp(V_{in}) + \exp(V_{jn}))$$

In the random parameters logit model the systematic utility component is expressed as a function of the alternative's attributes and an individual specific vector of preference parameters as follows:

$$V_{in} = \beta_n'X_i \text{ with } \beta_n = (\beta + v_n),$$

where β constitutes the vector of average preferences of the population for each attribute and v_n the individual's specific preference components which take on a normal distribution.

Our utility function was of the following form:

$$\begin{aligned} U_{ijt} = {} & \beta 0 + v_{0i} + (\beta 1 + v_{1i})^{*}\text{Educational group programme}_j \\ & + (\beta 2 + v_{2i})^{*}\text{Frequency}_j \\ & + (\beta 3 + v_{3i})^{*}(\text{Frequency}_j)^2 \\ & + (\beta 4 + v_{4i})^{*}\text{Waiting time}_j \\ & + (\beta 5 + v_{5i})^{*}\text{Telephone contact}_j \\ & + (\beta 6 + v_{6i})^{*}\text{Breast care nurse}_j \\ & + (\beta 7 + v_{7i})^{*}\text{General practitioner}_j \\ & + (\beta 8 + v_{8i})^{*}\text{Mecical specialist/Breast care nurse}_j + \varepsilon_{ijt} \end{aligned}$$

For a detailed explanation see Appendix: available in the online of the journal. Please find this material with the direct link to the article: http//www.informaworld.com/10.3109/02841860903536002. In short, we investigated changes in utility (i.e. preference or satisfaction) when a level of an attribute changed. The parameter estimates ($\beta 1$–$\beta 8$) of the utility function describe the magnitude of these utility changes, and indicated the relative importance of an attribute. A statistically significant parameter estimate indicates that the attribute is indeed important to respondents. However, statistical non-significance of a parameter of an attribute should not be seen as necessarily meaning 'not relevant' for each respondent since, due to heterogeneity in preferences, for some respondents the attribute may still influence their decisions. A positive or negative sign indicates that an attribute-level is either preferred or not preferred compared to the base level of the attribute. Preference heterogeneity was explored by examining the significance of standard deviations of error components around the mean parameter estimates. Respondents' characteristics were incorporated into the model as interaction terms with the attributes of the DCE to explore possible sources of preference heterogeneity.

Internal validity, i.e. the extent to which results are consistent with a priori expectations, was tested by examining the signs and significances of parameter estimates. We expected all attributes to have a significant influence on preferences for follow-up. Furthermore, it was expected that, in general, frequency would have a positive sign in the utility function and waiting time to have a negative sign. Since face-to-face follow-up by the medical specialist is common in current clinical practice, we expected a general preference for the medical specialist over the other healthcare professionals, and a general preference for face-to-face contact over telephone contact (hence a negative sign for the parameter estimate of telephone contact). No specific assumptions were made about preferences for the educational group programme. Regarding two-way interactions, we were specifically interested in the interaction between waiting time and contact mode. It was a likely possibility that there were differences in preferences for waiting time between waiting time at the hospital (face-to-face contact) and waiting time at home (telephone contact).

Additionally, a consistency check (two identical choice tasks) was incorporated in the survey, and respondents were asked to report whether they experienced difficulties understanding the choice tasks and choosing between the alternatives.

Results

Validity of responses

Most respondents (74%) found the choice tasks clear or very clear, 16% were indifferent, and 10% found them unclear. Of the 331 respondents, 310 (94%) passed the consistency check. The Kappa statistic (K) for the identical choice tasks was 0.72, representing a good agreement. Following recent recommendations [19], data from all respondents (n=331) were used for the main analysis. However, a secondary analysis was performed with a calibrated sample of respondents who found the choice tasks (very) clear (n=244). This analysis showed similar parameter estimates and model fit (data not shown). Furthermore, most parameter estimates were significant ($p<0.05$), and the parameter estimates of the attributes were in the expected direction, providing evidence of internal validity. In addition, the constant term was not significant, indicating there was no general preference for alternative 'A' over alternative 'B', when all attributes and levels were the same. Contrary to expectations, the two-way interaction between

contact mode and waiting time was not significant (p=0.687). Finally, an adjusted R-square of 0.369 in this study represented a good fit of the model, indicating that respondents made choices in a systematic way, based on changes in the scenarios [27].

Preferences, relative importance of attributes, and trade-offs

Table III shows the results of the discrete choice experiment. The two-way interactions between contact mode and other attributes did not improve the model fit nor did they alter conclusions, therefore only results of the main effects model are reported. The main effects model showed that in general, for type of healthcare professional, follow-up by the medical specialist was preferred to follow-up only by a breast care nurse or general practitioner, as indicated by their negative parameter estimates. The parameter estimates for medical specialist and breast care nurse alternating and the educational group programme (EGP) were not significant. This may indicate that, in general, a switch from the medical specialist performing the follow-up to alternating between the medical specialist and a breast care nurse, and whether or not an EGP is part of the follow-up, would not negatively (or positively) affect utility. Alternatively, it could mean that there is heterogeneity in preferences for these attributes.

As expected, more frequent visits per year and reducing waiting time also had a positive impact on utility. However, the significant negative frequency[2] variable indicates that there is a linear and quadratic effect for frequency. Hence, marginal utility of more frequent follow-up visits decreased considerably when frequency increased. There was a large decrease in utility for a change from face-to-face contact to telephone contact.

Table III. Results for the random parameter logit model (n=331) with main effects only, results for the model with interactions with experience, and relative importance of attributes. Results presented are mean parameter estimates, standard deviations and p-values.

		Main effects model[a] Parameter estimate (p-value)	Experience interaction model[b] Parameter estimate (p-value)	Relative importance[c] (ranking)
Random parameters in utility function[d]				
Educational group programme[1]	Mean	–0.138 (0.088)	-0.212 (0.011)	
	Standard deviation	1.171 (<0.001)	1.117 (<0.001)	
Frequency of visits	Mean	1.497 (<0.001)	1.541 (<0.001)	.13 (3)
	Standard deviation	0.429 (<0.001)	0.463 (<0.001)	
Telephone contact[2]	Mean	–2.027 (<0.001)	–2.279 (<0.001)	.36 (2)
	Standard deviation	1.533 (<0.001)	1.505 (<0.001)	
Breast care nurse[3]	Mean	–0.463 (<0.001)	–0.617 (<0.001)	.08 (4)
	Standard deviation	1.057 (<0.001)	1.126 (<0.001)	
General practitioner[3]	Mean	–2.124 (<0.001)	–2.195 (<0.001)	.38 (1)
	Standard deviation	1.749 (<0.001)	1.899 (<0.001)	
Waiting time	Mean	–0.007 (<0.001)	–0.008 (<0.001)	.05 (5)
	Standard deviation	0.007 (0.007)	0.008 (<0.001)	
Nonrandom parameters in utility function[e]				
Constant	Mean	–0.075 (0.109)	–0.076 (0.114)	
Frequency[2]	Mean	–0.212 (<0.001)	–0.215 (<0.001)	
Medical specialist/breast care nurse[3]	Mean	0.137 (0.110)	0.124 (0.159)	
Experience*educational group programme	Mean		0.698 (0.011)	
Experience*telephone contact	Mean		2.004 (<0.001)	
Experience*breast care nurse	Mean		1.101 (<0.001)	
LL(model)		–2303.323	–2259.043	
Adjusted pseudo R^2		0.369	0.377	

[a] The main effects model assumed no interactions were present.

[b] The experience interaction model incorporated respondents' previous experience with follow-up.

[c] The relative importance of attributes and their levels was determined by calculating the coefficient range, which is the difference between the smallest (negative) part-worth utility and the largest part-worth utility within the attribute levels, and dividing it by the sum of the coefficient ranges for all attributes and levels.

[d] Attributes and levels were assigned to be normally distributed random parameters.

[e] When random parameters were found to have an insignificant standard deviation for their distribution, they were included as a nonrandom parameter in the model estimations.

[1] Refers to the attribute 'attendance at educational group programme'. Relative to 'no attendance at educational group programme'.

[2] Refers to the attribute 'contact mode'. Relative to 'face-to-face contact'.

[3] Refers to the attribute 'healthcare provider'. Relative to 'medical specialist'.

The *relative* importance of the attributes and their levels were determined by calculating part-worth utilities [20]; their ranking is shown in Table III. Overall, contact mode (face-to-face contact) and healthcare provider (medical specialist versus general practitioner) were the most important attributes of follow-up for respondents, while waiting time, the educational group programme, and whether the healthcare provider was a breast care nurse or a medical specialist were least important.

Inputting parameter estimates and levels of attributes in the utility function provides information on how respondents were willing to trade between levels of attributes. For example, a change from the medical specialist to the breast care nurse performing the follow-up would result in a utility loss of 0.46, when all other attribute levels remain equal. However, this can be compensated by an increase in the frequency of visits. Utility for follow-up visits every six months (i.e. twice a year) is (β^*frequency + β^*(frequency)^2 = 1.497*2 – 0.212*2^2 =) 2.146 and for follow-up visits every four months (i.e. 3 times a year) (1.497*3 – 0.212*3^2 =) 2.583. Hence, increasing the frequency results in a utility gain of 0.44, which could compensate for the loss of utility due to a change in healthcare provider.

Exploring preference heterogeneity

Our estimation results demonstrated that there was a strong heterogeneity in patient preferences for follow-up characteristics (Table III). To gain insight into the strength of preference heterogeneity, individual parameter estimates were calculated of the 331 respondents. By counting the number of patients with a positive parameter estimate for a specific attribute-level, the percentage of the sample that preferred that attribute-level compared to the base level was calculated. Especially, preferences for follow-up by a breast care nurse and participation in the EGP differed greatly among respondents (Table IV). For the total study population, a change from the medical specialist to a breast care nurse resulted in lower utility, but 28% of patients would nevertheless prefer this kind of follow-up. Also, the possibility to attend the EGP did not seem to influence utility, but indeed 47% of the study population preferred participation to no participation.

To identify which patients might share specific preferences, the following interaction terms were incorporated into the model: chemotherapy, radiotherapy, hormonal therapy, living with a partner, older than 60 years, and high level of education. Only age and education level influenced preferences. Follow-up by a medical specialist was valued more positively by older than younger respondents (<60 years). Furthermore, older respondents and those with a low level of education were less likely to choose a scenario that included attending the EGP. Respondents with a higher education level positively valued an EGP in the follow-up. Though interactions between age, education and some attributes were significant, collectively they only minimally improved the fit of the model. Hence, much of the heterogeneity remained unexplained.

Table IV. Preference heterogeneity explored by individual parameter estimates (n=331): results presented are the number of respondents with a positive parameter estimate and negative parameter estimate for attributes of the discrete choice experiment (% of sample).

	Positive parameter estimate (% of sample)	Negative parameter estimate (% of sample)
Educational group programme (vs no educational group programme)	156 (47)	175 (53)
Increase in frequency of visits	328 (99)	3 (1)
Telephone contact(vs face-to-face contact)	17 (5)	314 (95)
Follow-up by a breast care nurse (vs medical specialist)	93 (28)	238 (72)
Follow-up by a general practitioner (vs medical specialist)	10 (3)	321 (97)
Increase in waiting time	0 (0)	100 (100)

Influence of previous experience on preferences

Our study population included some respondents who had experienced telephone follow-up, nurse-led follow-up, and the EGP. Hence, we were able to create interactions between having experienced an attribute and the choice data for this attribute. The results are presented in Table III, and showed that respondents who had attended the EGP had a significantly higher, and positive, parameter estimate for this attribute than those who had not. The same was true for respondents who had experienced follow-up by a breast care nurse. The parameter estimate for telephone contact was considerably higher for respondents who had experienced telephone follow-up, but telephone follow-up was still not preferred to face-to-face contact. These results indicated that there was indeed a tendency to prefer what one had personally experienced; however, the subgroups were small, and preference heterogeneity was still significant when previous experience was accounted for.

Discussion

Patient preferences

To our knowledge this is the first study to investigate patients' preferences for breast cancer follow-up

using discrete choice experimentation. Most patients preferred the medical specialist to perform the follow-up, but an alternating combination of the medical specialist and a breast care nurse was also acceptable to patients, and one in four patients preferred the follow-up to be performed solely by a breast care nurse. Face-to-face contact was much preferred to telephone contact. Furthermore, utility increased with an increase in the frequency of visits and when waiting time was reduced. Contact mode and type of healthcare provider were the most important characteristics of follow-up to patients.

The finding that alternating between the medical specialist and breast care nurse is acceptable to patients is not surprising. There is evidence that emotional concerns are more easily expressed to a nurse [7], while seeing a medical specialist provides a feeling of security [10]. Hence, alternating between both healthcare providers seems a good alternative [12]. In line with our findings, other studies have also found that the general practitioner was generally not preferred [12,28]. A study conducted among American breast cancer patients revealed that patients had concerns about the communication between oncologists and general practitioners [28]. Similar feelings among Dutch breast cancer patients may have caused the strong disutility for follow-up with a general practitioner, since in the Netherlands, general practitioners only have a marginal role in breast cancer treatment and follow-up. A dislike for telephone follow-up is not surprising as it is unknown to patients, and may seem unsafe when patients still believe that frequent clinical examination to detect a relapse is an essential part of the follow-up [10,11]. Even though we tried to provide information on the purpose and effectiveness of follow-up, we did not provide detailed information on the value of clinical examinations. Finally, the need for information has also been studied before, and in general information needs varied greatly [11]. This is in line with our finding that preferences for participation in the EGP were very heterogeneous. Furthermore, in our study younger patients ($<$60 years) and patients with a higher level of education had a stronger preferences for the EGP than older patients (and less educated), which is similar to other findings [10,11]. De Bock and colleagues did find that higher information needs were associated with receiving adjuvant hormonal therapy or chemotherapy, but we could not find evidence for the influence of treatment modality on preferences for the educational group programme.

Importantly, when interpreting these results, we have to realise that people tend to prefer what they know best or have experienced [24], which was confirmed in our study. Hence, preferences for participation in an unknown educational group programme (EGP) and telephone contact or follow-up by a general practitioner might have been underestimated, while the importance of follow-up by the medical specialist and face-to-face contact might have been overestimated. Moreover, this tendency to prefer what one has experienced might be part of the explanation why results of randomised clinical trials are in contrast with our findings. A very recent study by Beaver and colleagues found that telephone follow-up was acceptable to most patients, it significantly improved satisfaction, and it produced no excess anxiety compared with hospital follow-up [14]. A large randomised clinical trial by Grunfeld and colleagues investigating follow-up with the general practitioner also found high satisfaction rates for this type of follow-up [4]. However, in both studies 40–45% of the approached patients refused participation. Although reasons for refusal can vary, it may indicate that these alternative follow-up strategies were not acceptable to all patients, which is more in line with our findings.

Implications for clinical practice

The results of this study raise several possibilities regarding the introduction of innovations in breast cancer follow-up. One possibility is to introduce a follow-up strategy in which the medical specialist and breast care nurse (alternating) provide the follow-up. With an increasing population of breast cancer survivors, a less specialised strategy could already create possibilities for scarce specialised knowledge to be used elsewhere. It can also be speculatively argued that, due to the tendency to favour the follow-up strategy that one has personally experienced, simply implementing the follow-up strategy that is the least costly, might be efficient. However, our results show that even when respondents had experience with the breast care nurse or telephone follow-up, some still preferred alternative strategies. Rather, due to the heterogeneous preferences, it seems promising to introduce an individualised follow-up to maximise utility.

Identifying patient characteristics that predict preferences for follow-up would be of use in implementing flexible follow-up. Interestingly, our study could not identify any objective patient characteristics that were strongly associated with preferences for follow-up attributes. Age and education interacted with preferences to some extent, but other individual-level factors such as personality type, lifestyle, risk aversion, anxiety, and perceived quality of life after treatment may further explain respondents' preference differences. Better still, as preferences were hard to predict based on socio-economic or treatment characteristics, a self-selection procedure after treatment

may well be the most effective option to classify patients for different follow-up strategies. Future research could evaluate such individualised follow-up in terms of satisfaction and its economic impact. It is expected that individualised follow-up could decrease health care costs, because of preferences for less specialised follow-up (e.g. a follow-up visit to a nurse is likely to cost less than a visit to the medical specialist), telephone contact, and less frequent follow-up. However, individualised follow-up could also have a potential negative effect on costs because of loss of economies of scale and possibly increased use of health care services outside the hospital.

Limitations

Some limitations of DCEs in their application to this study must be mentioned. First, an important consideration in designing a DCE is the selection of attributes and levels. These were based on a literature review, local policy initiatives and expert opinions. Focus groups and other qualitative research methods could be part of future research to investigate whether important attributes were missing.

Second, though a response rate of 59% is generally high, the validity of the findings may have been affected by respondent selection bias, and it is unclear how this would affect preference estimates for follow-up strategies. However, sample characteristics were promising in the sense that respondents with different treatment modalities, treating hospitals, age, and educational level were well represented in the sample and matched those of the study population [29].

Third, a key element in the use of random parameter logit modelling is the assumption regarding the distribution of each of the random parameters. In our main analysis all attributes and the constant term were assigned as normally distributed random parameters to allow for a high flexibility in possible heterogeneity. To ensure that our results were robust for distributions, we performed a secondary analysis, in which the attribute levels general practitioner, telephone contact, and frequency, were assigned a log-normal distribution (based on the observed relatively limited heterogeneity in preferences in these attributes, see Table III). This led to highly similar effects and a marginal improvement in model fit (adjusted R-square of 0.372), but restricted respondents' preferences to be either all positive or all negative for a given attribute level. Since an important aim of our study was to explore preference heterogeneity, allowing respondents to have either a negative or positive preference for an attribute level, the analysis results with normal distributions for the random parameters were used for the purpose of this paper.

Fourth, respondents had to make a so-called forced choice, and were not offered an 'opt-out' or 'status-quo' alternative in the experiment. It is argued that the exclusion of an opt-out or status-quo option is a violation of the underlying welfare measures of the economic experiment, since it makes it impossible to estimate the value of doing nothing, which may be real market behaviour [30]. However, we felt that the inclusion of such an option had more disadvantages than advantages. A potential problem of an opt-out alternative is that if the respondent feels that the choice task is cognitively demanding, it will be tempting to simplify it by choosing the opt-out or status-quo option, even though this would not provide the highest utility. Moreover, even though in clinical practice women could choose not to have follow-up, there is no evidence in the literature that this is common in clinical practice. Adding a status-quo alternative would have been a possibility, but also raised two concerns. First of all we were cautious for the 'status-quo bias', the tendency to choose what respondents know best [24], since respondents were already experienced with breast cancer follow-up. Second, the status-quo alternative differed among respondents, causing econometric and interpretation difficulties.

Finally, levels of anxiety or psychological distress of participants were not measured in this study, while it could be speculated that anxiety and psychological distress influence patient preferences and adherence to a follow-up strategy. Future research should incorporate such individual-level factors, and when appropriate, they might be taken into account in the decision-making process for a follow-up strategy. This is in line with recommendations from governmental and professional organisations that cancer patients be screened routinely for the presence of heightened psychological distress [31,32].

Conclusion

On balance, DCEs have great potential for medical decision making by offering a valid and reliable approach to provide estimates of the most valuable characteristics of follow-up to patients. We have investigated how changes in breast cancer follow-up affect patients' preferences or utility. The results of this study contribute to the literature findings that overall patient satisfaction would not differ significantly if patients have follow-up by medical specialist and breast care nurse alternating compared to follow-up by a medical specialist only. Furthermore, we found heterogeneity in preferences for most attributes, indicating that one strategy does not fit all. Since preferences are difficult to predict, the introduction of individualised follow-up based on self-selection seems to be a promising method to maximise benefits

in terms of patient satisfaction. Subsequently, it would be interesting to investigate the economic impact of such an individualised follow-up and whether patients who choose their own follow-up are indeed more satisfied than patients assigned to a standard follow-up strategy.

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Appendix

An RPL model takes account of preference heterogeneity by placing a distribution around some, or all, parameters. Furthermore, it allows one to capture the fact that multiple observations are obtained from a single respondent, which is most often the case in a DCE survey where each respondent typically evaluates multiple choice sets. In the RPL model, the dependent variable was whether or not a scenario (A or B) was selected by the patient in a given choice set, while the independent variables were the attributes. The attribute "frequency" was coded in terms of a linear and quadratic effect (i.e., frequency^2) to investigate whether the incremental utility of a greater number of contacts decreased when frequency increased. All attributes and the constant term were initially assigned as normally distributed random parameters. A parameter with an insignificant standard deviation for its distribution, was re-specified as a nonrandom parameter, and the model was re-estimated [27]. The RPL model was estimated for the total sample, using 500 Halton draws.

The function to be estimated was of the following form:

$$\begin{aligned} U_{ijt} = {} & \beta 0 + \nu_{0i} + (\beta 1 + \nu_{1i})^{*}\mathrm{EGP}_j \\ & + (\beta 2 + \nu_{2i})^{*}\mathrm{Frequency}_j \\ & + (\beta 3 + \nu_{3i})^{*}(\mathrm{Frequency}_j)^2 \\ & + (\beta 4 + \nu_{4i})^{*}\mathrm{Waiting\ time}_j \\ & + (\beta 5 + \nu_{5i})^{*}\mathrm{Telephone\ contact}_j \\ & + (\beta 6 + \nu_{6i})^{*}\mathrm{BCN}_j + (\beta 7 + \nu_{7i})^{*}\mathrm{GP}_j \\ & + (\beta 8 + \nu_{8i})^{*}\mathrm{MS/BCN}_j + \varepsilon_{ijt} \end{aligned}$$

where

- U_{ijt} is individual i's utility (i.e., satisfaction) associated with a specific follow-up scenario j in choice observation t.
- $\beta 0$ represents the constant term and shows the general preference for scenario A over B when all attributes and levels are the same.
- $\beta 1$–$\beta 8$ are the parameter estimates of the model that indicate the importance of each attribute as it occurs in scenario j. The sign of a parameter estimate reflects whether the attribute has a positive or negative effect on utility. "EGP" is a dummy variable for EGP being available or not, "telephone contact" is a dummy variable for telephone vs. face-to-face contact, and "BCN" (breast care nurse), "GP", and "MS/BCN" (alternating between medical specialist and breast care nurse) are dummy variables reflecting the different types of follow-up contact persons, with "MS" (medical specialist) as a base level. The base levels reflect current practice levels in the Netherlands.
- The different ν_is correspond to the individual specific error terms for every parameter which are constant across all observations for the individual and are assumed to be independently normal distributed, and ε_{ijt} is an error term which captures any remaining unobserved error and is assumed to be IID gumbel distributed among observations [27].

To test moderating effects of age, education, treatment modality and hormonal therapy we extended the model with the product variables of the corresponding individual characteristics and the variables manipulated in the DCE.