

Patient preferences for follow-up in breast cancer

5-2-2016

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Date 05-02-2016

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Summary

Introduction

Breast cancer is the most frequent cancer for women. One in every eight women will develop breast cancer. In 2010 around 15.000 women were diagnosed with breast cancer. When the patient is declared breast cancer free, patients could participate in a follow-up program. The aim of a follow-up is to determine physical symptoms due to treatment, determine the need for psychosocial support and to detect possible recurrence or second primary tumors. Patients often have more follow-up consults than guidelines suggest, while a less intense follow-up is as effective as a more intensive follow-up. Research showed that patients have different preferences for follow-up content and could be the result of a fear of cancer recurrence. Fear of recurrence is associated with impairment in physical functioning, psychological distress and a lower quality of life. In this study, patient preference and risk perception will be investigated to find differences in preferences between risk perception groups.

Method

A quantitative and qualitative research is performed to elicit the preferences of patients. For eliciting the quantitative data, a questionnaire is developed. The questionnaire contains questions regarding risk perception and a Discrete Choice Experiment to elicit the preferences of patients. Patients are categorized in different risk perception groups based on the chance of developing a local regional recurrence found in earlier research. In discrete choice experiment methods, a patient has to choose the preferred hypothetical scenario in a choice set of questions. These scenarios describe several follow-up content. Regarding the qualitative method, the researcher asked the respondents an open question to determine which content they prefer in their follow-up. This study is performed at two hospitals and data collection took place from the 14th of September until the 23rd of October.

Results

A total of 89 questionnaires were used in the analysis regarding the quantitative method and 72 regarding the qualitative method. The risk perception groups show different fear of recurrence. This fear increases with a higher risk perception of developing a recurrence. Most respondents underestimate or overestimate their risk. Regarding the general preferences of the research population, differences in preferences are found between the quantitative and qualitative research in frequency of follow-up consults and type of healthcare professional.

Conclusion

Differences are found between the risk perception groups. Respondents that overestimate or underestimate their risk of a recurrence have preferences for a long personal follow-up duration. Respondents with the correct perception of risk have preferences for a less intensive follow-up. However, almost all results regarding the preferences of the risk perceptions groups are not statistically significant. More research is needed to determine the relation between risk perception and preferences in which a larger number of patients must be included.

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1. Introduction

Breast cancer is the most frequent cancer that occurs among woman in the Netherlands (1). One in every eight women in the Netherlands will get breast cancer (2). In 2010 around 15.000 women were diagnosed with breast cancer and it is expected that this number will increase to over 17.000 women in 2015. This increase of incidence rates can be explained by several aspects, such as the increased use of mammography and cytology and the introduction of breast cancer screening programs. In 2010, around 3.700 women died of breast cancer in the Netherlands. The five year survival in all age groups is 80% (3). It is estimated that there are 119.000 former breast cancer patients in 2005 that lived in the Netherlands. This number may increase to 194.000 breast cancer survivors in 2015. 80% of these women still needs to use healthcare related to breast cancer (3). When the curative treatment is ended and the patient is declared breast cancer free, the patient participates in a follow-up program in the hospital.

1.1 Current guidelines of a follow-up program

In the Netherlands the follow-up program is part of the standard medical care after breast cancer treatment (4, 5). The primary purpose of follow-up is the early detection of local regional recurrences or a second primary tumor, detecting side-effects of treatment and providing psychosocial support (6). The follow-up has a minimum duration of five years. In the first year of the follow-up, the patient will visit a healthcare professional every three months. In the second year, the patients visits the hospital every six months and annually in remaining three years of follow-up. During these visits, patients receive a physical examination and an annual mammogram. The annual follow-up visits continue until the age of 60. Patients older than 60 years continue in the national breast cancer screening program or are referred to the general practitioner (7). These follow-up practices vary between hospitals in the Netherlands. Patients often attend more follow-up visits than the guidelines recommend (8). This standard is set by the National Breast Cancer Consideration Netherlands (6). The guidelines do not take the individual differences of a breast cancer recurrence into account.

1.2 Effectiveness of the follow-up program

There has been much debate about the effectiveness of breast cancer follow-up, due to the fact that most cancer recurrences are not detected during the routine follow-up visits in the hospitals. Most recurrences are detected when patients develop symptoms between the follow-up appointments, in which they present these symptoms to their general practitioner (5). Therefore, a reduction in the intensity of follow-up could be achieved without any adverse effects on the prognosis (4). This decrease in the current pattern would result in less waste of resources. Besides the routine follow-up, Rojas et al (2009) conclude that the less intense follow-up (the follow-up without the laboratory and radiology testing) is as effective as the more intense follow-up, while the intensive follow-up is more expensive (9).

1.3 Patient preferences for the follow-up program

Several studies investigated the preferences of patients regarding the follow-up of breast cancer. Research by Bock et al (2004) analyzed the needs and preferences of patients in routine follow-up after treatment for breast cancer (10). More than 50% of the patients preferred lifetime follow-up, twice a year, performed by a hospital doctor. Younger age of patients was related to a greater need for information during the follow-up. Despite the questionable added prognosis value of the follow-up, patients still prefer a follow-up visit every three months over visits every four, six or twelve months.

Research by Renton et al (2002) surveyed the opinions of patients on routine follow-up (11). They have shown that patients are satisfied with the current breast cancer follow-up arrangement but they would accept some changes. This change would take place in the healthcare professionals for the follow-up. The study showed that the patients have confidence in the medical staff. 64% of the patients would be satisfied if their healthcare professional in a follow-up was a nurse and 38% would be satisfied with a general practitioner.

Research by Kimman et al (2010) used a discrete choice experiment to investigate the patient preferences for breast cancer patients in the follow-up (12). In this research, they evaluated reduced follow-up strategies. The research showed that patient satisfaction would not differ significantly if the patient had a follow-up with a medical specialist and breast care nurse compared to a follow-up with only a medical specialist. Furthermore, they found heterogeneity in the preferences of patients. This indicates that a one size follow-up strategy does not fit for all patients.

Research by Montgomery et al (2008) studied the expectations of patients in the follow-up (13). Their research showed a large difference in expectations regarding the duration of the follow-up between patients under and above the age of 50 years. Patients below 50 years expected a higher frequency in clinical visits than patients above 50 years. In the overall population more than 60% of the patients felt that they would have less anxiety and therefore would be more reassured when they had more clinical visits. When the patients were informed about the effectiveness of a routine-follow regarding the ability to detect a recurrence, still more than 60% preferred regular clinical visits. More than 30% of the patients would be happy not to come back to the clinic (13). When patients were not informed about the effectiveness of follow-up, they expect a higher chance of survival when more tests are performed. Therefore patients should be better informed about the effectiveness of follow-up so that unrealistic expectations could be prevented (7).

As the survival times of breast cancer survivors increases it becomes more important to investigate the impact of the long-term outcomes of breast cancer and its treatments. Some physical or psychological problems such as anxiety and depressive symptoms can endure for months or years after completion of the treatment. One of the reason that follow-up is established is to determine the need for psychosocial support (13). However, the importance of the psychosocial support differs between the patients and the healthcare professionals. Healthcare professionals consider psychosocial support as an important aspect in the follow-up. This is rarely mentioned by the patients (7), while between 20 and 30% of the women in either mastectomy or breast conservation breast cancer treatments develops an anxiety or depressive illness (14-16). Primary care physicians often do not diagnose these mental problems, especially in older patients, because the services are underdeveloped (17). Research has shown that it is difficult to reveal depression and anxiety in patients unless professionals questioned them (18). Patients often do not feel comfortable raising emotional or psychological concerns towards their healthcare professionals in the follow-up. Reasons are that the consults were too physical. Patients were afraid to ask for help because they thought it took too much time from the specialist and that the clinics are not oriented for the emotional needs. Patients also did not ask for psychological aid, because they were afraid for appearing to be ignorant or they felt that the questions were not relevant (19).

The differences in patient preferences could be the result of a fear of cancer recurrence. When the curative treatment is finished, the patient can develop a fear of cancer recurrence (18). Even long-term cancer survivors, who are cancer free for at least five years, have uncertainties about the recurrence of a cancer or the late effects of the treatment. The psychosocial impact of a breast cancer diagnosis has a greater impact on younger women (20). Fear of recurrence is associated with impairment in physical functioning, psychological distress, stress-response symptoms and a lower quality of life (21). When the psychological status of a patient during a follow-up is examined it might improve the patient's coping abilities with the disease. Additional rehabilitation programs are available for breast cancer patients in the follow-up. These programs can provide physical or mental aid for the problems that are the result of breast cancer. Women below the age of 50 years have a higher fear of recurrence than women with an age 50 years and above (22). Also a difference is found in age groups regarding the need for information. Patients who needed less information had a higher quality of life and were more satisfied with interpersonal aspects (10). A higher fear of recurrence was shown at mothers because they are afraid to leave their children behind (22). Married women showed a higher fear of recurrence than single women and unemployed patients and housewives showed higher fear of recurrence than retired and employed patients (23).

1.4 Fear of recurrence

Fear of recurrence can be defined as the fear or worry of the patient that the breast cancer might come back in the same breast or another area of the body, or that a new breast cancer in either breast will develop (21). A recurrence of breast cancer can be the result of developing a new primary breast cancer, metastases or a local regional recurrence. A local regional recurrence of breast cancer is defined as a recurrence of the cancer in the breast, chest wall, axillary, infraclavicular, supraclavicular or parasternal lymph node area after curative treatment (24). In a research study of Clemons et al (2001), the overall incidence of a local regional recurrence was 13% after mastectomy and 12% after breast conserving therapy in a ten year survival (25). This relapse of breast cancer is higher in the first five years after curative treatment. Respondents have an overall incidence between 20 and 30% after mastectomy or breast conserving therapy with a combination of chemo and radio therapies (26, 27).

According to a theoretical model of fear of recurrence based on Leventhal's Self-Regulation Model of Illness, fear of recurrence is the result of the following three factors (28):

- The perception of personal risk to a recurrence. This perception can be influenced among different factors such as the cancer stage and the treatment received.
- The emotional state of the patient. Especially the factor anxiety can be an increasing factor.
- Greater perceived physical, economic and social consequences that are associated with cancer.

Several studies measured the risk perception of former breast cancer patients. Results of these studies show that women dramatically overestimate their risk of having breast cancer while others conclude they underestimate their risk (29-31).

1.5 Problem description

Due to an increased breast cancer incidence and a better survival rate, the number of patients in the follow-up increases. Due to this increase of patients, the burden on caregivers for breast cancer in the follow-up is growing, which can result in problems for the amount of patients that can be treated in a hospital. Patients are regularly more followed than guidelines recommend. According to the healthcare professionals, a reason for this higher frequency of follow-up is the patient preferences. Earlier research showed that the preference of patients varies over the length, frequency and provider of follow-up (10-13). This difference in patient demand regarding follow-up can be caused by the risk perception of a patient, which is the result of physical and/or psychological factors such as anxiety and depression due to fear of recurrence. Risk perception studies examine the judgments that people make when they are asked to characterize and evaluate hazardous activities and technologies (32). Risk perception to a disease has been studied often to predict the individuals' propensity to take preventive action to increase the health behavior of people.

By reconsidering the follow-up program, it is possible to develop more individual and cost-effective follow-up scenarios, instead of having a one size fits all follow-up. To formulate and evaluate new follow-up approaches the expectations of the patients regarding the follow-up must be clearly addressed (33). An increase in patient satisfaction can be obtained with an individualized follow-up where the patients' needs and preferences are taken into account (12, 33).

1.6 Aim of this research

This study investigates the patient preferences and the risk perception of the patient and tries to attempt to find differences in preferences between different risk perception groups. By investigating this, it will be visible how risk perception influences the need for follow-up in frequency, duration, type of contact and healthcare professional. Also the patients' goals for follow-up are determined, so it becomes visible what the patients' expectations and aims are regarding a follow-up. When the influences of these factors are determined a more individualized follow-up could be realized. For instance, if the results show that respondents that underestimate their risk prefer a less intensive follow-up, certain measures such as patient education regarding the effectiveness of follow-up and more physical and psychological support for patients could be a solution to decrease the risk perception of patients that overestimate their risk of recurrence. By doing this, the follow-up preferences could be altered.

1.7 Research Question

What is the relationship between patients' risk perception of cancer recurrence and their preference for follow-up in terms of process and content?

To answer this research question the following sub questions are formulated.

1. Do the physical and psychological symptoms caused by breast cancer and the treatments for breast cancer influence the risk perception of patients?
2. What are patients' preferences with regard to process and content of follow-up?
3. What are the patients' aims in follow-up?
4. Does the perception of patients' risk of recurrence influence the need for follow-up?

2. Research Method

2.1 Research design

A structured literature review is performed, in order to get insight in the breast cancer follow-up. Through these data and consultation with healthcare professionals the research question, sub questions and the questionnaire design are established. Quantitative and qualitative research is performed to elicit the preferences of the respondents. For the quantitative research data is collected by using a questionnaire. A qualitative research was performed by making personal notes in face-to-face consults with respondents that took place after completing the questionnaire. The quantitative method will be explained in paragraph 2.5 *Questionnaire* and the qualitative method in paragraph 2.6 *Interview*. Firstly, the preference measurement instrument is briefly explained, which was used to elicit the indirect preferences in the quantitative method.

2.2 Discrete choice experiment

To elicit the respondents' preferences for the follow-up, this study used a Discrete Choice Experiment (DCE) in the questionnaire. To determine the specific preference measuring method used in this study, several methods are compared and discussed. Evaluating these methods resulted in a DCE to apply in this study. The evaluation of these methods is shown in Appendix 6.1 *Preference measure instruments*. A DCE is a conjoint analysis method. This method has been successfully applied in quantifying the preferences in healthcare (34). A DCE is based on the idea that each service or good can be described by its characteristics and that the evaluation of a service or good depends upon the nature and levels of these characteristics. These characteristics are called attributes. The levels of characteristics of the scenarios are called attribute levels. Each attribute has a certain amount of levels. Respondents are presented with hypothetical scenarios involving different levels of characteristics and are 'forced' to make a trade off in the level characteristics between scenarios. After trading off these levels, the respondent chooses the hypothetical scenario with the most preferred level characteristics (35).

2.3 Attributes and levels

For determining the steps involved in producing a DCE, the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) checklist is used. This checklist gives a clear overview of steps which are needed for producing conjoint-analysis research in healthcare such as determining the attribute and level selection or the construction of task needed for a DCE design (35). The attributes and levels used in the questionnaire are shown in Table 1 and are based on literature reviews and discussion with healthcare professionals. More information regarding the attributes and levels of DCE used in this study can be found in Appendix 6.2 *Constructing the DCE*.

Attributes	Duration of follow-up	Frequency of consults	Type of contact	Type of healthcare provider
Levels	1 year	Every 3 months	Face-to-face	Surgeon
	3 years	Every 6 months	Telephone	Nurse practitioner
	5 years	Every 9 months	E-mail	General practitioner
	Lifetime	Every 12 months	Video call	Breast cancer nurse and surgeon

Table 1. Attributes and levels

2.4 Experimental design

As shown in Table 1, this study contains four attributes and four levels. If all combinations of the four attributes and four levels are used, this will result in ($4^4 =$) 256 hypothetical scenarios. Since presenting all these scenarios would be too burdensome for the respondent, a subset of scenarios was used. Statistical questionnaire design software (Sawtooth 6.4.6.) is used to determine a 24 full DCE scenario resulting in twelve choice set questions. The design made by Sawtooth ensured orthogonality (meaning that a certain attribute level only occurred once in a choice set) and ensured a balance resulting in the equal occurrence of each number of attribute level in the total DCE design. With these 24 scenarios this study could estimate the main effects between the attributes.

2.5 Study population

Inclusion criteria and exclusion criteria

A patient in this research is: an individual who has had a diagnosis of breast cancer, has completed the treatment and is currently cancer free and attend the follow-up. There are multiple treatment and therapies for breast cancer. For this study all treatment and therapy groups are included, resulting in a research population that had a mastectomy or breast saving operation and received the following therapies: radiotherapy, chemotherapy, immunotherapy and hormone therapy.

Respondents were excluded if they were male or when they were not able to understand and read the Dutch language. Healthcare professionals excluded respondents if they had a suspicion that they were not capable to complete the questionnaire at that moment. Respondents were also excluded if they did not complete the full questionnaire.

Sample size

To determine the needed sample size for this study the rule-of-thumb formulated by Orme (2006) was used (36). Using this rule-of-thumb, a minimal number of 84 respondents is needed. The rule-of-thumb and the exact calculation of the sample size needed in this study is shown in Appendix 6.2.1 (Figure 4).

2.6 Data collection

The research questions are answered by questioning patients, using a paper questionnaire. Besides the paper questionnaire, an online questionnaire was made in LimeSurvey in case the patient would like to participate on a later moment. In this case, the patient could leave her e-mail address and the researcher would send her an e-mail with the LimeSurvey link. This study aimed to include 84 respondents based on the rule of thumb by Orme and tried to divide the research population between the two hospitals.

2.7 Pilot test

A pilot-study was performed with eight respondents to determine if there were problems in the interpretation of the questionnaire. The pilot test revealed that adaption in the questionnaire was necessary. Respondents had difficulties regarding the risk perception questions. After literature research, these questions were changed into less difficult questions and are based on a Likert scale. The former risk perception questions were based on a case in which the respondents have to fill in the risk of getting a recurrence for each case. Furthermore, the physical symptoms are adapted. At first this was an open question and this was changed into a Likert scale in which the respondents had to fill in the degree of symptom caused by the breast cancer of the received treatment. After changing the questions, a new questionnaire was made. Unfortunately after implementing this questionnaire for two weeks a flaw was found in the DCE design. This problem occurred in the ratio between levels. This resulted in that some combinations of levels did not occur, meaning that the relation between these levels could not be analyzed. A new DCE design was made in Sawtooth and implemented in the questionnaire.

2.8 Questionnaire

The questionnaire consists of 44 questions that were divided in four parts. The different parts are discussed below. The complete questionnaire is shown in Appendix 6.6 *Questionnaire*.

Part 1: Patient characteristics

In this part, general patient characteristics such as age, age diagnosis, living and work situation are asked.

Part 2: Risk perception and fear of recurrence

This part consists of three questions. Two questions are asked to determine the risk perception of the respondents. The operationalization of the risk perception used in this study is based on a research from Gagnon et al (1996) and is slightly adapted for this research (29). In this study, fear of recurrence is operationalized as the perceived risk (chance). The perceived risk perception is an estimation of the respondent of developing a local regional recurrence. In the first question, the respondent answers what she believes is her own risk of getting a recurrence of breast cancer. In the second risk perception question, the respondent has to fill in her perception of developing a recurrence for a former breast cancer survivor in general. At last, the respondent has to fill in her fear for developing a recurrence on a scale (0 – 100) in which a higher value represents a higher fear for a recurrence.

Part 3: Discrete choice experiment

In order to examine the preferences of the respondents for follow-up, a discrete choice experiment is used. A total of twelve DCE choice sets are used. Each choice set consists of two scenarios in which the respondent has to choose the most preferred scenario. An example of a DCE choice set is shown in Figure 1 (the actual DCE questions are in Dutch).

Scenario 1	Scenario 2
<p><u>During the rest of your life</u>, you will attend the breast cancer follow-up in which you will have contact with <u>a surgeon by phone</u> every <u>9 months</u>.</p>	<p>The total duration of your follow-up is <u>5 years</u>. Every <u>12 months</u> you will have <u>personal</u> contact with <u>your general practitioner</u>.</p>
<input type="checkbox"/>	<input type="checkbox"/>

Figure 1. Example DCE choice set

Part 4: Symptoms and follow-up goals

As fear of a recurrence increases with the emotional state of a patient and the physical consequences of a patient that are associated with cancer, this part treats different symptoms that could be the result of breast cancer or the treatment that they received. A total of eleven physical and psychological symptoms are mentioned, of which literature has shown that they could be a result of breast cancer or received treatment therapies (16, 18, 37, 38). Each symptom is based on a five-point Likert scale in which the respondents could determine the degree of severity they endure. Research done by Kwast et al (2013) shows five follow-up goals that patients find important (7). These goals are: *Examination of the breast*, *Reassurance*, *Guidance of patient (answering questions)*, *Evaluation of treatment and treatment side-effects* and *Psychosocial support*. To determine which aspect the respondent would find most important during the follow-up, these five goals are used. Subsequently, part four consists of questions to determine the relationship with their follow-up healthcare professional (derived from the CQ-index questionnaire for Mamma care from the Centrum of Customer Experience care from NIVEL). This part consists of questions to determine if respondents made use of additional aid, such as a psychologist and contains other follow-up related topics.

2.9 Interview

As mentioned in paragraph 2.1 *Research design*, this study performed a qualitative research. The researcher asked the respondents an open question to determine which healthcare professional, duration, frequency and type of contact they prefer in their follow-up. This interview was performed in the research room after the respondent completed the questionnaire. By performing this additional research method, this study can determine if there are similarities or differences in the direct preferences and the indirect preferences of respondents derived from the DCE data.

2.10 Patient recruitment

Respondents are recruited by nurse practitioners by whom they attend their breast cancer follow-up. In discussion with the nurse practitioners and surgeons, it is decided that patients could participate in this study after their follow-up consult, because patients are often anxious before a consult. At the end of their consult, the nurse practitioner informed the patient about this study and the respondent would receive a letter of information. In this letter of information the patient could read the aim of the study, information about the duration and the rights of the patients and if the patient is interested to give the results of their questionnaire to the Dutch Cancer registry. The patient letter of information is shown in Appendix 6.7 *Patient letter of information*. If the patient agreed to participate in this study, the nurse practitioner informed the researcher. The patient could complete the questionnaire in a research room, while the researcher was available for questions. When patients agreed that the Dutch Cancer Registry could use their results, they had to fill in her hospital number and signature on the permission form.

2.11 Data analysis

All paper questionnaires were manually transferred into LimeSurvey and thereafter transferred to IBM SPSS Statistics 22. Before the DCE data could be analyzed, values had to be assigned to the different attribute levels. Therefore dummy coding was used. As mentioned in the paragraph 2.2 *Discrete Choice Experiment*, the respondent must choose the preferred scenario in a choice set in which each hypothetical scenario has four certain attribute levels. At first the hypothetical scenarios were coded in which a value 1 was assigned when the respondent chose for scenario 1 and a value 2 was assigned when the respondent chose scenario 2.

To determine the preferences regarding the attribute levels in these scenarios, each attribute level was coded into 0 and 1. Dummy coding is a way of representing groups of levels using only 0 and 1. By doing this, several variables had to be made. The attribute level was assigned the value 1 when it occurred in the scenario and a 0 when it did not occur. An example (Table 9) of the dummy coding performed in this study can be found in Appendix 6.3 *Dummy variables discrete choice experiment*.

The number of variables that is needed for dummy coding, is one less than the number of levels. Because this study uses four variables, three dummy variables were needed and one baseline level. All attribute levels are compared with the baseline variable. Therefore, this study had a total of twelve dummy variables and four baseline variables.

After assigning each dummy variable, a certain value of zeroes or ones shows the difference in scoring between the choice sets of scenarios, to determine which attribute level was preferred. If a certain attribute level occurred in scenario one, this level had the value 1. When this same level occurred in scenario two (instead of scenario one) this attribute level had the value -1. When this attribute level did not occur in both hypothetical scenarios this level had the value 0. This was performed for each attribute level in all scenarios, resulting that each DCE choice set had twelve dummy variables in SPSS. The coding of the variables in different subgroups used in the analyses in SPSS are shown in Appendix 6.4 *Recoding the data*.

2.12 Statistical analysis

After recoding the data, the characteristics of the respondents are analyzed by using a descriptive analysis. A descriptive analysis is also used to determine the follow-up aims and the relationship between patient and healthcare professional. Regarding the statistical level of performed analyses, a *P* value (statistical level) of below 0.05 will be accepted as significant.

Regarding the variables *living situation*, *work situation*, *education* and the questions for determining the relation between patient and healthcare professional, a Chi-square analysis was performed to determine if there are differences in those variables between the two hospitals.

To determine if there are differences between the hospitals regarding the background variables, an independent T-test is performed regarding the variables *Age patient* and *Age diagnose breast cancer*. With the T-test, the different means of the variables *age* between both population groups of the two hospitals are determined. In the T-test, the variables *age* and *diagnose age* were the dependent variables. The variable *hospital* was the independent variable.

A One-Way-ANOVA analysis is used to determine the relation between the mean fear of recurrence and risk perception. In this analysis, the fear of recurrence is the dependable variable and the variable perception is the factor variables. With the One-Way-ANOVA test, this study determined if there were differences in fear of recurrences in the different risk perception.

To analyze the DCE data, a logistic regression analysis is performed. With this analysis, the utilities of each attribute level are calculated. A logistic regression analysis is performed to determine the preferences of the total research population. This test is also performed in which the total population was split into three different risk perception groups, resulting in three logistical regression analyses (one analysis per risk perception group).

When the utilities of the attribute levels are determined, the importance of the four attributes could be calculated. By doing this, each attribute is assigned with a certain weight (importance). All four attributes combined, gives a total attribute importance of 100%. With this attribute importance, insight could be given in which attribute the respondent finds most important when making her choices in the choice set. To determine the attribute importance, the difference between the highest and lowest utility is determined for each attribute and divided by the sum of differences of all attributes. By doing this, the importance of each attribute is obtained.

To determine if there are differences in the importance of the follow-up goals between the risk perception groups a Chi-square analysis was performed. Based on their risk perception of a recurrence and stratified by the years since last curative treatment, patients are divided into three risk perception groups. The stratification of patients into the different risk perception groups is shown in Appendix 6.5 Table 13. A Chi-square analysis is performed to determine the relation between risk perception and the symptom groups. This test was also performed to determine if the risk perception decreases between the different follow-up duration groups and to determine the relation between the variable risk perception and variables *breast cancer history* and *cancer occurrences in the family*.

3. Research results

3.1 Patient characteristics

This part is confidential

3.1.1 Risk perception

Based on their risk perception of a recurrence and stratified by the years since last curative treatment, patients are divided in the following three groups; *underestimation of risk*, *correct estimation of risk* and *overestimation of risk*. A total of 52 respondents underestimate their risk of a recurrence, eleven respondents are correct in determining their risk of a recurrence and 26 respondents overestimate their risk of a recurrence (Table 3). When patients compared their own risk of a recurrence to other breast cancer survivors, around 50% of the respondents expects to have same risk of developing a recurrence. However, around 40% of the respondents reports to have a lower risk in developing a recurrence than a former breast cancer patient (see Table 14, Appendix 6.5).

Table 3 shows the perception of risk in different follow-up groups ($p = 0,214$). A total of 56 respondents are currently attending their follow-up between 1-5 years. A total of 25 respondents are currently attending the follow-up between 6-10 years and a total of eight respondents are currently attending their follow-up longer than 10 years.

Follow-up groups/ perception group	Underestimation of risk	Correct estimation of risk	Overestimation of risk	Total
1–5 years follow-up (n [%])	-	-	-	-
6–10 years follow-up (n [%])	-	-	-	-
Longer > 10 years (n [%])	-	-	-	-
Total	-	-	-	-

Table 3. Relation between risk perception and different groups of follow-up duration

It is expected that with increased (recurrence free) time since end of the curative treatment, the perception of risk of the respondents regarding a recurrence declines. This assumption is shown in Table 3. However, the differences in risk perception based on time since last curative treatment in Table 3 are not statistical significant. A certain trend that the perception of risk declines is visible in the results. A third of the respondents that are attending their follow-up between 1-5 years, are categorized as respondents that overestimate their risk of a recurrence. This percentage is lower in other follow-up groups. The respondents that have the correct perception of risk increases during the years.

3.1.2 Fear of recurrence

Now this study wants to determine whether there are differences in fear of recurrence between the three risk perception groups. Figure 2 shows the relation between the risk perception groups and the fear of recurrence ($p = 0,036$). Here, it is shown that the fear of a recurrence differs between the risk perception groups. The fear of a recurrence increases if patients expect they have a higher risk of a recurrence. The overall mean fear of recurrence in this study population is 32,7.

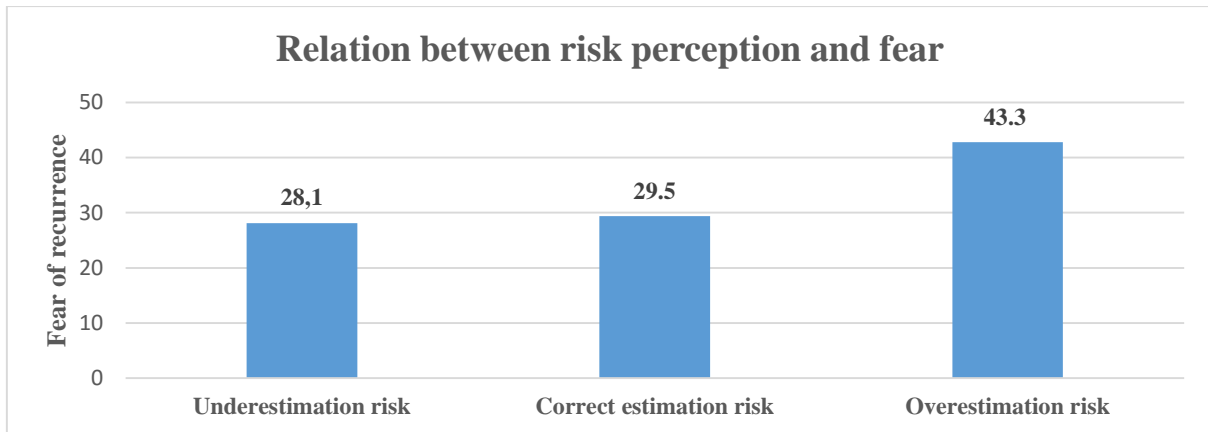


Figure 2. Relation between risk perception and fear of recurrence

3.2 Relation between physical and psychological symptoms and patients' risk perception

To determine if there is a relation between risk perception and symptoms, the current psychological and physical symptoms are used. The number of respondents that has psychological symptoms decreases during the follow-up. However, the number of respondents that has physical symptoms increases during the follow-up (see Table 19, Appendix 6.5). Table 4 shows the relation between the current psychological/physical symptoms groups and the risk perception groups.

Groups		Underestimation of risk	Correct estimation of risk	Overestimation of risk	Total
Psychological symptoms (p = 0,230)	Symptoms (n [%])	-	-	-	-
	No symptoms (n [%])	-	-	-	-
Physical symptoms (p = 0,522)	Symptoms (n [%])	-	-	-	-
	No symptoms (n [%])	-	-	-	-

Table 4. Relation between risk perception and symptom groups

Regarding the relation between psychological symptoms due to breast cancer or received treatment or therapy and risk perception (p = 0,230), most respondents are categorized as respondent without psychological symptoms. However, the relation between psychological symptoms in Table 4 are not statistical significant. A certain trend is visible. About half of the respondents with psychological symptoms overestimated their risk of recurrence. This overestimation of risk is lower in the group without symptoms. The relation between physical symptoms and risk perception (p = 0,522) shows a similar trend. More than a third of the respondents with physical symptoms overestimate their risk of a recurrence compared to the group that reports having no physical symptoms.

3.2.1 Frequencies anxiety and depression

In this study, the frequencies of psychological symptoms are decreased during the follow-up (see Table 20, Appendix 6.5). More respondents experienced depressive or anxiety symptoms in the beginning of the follow-up compared to their current situation. Although the amount of symptoms decreases, it is visible that these symptoms still affect a large population. Almost half of respondents (46.1%) report that they still experience depressive feelings and more than half of the respondents (55.1%) experience anxiety.

3.3 Patients' preferences with regard to process and content of follow-up

At first the preferences of the total population with regard to the content follow-up are determined. The content of follow-up is divided into four attributes: *duration*, *frequency*, *type of contact* and *healthcare professional*. The weights of the attributes are calculated to determine which attribute has the most impact. In Table 5 the weights of each attribute and the coefficients (β) and significance (*Sig*) per attribute level are shown. The respondents find *duration* of follow-up the most important attribute. Respondents prefer a lifetime follow-up instead of a shorter follow-up. The least important attribute was *frequency* of follow-up. It seems that respondents do not have strong preference for a follow-up consult of four times, three times, every nine months or annual. This importance of attributes reflects the degree to which respondents base choices with regard to follow-up on the outcome on this attribute. Based on the importance of the attributes, the respondents make their choices of scenarios mainly on the duration of the follow-up and type of healthcare professional that does the follow-up.

Now that the weights of the different attributes are calculated, we are interested in which attribute levels are most valued by the respondents. Within an attribute the levels with the largest coefficients are most preferred and the levels with the lowest coefficients are least preferred.

Attribute	Attribute level	β	Sig	Weight (importance)
Duration	Lifetime	-	-	-
	3 years	-	-	
	5 years	-	-	
	1 year (baseline variable)	-	-	
Frequency	3 months	-	-	-
	6 months	-	-	
	12 months	-	-	
	9 months (baseline variable)	-	-	
Contact	Personal	-	-	-
	Telephone	-	-	
	E-mail	-	-	
	Video call (baseline variable)	-	-	
Healthcare professional	Surgeon and breast cancer nurse	-	-	-
	Nurse practitioner	-	-	
	Surgeon	-	-	
	General practitioner (baseline variable)	-	-	

Table 5. Coefficients per attribute level

Regarding the qualitative method, the preferences of a total of 72 respondents are analysed. These results show that respondents have the largest preference for a personal lifetime follow-up with an annual consult with a nurse practitioner. No preferences is found for contact by email or video call, however some respondents showed interest in the combination telephone and personal contact. In general, patients would not prefer any other follow-up contact beside face-to-face follow-up because other follow-up contacts are not personal enough. Other reasons for disliking the contact by email or video call are that respondents do not have the capability or capacity to perform this type of contact. Respondents strongly prefer an annual consultation, because they do not want to be confronted with their breast cancer too often. Multiple respondents reported they only fear a breast cancer recurrence days/weeks before a follow-up consultation. However, some respondents mentioned that more follow-up consults (twice a year) are preferred in the first follow-up years. Regarding the healthcare professional, most respondents preferred a nurse practitioner. There was almost no preference for the healthcare professionals surgeon and nurse, surgeon or general practitioner. Patients find that the nurse practitioner has enough expertise to perform the follow-up. They especially appreciate the nurse practitioners because they are approachable, qualified and takes time for a follow-up consult. Respondents reported that they find it easier to express their emotional concerns to a nurse compared to other health professionals. Some patients reported that it is not necessary that a surgeon should be a follow-up health professional regarding the higher healthcare costs. Patients mentioned that they prefer nurse practitioner over a surgeon because a consult with a surgeon is shorter. As shown in the quantitative method, the qualitative method also shows that respondents do not have preference for a general practitioner as their health professional in the follow-up. This dislike of this health professional is caused because patients expect that a general practitioner would lack breast cancer knowledge and is too busy to be a follow-up professional. There were some patients that did not have a preference for a certain healthcare professional as long follow-up consults took place in the hospital.

3.3.1 Other factors that can influence the follow-up preferences

A quarter of the respondents has a preference for a female healthcare professional in the follow-up. The remaining respondents have no preference regarding the sex of the healthcare professional. None of the respondents has a preference for solely a male healthcare professional. Respondents reported that they do not have a strong preference regarding the gender of the healthcare professionals, as long they are capable to perform a follow-up. As mentioned in paragraph 3.1 *Patient characteristics*, there are multiple patients with a cancer history or family members that had breast cancer. Regarding the relation between former cancer history and the risk perception groups, we cannot determine if having cancer in the past influences the risk perception of patients ($p = 0,108$). The variety of cancer history between the perception groups is not consistent. Most of the respondents who had cancer in the past, had breast cancer and overestimated or underestimated their risk of a recurrence. This variety of risk perception is also found in respondents that had cervical and skin cancer. This analysis is shown in Appendix 6.5 (Table 15).

Regarding the relation between family cancer occurrences and risk perception ($p = 0,021$), no direct relation is found between the occurrence of breast cancer in the family and the perception of risk. A third of the respondents reported that breast cancer occurs in the family. In this group, a quarter of the respondents overestimates its risk of a recurrence. This variety in risk perception between the groups is almost similar in the group of respondents who reports that cancer did not occur in the family. This analysis is shown in Appendix 6.5 (Table 16).

3.4 Aims of the follow-up to patients

Follow-up goals \ degree of importance	Not important (n [%])	Not very important (n [%])	Neutral importance (n [%])	Important (n [%])	Very important (n [%])
Physical examination	-	-	-	-	-
Reassurance	-	-	-	-	-
Psychological support	-	-	-	-	-
To discuss treatment and side effects of the treatment	-	-	-	-	-
Guidance of patients; answering questions	-	-	-	-	-
Total	-	-	-	-	-

Table 6. Patient follow-up goals

Table 6 shows the five patient's goals of follow-up. The most important goals in follow-up are: physical examination, reassurance and answering questions. Of less importance are: psychological support and discussing the side effects of the treatment. During the face-to-face contact, patients reported that besides the personal contact in the hospital the mammography was also an important aspect of the follow-up to provide additional reassurance. A relation between the importance of psychological and living situation was found ($p = 0,001$), in which respondents that live alone find this psychological support more important than respondents that live together (see Table 17, Appendix 6.5). One of the reasons that the follow-up for breast cancer was established, is to provide psychological support to patients. A total of 35 respondents reported that they received help from these rehabilitation programs. 31 respondents made use of physical therapy, ten respondents used the aid of a psychologist, four respondents received additional help from a healthcare professional from cancer rehabilitation and one respondent received aid from a dietician.

No relation is found between the risk perception groups and the importance of the goals: *Reassurance* ($p = -$), *Physical examination* ($p = -$), *Psychosocial support* ($p = -$), *Guidance of patients; answering questions* ($p = -$), and *To discuss the effects of the treatment* ($p = -$) (see Table 18, Appendix 6.5). However, a trend is found between risk perception and psychosocial support. Most respondents that find psychosocial support important are respondents that are correct with their perception of risk or respondents that overestimated their risk. More respondents that underestimated their perception of risk find psychosocial support of a neutral importance.

3.5 Relation between risk perception and preferences

In the first sub question, the total preferences of the research population regarding the need for follow-up are determined. In this research question, the relation between risk perception groups and the type of follow-up they prefer is determined. The results of these analyses are shown in Table 8 (next page). Here, it is shown that the attribute importance is different between the risk perception groups. However, the attribute duration of follow-up is still found the most or second most important attribute. All risk perception groups find the frequency of follow-up consult the least important attribute.

Table 7 shows the most preferred attribute levels of all risk perception groups. It is expected that respondents that overestimated their perception of risk would have preference for an intensive follow-up duration, because they expect to have a high risk of a recurrence. However, the same preferences of content are found in the group that underestimated their perception of risk, when it is expected that this group would prefer a less intensive follow-up. Both risk perception groups prefer a long intensive follow-up.

Noticeable is that the group that had the correct perception of risk of a recurrence prefers a much less intensive follow-up compared to the other risk perception groups regarding duration, frequency of consults and type of contact. Figures regarding the preferences in attribute levels of the different risk perception groups are shown in Appendix 6.5 (Figure 6-8).

Underestimation of risk (n = 52)	Correct estimation of risk (n =11)	Overestimation of risk (n = 26)
Lifetime -	5 years -	Lifetime -
Four consults per year -	An annual consultation -	Four consults per year -
Personal -	Video call -	Personal -
Surgeon and breast cancer nurse -	Nurse practitioner -	Surgeon and breast cancer nurse -

Table 7. Most preferred attribute level per risk perception group

Attribute levels	Underestimation of risk		Correct estimation of risk		Overestimation of risk	
	β	Sig	β	Sig	β	Sig
3 years	-	-	-	-	-	-
5 years	-	-	-	-	-	-
Lifetime	-	-	-	-	-	-
1 year (baseline variable)	-	-	-	-	-	-
3 months	-	-	-	-	-	-
6 months	-	-	-	-	-	-
12 months	-	-	-	-	-	-
9 months (baseline variable)	-	-	-	-	-	-
Personal	-	-	-	-	-	-
Telephone	-	-	-	-	-	-
E-mail	-	-	-	-	-	-
Video call (baseline variable)	-	-	-	-	-	-
Nurse practitioner	-	-	-	-	-	-
Surgeon	-	-	-	-	-	-
Surgeon and breast cancer nurse	-	-	-	-	-	-
General practitioner (baseline variable)	-	-	-	-	-	-
Attribute importance	Underestimation of risk		Correct estimation of risk		Overestimation of risk	
Duration	-		-		-	
Frequency	-		-		-	
Contact	-		-		-	
Healthcare professional	-		-		-	

Table 8. Coefficients attribute level per perception group

4. Discussion

4.1 Findings and comparison with literature

This study examined the preferences of patients in the follow-up of breast cancer, in which the relation between risk perception and the preferences for follow-up was determined. The aim of this research was to determine if differences in preferences could be found between different risk perception groups. If certain preferences could be related to perception of risk, a more individualized follow-up could be realized.

Firstly, it was investigated if there is a relation between physical and psychological symptoms and the risk perception of patients. No statistical differences were found. The results showed certain trends. Especially patients with psychological symptoms overestimated their risk of a recurrence compared to patients without psychological symptoms. This trend was also seen in the relation between physical symptoms and risk perception. However, it is difficult to determine if these trends are valid. Several studies have investigated whether patients, that received more physical and psychologically aversive treatments such as chemotherapy or mastectomy, have a higher fear of recurrence than patients that received a breast conserving surgery. While some studies find a direct relation between a more physical and psychological aversive treatment and a higher fear of recurrence, other studies did not find that relation (21, 39).

Two methods were used to determine the total follow-up content preferences of the patients. The quantitative method shows that respondents have the highest preference for the following follow-up program: a personal follow-up with four consults per year with a surgeon and breast cancer nurse for the rest of their lives. Results from the qualitative method show that respondents have a preference for the following follow-up program: a personal annual follow-up consult with a nurse practitioner for the rest of their lives. Differences are found in preferences between the quantitative and qualitative methods regarding frequency and type of healthcare professional. Both methods showed similar results in preferences regarding the duration of the follow-up. Respondents had a preference for a long follow-up, at least ten years and preferably lifetime follow-up. This preference for a lifetime follow-up is earlier confirmed in research done by de Bock et al (2004), in which more than half of the patients preferred lifetime follow-up (10). The quantitative results show that respondents have the highest preference for four follow-up consults per year. If we compare this frequency with the qualitative data, most respondents have preferences for an annual follow-up consult. This difference in frequency between the two methods could be explained by that the respondent does not find frequency of follow-up consults an important follow-up aspect, which was shown in the low attribute importance in the quantitative data (see Table 5). Another difference in preference between two methods is found in the type of healthcare professional. The quantitative results show that the respondents have the largest preference for a surgeon and breast cancer nurse in which a nurse practitioner was the second preferred healthcare professional. However, the qualitative results show that respondents have the largest preference for a nurse practitioner and have no preference for a surgeon and a nurse. Both methods show that patients find a nurse a very important healthcare professional.

Patients often report that they appreciate the nurse practitioner because she is approachable, qualified and takes time for a follow-up consult. Also some respondents reported that they appreciate the nurse practitioner because they could express their emotional concerns more easily to a nurse, which is also confirmed in other studies (11, 12). Multiple studies had interest in a general practitioner leading follow-up care (11, 40, 41). Grunfeld et al (2006) found that a follow-up led by a general practitioner is evenly effective as a specialist follow-up (41) and that patients were satisfied having a follow-up in the primary care (40). However, patients in this study do not share this preference. Respondents reported that the general practitioner would lack breast cancer knowledge and is too busy to be a follow-up professional. However, some patients reported that they would return to their general practitioner if the hospital follow-up ended which is also confirmed in other research (7, 19).

Another aim of this study was to determine the patients' aims in follow-up. Results showed that respondents find the aspects physical examination and reassurance the most important goals in follow-up. The importance of these goals corresponds with comments of the patients during the questionnaire. Besides the physical examination, patients mentioned that the annual mammography is also an important part of the follow-up in reassuring that they are still breast cancer free. As shown in the qualitative data, respondents had a high preference for the personal and lifetime follow-up. Finding the physical examination important corresponds with the high preference for a personal follow-up. Respondents reported that this personal contact with their healthcare professional is especially appreciated for the physical examination. If we look at the number of respondents that performed self-examination it becomes clear why respondents find the goal *physical examination* very important. 29 respondents reported that they regularly perform self-examination (ranging from daily to weekly). 24 respondents (27.0%) reported that they give themselves a physical examination on a monthly base. The remaining 36 respondents (40.4%) said they rarely or never give themselves a physical examination. Respondents reported that they do not often perform self-examination because the follow-up includes a physical examination. Finding reassurance as the most important follow-up goal corresponds with the high preference for a lifetime follow-up. Respondents often reported that they prefer a lifetime follow-up just to reassure that the cancer did not return. Of less importance were the goals: *to discuss the treatment and side effects* and *guidance*. Respondents still appreciate these aspects of the follow-up. 87.6% (important and very important combined) of the respondents finds this goal important. This corresponds with results from earlier research (10). Patients find the aim *psychosocial support from healthcare professionals* the least important aim of follow-up, which is also confirmed in previous research (7). Especially respondents that underestimate their risk did not find the psychosocial support important. The low appreciation of the psychosocial support could be explained by that patients are afraid to ask for psychological support. Research showed that patients often do not feel comfortable raising emotional or psychological concerns towards their healthcare professionals in the follow-up (18, 19). However, a difference in the importance of the psychological support was found in the type of living situation. Respondents that lived alone find this goal more important than respondents that live together. While the psychological symptoms decrease during the follow-up, the number of respondents with physical symptoms increases. Regarding anxiety and depression symptoms, this study showed that a larger number of respondents endures these symptoms compared to previous studies. However, these anxiety and depression symptoms decrease during the follow-up. Still 46.1% of the respondents has depressive symptoms and 55% of the respondents has anxiety symptoms. The increase of the physical symptoms group could be the result of side effects due to the treatments they recently received or still receive, which can cause different physical or mental side effects. A total of five respondents reported that their therapy treatment ended this year. A total of fifteen respondents reported that they still receive hormone therapy and one respondent reported that she still receives immunotherapy.

Lastly, the aim of the study was to determine if the perception of the risk of recurrence influences the need for follow-up. Results showed some differences between the risk perception groups. All risk perception groups find the duration of follow-up the most important attribute and the amount of follow-up consults the least important attribute. Respondents that overestimate and underestimate their risk of a recurrence had exact the same preferences for follow-up content. The preferences of both risk perception groups show that patients have preference for a personal lifetime follow-up consisting of four consults per year with a surgeon and breast cancer nurse. Only a difference in preferences between the groups was found in the respondents that had a correct perception of risk. This group had the highest preference for a five year annual follow-up consult by video call with a nurse practitioner.

4.2 Limitations

Multiple limitations are found in this study. The limitations in each aspect of this study are discussed in the following paragraphs.

4.2.1 Statistical significance

The main limitations in this study are the weak statistical differences found in the qualitative data. Multiple attribute levels have a significance level > 0.05 . A mistake was made in determining the minimum number of respondents needed for a DCE analysis. By using the rule of thumb of Orme, a minimum sample size of 84 respondents is needed for the DCE analysis in this study. Multiple attribute levels are not significant in the total preferences of this study population. Because this study maintains three DCE analyses (a DCE analysis for each risk group), a total minimum population of 252 (3×84 respondents per perception group) was needed. Therefore, no significant statistical differences could be found between the risk perception groups. However, achieving this number of respondents (equally divided into the three risk perception groups) would require a larger number than 252 breast cancer survivors. This is due to the different risk perception groups that are not equally distributed. The respondent that underestimate their risk represents approximately 58.4% of the total population, the respondents with the correct risk perception group represents approximately 12.3% of the total population and the respondents that overestimate their risk represents approximately 29.2% of the total population.

4.2.2 Discrete choice experiment design

Earlier research, that also performed a DCE, showed that patients have a preference for an alternating combination of follow-up with a breast cancer nurse and a surgeon (12). However, they referred the breast cancer nurse and the nurse practitioner as breast cancer nurses in their scenarios. Therefore, it could occur that respondents did not know the difference regarding the description of a breast cancer nurse when choosing a scenario. This research did not merge the two healthcare professionals as breast cancer nurses and the researcher noticed that some respondents did not know the difference between a nurse practitioner and a breast cancer nurse. Therefore, it is possible that some respondents thought they were the same healthcare professional when they chose their preferred scenarios. The nurse practitioner was the second most preferred healthcare professional in the quantitative data. The healthcare professional was the second most important attribute when patients chose their scenarios. Therefore, it is possible that the coefficient of the surgeon and breast cancer nurse is overestimated and that the coefficient of the nurse practitioner is underestimated. This would correspond with the qualitative data, which showed that the nurse practitioner is the most preferred healthcare professional.

4.2.3 Psychological and physical symptoms

To determine the relation between risk perception and the psychological and physical symptoms 22 symptoms are used, based on a five-point Likert scale. Research showed it is difficult to reveal the psychological complaints, especially depression and anxiety in patients (18). The number of respondents with anxiety and depressive symptoms in this study is considerably higher than literature suggests. Literature shows that anxiety or depression affects 20-30% of women in either mastectomy or breast conservation breast cancer treatments (14-16). This study shows that in their current situation anxiety affects more than half of the respondents (55.1%). Three respondents report that they experience many anxiety symptoms (3.4%) and 46 respondents experience some symptoms (51.7%). This higher percentage of respondents that endure anxiety and depression could be the result of not using an official measure instrument such as the Hospital Anxiety and Depression Scale (HADS) or State-Trait Anxiety Inventory (STAI). Therefore, it could occur that the method of questioning used in this study is too limited to reveal anxiety or depression symptoms.

Also some difficulties occurred in determining the degree of physical and psychological symptoms. Some respondents did not know exactly the degree of the symptoms they endured in the beginning of the follow-up or they had difficulties to distinguish a certain symptom because they had other chronic illnesses. Bias could also occur in determining the symptom groups. A cut-off point is determined in the total sum of the physical and psychological symptoms, in which respondents that scored lower than 40 were coded as a group with symptoms and respondent that scored above 40 are coded as a group without symptoms. This cut-off point is based on an assumption of this study. The calculation of this scoring is shown in Appendix 6.4 *Recoding the data*.

4.2.4 Risk perception and fear of recurrence

All respondents completed the questionnaire after their follow-up consult. Research showed that patients are less worried, anxious and frightened after the follow-up consult (11). Therefore the risk perception of a breast cancer recurrence could be influenced. Especially respondents that are currently attending their follow up between 1–5 years underestimate or overestimate their risk of a recurrence. Earlier research showed that patients are often inaccurate in their perception of risk (29-31). Research shows that the risk of a recurrence is between 20-30% in the first five years and decreases over the years (25). This study classified the patients in different risk perception groups based on their perceived perception of risk and the amount of years they are currently attending their follow-up. However, the risk of local regional recurrence depends on various factors such as age, tumor size and nodal status (25). This study did not take into account the tumor size and nodal status of patients. Patients who had a larger tumor size or more infected nodals could have a higher risk of recurrence. Therefore, this study could misplace patients in risk perception groups. Patients could be categorized as respondents that overestimate or underestimate their risk, while in reality they respectively did not overestimate or underestimate their risk of a recurrence. Besides the perception of risk of a recurrence and psychological and physical impairments, fear of recurrence increases economic and social state that are associated with breast cancer (22). This study did not take into account the social or the economic state of the respondent.

4.2.5 Data collection

Another limitation that could cause bias in the results is in the collection of the data. An example of a DCE question was available in the patient letter and in the questionnaire. Before the respondent started with the questionnaire, the researcher briefly explained the DCE example question and reported that the risk perception is due to a local regional recurrence. Still respondents, especially older patients, had difficulties with the DCE questions. They often compared the scenarios with their own follow-up and if there was not a scenario that looked similar to their current follow-up, they passed this question. Respondents that completed the questionnaire on LimeSurvey did not receive additional information but could ask questions by e-mail. However, no respondent contacted the researcher for questions. The questions in LimeSurvey were compulsory. Therefore, it could occur that respondents did not understand a question but just completed it, so that they could go to the next part of the questionnaire. Besides difficulties with the questionnaire, bias could occur in providing information to the respondents. There were multiple respondents of higher age that forgot their reading glasses or respondents that had difficulties with reading or writing. In this situation the researcher read the questions and noted the answers. Another limitation in the data collection was the influence of persons that accompanied the respondents. Some respondents were accompanied by their partner, friends or child(ren) and were possibly influenced by them during the questionnaire. Respondents that completed the questionnaire at home could also be influenced by family or friends.

4.2 Recommendation

To our knowledge this is the first study that examined the relation between risk perception and the follow-up preferences of breast cancer patients. Risk perception is an important aspect to examine because inaccurate perception about risk can have important behavioral and psychological consequences. To determine the risk perception this study used the risk perception based on research done by Gagnon et al (29). There are multiple studies that examined the risk perception of breast cancer patients and there is a large inconsistency in how perception of risk should be assessed. Some studies that measured the risk perception suggest that women dramatically overestimate their risk of having breast cancer while other studies conclude they underestimate it (30, 31). In future research, studies could use different risk perception methods to decrease bias. Future research could investigate the difference between perceived risk and actual risk of a recurrence in relation with the patients' follow-up preferences. Also future studies should include the economic state and social status of patients, because these factors influence the fear of recurrence.

As mentioned in the discussion, the number of respondents with anxiety and depression symptoms in this study is larger than literature suggests. Therefore, bias regarding psychological and even the physical questions could occur in this study. To determine psychological and physical symptoms, future research should use valid instruments to determine the degree of these symptoms. By doing this, a more accurate relation between risk perception and the symptoms could be determined.

Also a recommendation could be made regarding the DCE design. This study used 24 full profile hypothetical DCE scenarios. The researcher noticed that respondents, especially older patients, had difficulties with these questions. By maintaining a partial profile with fewer attributes shown in each scenario, the cognitive burden for the patients could be decreased. However, using partial profile scenarios would increase the number of DCE questions for determining the exact coefficients of the attribute levels and could therefore increase the cognitive burden. Therefore, future research should first use a questionnaire with partial DCE scenarios and a questionnaire with full profile DCE scenarios during the pilot test to determine which type of profile patients will find least difficult.

Another recommendation could be made for both hospitals regarding the patient education for developing a local regional recurrence. The researcher in this study noticed that some respondents that had a mastectomy claimed that they do not have a risk of a recurrence because the breast that contained the tumor is removed. The perceptions of these respondents are not correct, because the risk of a local regional recurrence is almost similar in both groups.

4.3 Conclusion

Taking the limitations of this study into account, this study cannot conclude if there is a relation between patient preferences and risk perception due to fear of a recurrence. Differences in preferences regarding content and the patients' aim of follow-up are found between the risk perception groups. However, almost all these differences are not statistically significant. A trend was found between risk perception groups in the importance of psychosocial support. Patients who had the correct risk estimation and patients that overestimated their risk, find this aim more important than patients that underestimate their risk. Regarding the content of follow-up, respondents that underestimated and overestimated their risk of a recurrence showed similar preferences. It is possible that the perceived risk perception of patients is not a strong indicator to determine differences in preference. Further research is needed to determine the exact relation between risk perception and patient preferences in which a larger number of respondents should be included to ensure more statistical proof.

5. Literature

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6. Appendix

6.1 Preferences measure instruments

The preference of patients can be assessed by different methods. There are general methods, such as ranking or rating or more specific methods such as standard gamble (SG), time trade-off (TTO), visual analogue scale (VAS) and discrete choice experiment (DCE). A difference between general methods and specific methods (with exception of the visual analogue scale) is that general methods do not involve a trade-off between different health states or scenarios (42).

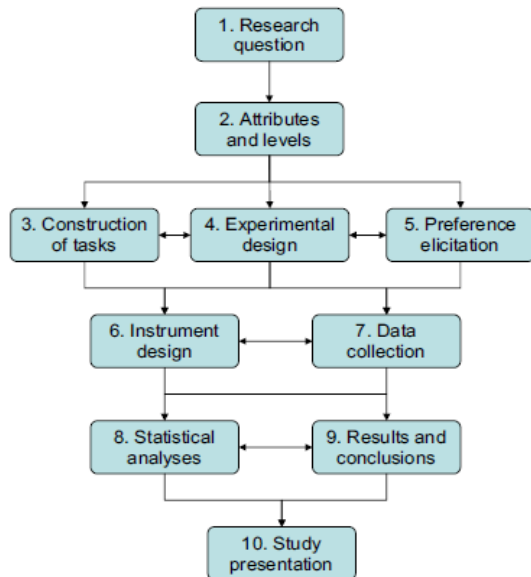
The main limitation of the SG is that it is cognitively demanding for respondents, because it requires the consideration of complex probabilities, which often results into high valuations of a scenario. A limitation of the TTO is that it only reflects decisions under certainty, not uncertainty (42). The VAS has several limitations. Just like the TTO technique, the VAS only reflects decisions under certainty and there is no trade-off between different scenarios. The VAS technique as a sole method is considered as inadequate, but combined with the SG or TTO it can play a useful role (43).

Another technique to elicit the preference of patients is conjoint analysis (CA). CA consists of different methods; ranking, rating and the discrete choice experiments. The aim of a CA is to determine the value that consumers give on a certain product or service, so that these products can be optimized. In the ranking method the respondent must rank different scenarios on an order of attractiveness from bad to good. In the rating method scenario the respondent has to rate each scenario individual on attractiveness and in the discrete choice experiment the respondent is asked to choose their preferred scenario from two or more scenarios (44). Originally CA is developed in the field of economics and marketing, but there is growing demand for discrete choice experiments in health economics, because it allows for analysis of preferences for multiple attributes services in the healthcare (45).

The DCE method can be used to determine the preference of a consumer regarding healthcare related products and programs (44). DCE is based on the idea that each service or good can be described by its characteristics and that the evaluation of a service or good depends upon the nature and levels of these characteristics (12, 46). In a DCE a healthcare consumer is offered a series of choices between two or more hypothetical healthcare scenarios. These scenarios have the same attribute but differ in levels. With DCE an estimation can be made of the relative value of different aspects of care and the trade-offs between the aspects. To carry out a DCE the most important attributes of the healthcare products or program have to be identified and assigning different levels to each attribute. The main advantage of the DCE technique over the TTO and SG is that with the DCE it is possible to assess multiple attributes rather than the usual dichotomous choice between one attribute and survival (47). A limitation of the DCE technique is the cognitive burden that is associated with completing a choice experiment. This cognitive burden for respondents is higher when the number of hypothetical scenarios, attributes and levels increases because they have to trade-off of more attributes. Therefore, the specific amount of these factors must be taken into account (48). The DCE has been successfully applied in measuring preferences in cancer treatments (12, 49) and gives choices a more closely resemble of real life decisions compared to the other methods (50).

6.2 Construction of the DCE

Bridges et al made a checklist for conjoint analysis in healthcare. This checklist consists of different steps that are needed for producing good conjoint-analysis in healthcare (35). This checklist is visible in Figure 3.



In this checklist there are ten different steps visible, certain steps such as step 1 research question are already determined. Steps 2 till 4 are explained below.

Figure 3. Checklist of Bridges et al

Step 2. Attributes and levels

Discussions with healthcare professionals and literature study constructed the following attributes that will be used in this study: *frequency*, *duration*, *contact* and *healthcare professional*. The levels of characteristics of the scenarios are called attribute levels. Each attribute consists of a number of levels. Literature suggests that a limit is set to three or four levels per attribute (35). For the attribute frequency and duration the national guideline for breast cancer follow-up is used. The minimum attribute duration level is follow-up of one year. A minimum of one year is required to monitor the wound healing resulted from the surgery and post-morbidity (e.g. psychological or physical problems). The other duration levels are: three years, five years and lifetime. The level three years is chosen because it is the mean of the recommended follow-up duration. Lifetime follow-up is chosen because literature showed that some patients would prefer a lifetime follow-up (10). The national guidelines recommend a consult every three months in the first year of the follow up, every six months in the second year of follow up and annual in the remaining three years. Regarding the level frequency we established the levels three months, six months, nine months and twelve months. Regarding the type of contact, the attribute levels are face-to-face, telephone, by e-mail and video call. A face-to-face visit to a healthcare provider consists of a short physical examination and a discussion about the well-being and recovery of the patient. A telephone follow-up consists of a discussion about the well-being and recovery of the patient via the telephone. An e-mail follow up consists of a discussion about the well-being and recovery of the patient via the e-mail. A video call follow-up consists of a discussion about the well-being and recovery of the patient via the computer. The patient can arrange face-to-face consults with the healthcare provider when needed.

Step 3. Constructing the tasks

When using a conjoint-analysis there are two different types of profiles. There are full or partial profiles. A full DCE profile shows all attributes. A partial DCE profile consists of only a subset of attributes. A partial profile could be used when researchers believe that a full profile could be too difficult for patients. However, less attributes in a profile results in more DCE questions. For this study a full profile scenario is chosen. Each profile contains four attributes with a specific level. This study has chosen for a full profile because the questionnaire already exists of multiple questions and a partial profile would result in more questions.

Step 4. Experimental design

With the four attributes and four levels the combinations of 256 scenarios ($4^4 = 256$) are possible. This study determined that a specific combination of attribute levels cannot be used in this study. The attribute levels *nine months* and *one year* cannot be combined. In this scenario the patient has a follow-up of one year and every nine months a follow-up consult. This would result in three months of follow-up that will be unused. Since presenting all 256 scenarios would be too burdensome for the respondent, a fraction of these scenarios must be used. Research has showed that for a DCE the maximum amount of attributes is six and the maximum amount of levels is three or four per attribute and that a maximum of twenty choice set of scenarios is accepted (35). To determine the number of scenarios needed to ensure a balanced choice set of attributes and levels, the program Sawtooth 6.4.6. is used to determine all possible designs. This program produced the most orthogonal design, which results that not the same attribute level occur twice in a DCE choice set. With this program 24 scenarios are determined resulting in twelve DCE choice set questions. The statistical efficiency and respondent burden must be balanced to minimize the overall error in the questionnaire responses. A higher amount of attributes and levels can cause overlap between attributes. This overlap takes place when an attribute in a choice question (between two or more scenarios) has the same level for a given attribute. This overlap can have positive effect for the response efficiency, because it simplifies the choice questions by reducing the attribute differences between scenarios. However, overlap may reduce the design efficiency because it potentially limits the amount of trade-off information obtained by the design (51).

6.2.1 Determining the sample size

For determining the sample size the rule-of-thumb by Orme was used which is shown in Figure 4.

$$\frac{nta}{c} \geq 500$$

- N = the number of respondents
- T = the number of tasks
- A = the number of alternatives per task
- C = the number of analysis cells

Figure 4. Rule-of-thumb for determining DCE sample size

The number of tasks is the number of DCE questions that the respondent will receive. The number of alternatives is the number of scenarios the respondent can choose in each question. This study used two scenarios in each DCE choice set. The number of analysis cells is equal to the largest number of levels of the attributes. The maximum amount of analysis cells (levels) that is determined for an attribute is four. The number of tasks is established at twelve. By performing this rule-of-thumb a minimal amount of 84 respondents was needed.

6.3 Data analysis discrete choice experiment

To analyze the DCE results in SPSS dummy coding is needed. With dummy coding each attribute level is recoded into 0 and 1. Dummy coding is a way of representing groups of levels using only 0 and 1. To use this dummy coding several variables have to be made. The number of variables that are needed is one less than the number of levels. This study contains four variables resulting in three attribute levels and one baseline level. An example for the dummy coding for an attribute is shown in Table 9. All the variable levels of the other three attributes are processed the same.

Attribute Duration	Dummy Variable 1	Dummy Variable 2	Dummy Variable 3
3 year	1	0	0
5 years	0	1	0
Lifetime	0	0	1
1 year (baseline variable)	0	0	0

Table 9. Constructing the dummy variables

Each DCE scenario has four attributes and each attribute has four levels resulting in three variables dummy variables. For each attribute there is a baseline level. This baseline level is the level which remaining attribute levels are compared with. This baseline level has the value 0, meaning that if the other three dummy levels are zeroes; this baseline level is shown in the scenario. For this study a total of twelve dummy variables are made and four baseline variables.

For the first dummy variable in each attribute the value 1 will be assigned and will be compared to the baseline level. The other two dummy variables (variables 2 and 3) in this attribute will have the value 0. For the second dummy variable the value 1 will be assigned and will be compared to the baseline level. The other two dummy variables in this attribute (dummy variables 1 and 3) will have the value 0. At last the third dummy variable will have the value 1 and will be compared to the baseline level. The other two dummy variables in this attribute (dummy variable 1 and 2) will have the value 0. Missing answers in SPSS are coded as 0.

6.4 Recoding the data

Data from the first part of the questionnaire, which consist of the characteristic of the respondent, are recoded. The variable *education* had ten possible answer categories. For analyzing these ten categories they are recoded in the following categories: *lower*, *intermediate* and *higher education*. Respondents that followed the education ‘lager onderwijs’, ‘lager voortgezet onderwijs’ and ‘lager beroepsonderwijs’ are coded as *lower education*. Respondents that followed the education ‘middelbaar algemeen voortgezet onderwijs’ and ‘middelbaar beroepsonderwijs’ are coded as *intermediate education*. Respondents that followed the education ‘hoger algemeen voortgezet onderwijs’, ‘voorbereidend voortgezet onderwijs’, ‘hoger beroepsonderwijs’ and ‘universitair onderwijs’ are coded as *higher education*.

The variable *living situation* is recoded into two groups. If respondents reported that they live together with a partner and or children they were recoded into group 2. If the respondent reported that they live alone they were recoded into group 1.

The variable the amount of years they are currently attending the follow-up are coded into three follow-up groups. If a respondent is attending her current follow-up between 1 and 5 years, she was coded into 1. If a respondent is attending her current follow-up between 6 and 10 years she was coded into 2. If a respondent is currently attending her follow-up longer than 10 years she was coded into 3.

Risk perception is recoded into three risk perception groups and stratified by the number of years the patients are currently attending her follow-up. Patients that currently attend their follow-up between 1-5 years were recoded into the group *underestimation of risk* if they marked risk percentages <20%. Patients in this group that marked risk percentages between 20–30% are recoded into the group *correct estimation of risk* and if they marked risk percentages >30% they were recoded into the group *overestimation of risk*. Patients that currently attend their follow-up between 6–10 years were recoded into the group *underestimation of risk* if they marked risk percentages <12%. Patients were recoded into the group *correct estimation of risk* if they marked risk percentages between 13–20% and if they marked percentages >20% they were recoded into the group *overestimation of risk*. Patients that currently attend their follow-up longer than ten years were recoded into the group *underestimation of risk* if they marked risk percentages <8%. Patients were recoded into the group *correct estimation of risk* if they marked risk percentages between 8-12% and if the marked risk percentages >12% they were recoded into the group *overestimation of risk*.

Regarding the recoding of the data of the physical and psychological symptoms the sum of all answers will be first determined. As stated before there were five possible answers. These possible answers and the scoring are shown in Table 10.

Answering categories	Scores
Always suffer from	1
Usually suffer from	2
Sometimes suffer from	3
Rarely suffer from	4
Never suffer from	5

Table 10. Possible symptom answer categories

A total of eleven questions are mentioned for the psychological and physical symptoms. A minimum score of 11 and a maximum score of 55 points could occur (11 x 1 = 11 points and 11 x 5 = 55 points). If a respondent mainly crossed category 5 (and in lesser extent score 4), this study assumed she did not develop symptoms due to breast cancer. The answering category *rarely suffer from* indicates that breast cancer did not have a significant influence in causing that symptom. If a respondent only chose category 4 a maximum score of 44 points will be the result. In order to take into account that these symptoms still could have some impact on the patient a cut-off score was made. This cut-off score is 40 points. This cut-off score indicates that respondents that crossed category 4 are still included in the symptom group. Therefore, all respondents that scored below 40 points are coded as respondent with symptoms. Respondents that scored higher than 40 points are coded as respondents without symptoms.

The psychological symptoms anxiety and depression are recoded into three groups. A respondent is coded into *Many symptoms* if she marked the answers always or mostly. A respondent is coded into *Some symptoms* if she marked sometimes or rarely. A respondent is coded into *No symptoms* if she marked *never*.

The patient goal: *Psychological support* is recoded into three groups. If the respondent reports that she finds this aim *very important* or *important* she is coded as important. If the respondent reports she finds this aim a *neutral* degree of importance she is coded as neutral. If the respondent reports she finds this aim *not very important* or *not important* she is coded as not important.

6.5 Tables and figures

This part is confidential

6.6 Questionnaire

This part is confidential