

Patient preferences for breast cancer follow-up

A discrete choice experiment

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Master thesis for Health Sciences

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Cover: Logo of Timaru **Pink Ribbon Women's Duathlon** (www.takethechallenge.co.nz)



Preface

This study focuses on determining preferences for follow-up of breast cancer patients and took place from September 2007 until May 2008 at the MST Hospital (Medisch Spectrum Twente) in Enschede, The Netherlands. Medisch Spectrum Twente is a conglomeration of different hospitals in the Eastern part of The Netherlands. A special division of the MST is the Centre for Mammacare. This Centre treats and offers follow-up to many breast cancer patients from the Twente region and other parts of the Netherlands.

Determining patient preferences was a new field of investigation for me. It proved to be a very interesting one, and a very important one as well. Patient preferences are more and more involved in medical decision making, besides evidence-based medicine. This study has benefited from the help and support of some people. In this preface I would like to thank some of them in particular.

First of all I would like to thank prof. dr. M.J. IJzerman and dr. J.M. Hummel of the University of Twente, and dr. J.M. Klaase and C. Bandel of the Centre for Mammacare for their guidance in this study. They provided me with great support and feedback, which resulted in a study I am very proud of to present to the reader.

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Finally many thanks go to the secretaries of department 28-1 of the MST hospital and the Centre for Mammacare, for their extensive effort to provide the patients with the questionnaire this study is based on.

I hope this study will contribute to breast cancer follow-up that is satisfying for the hospital, as well as for the patient.

Enschede, June 2008

Timon Sibma



Executive Summary

In the Netherlands about 12500 women (1 out of 8) are diagnosed with breast cancer annually. Combined with the fact that the survival rate of breast cancer patients is approximately 88% because treatments become more effective, makes that an increase of number of patients is expected. This increase causes breast cancer to be a very relevant point of interest in Dutch healthcare, because only a limited number of resources and capacity is available.

After primary treatments a surveillance strategy starts, provided by the health care institution where the patient received treatment. Different reasons exist for follow-up although no clear evidence exists for the effectiveness of follow-up. It is an international trend that, besides evidence based medicine, patient perspectives and preferences are taken into account when it comes to decision making in health care. Although this Shared Decision Making typically focuses on individual cases, this approach can be uplifted to a more general model in which patient preferences are involved when new policy is created. This is also true for breast cancer follow-up. Many studies focus on the cost-effectiveness of follow-up, but lack to take patients preferences into account.

This study investigates the preferences of patients for follow-up, whether preferences between 3 predefined risk groups differ, and if coping style and the fact that time to the primary treatment increases, affect preferences. A Discrete Choice Experiment was applied to elicit preferences in which 125 respondents were included. Different scenarios that varied in 3 characteristics (total time span, frequency per year, and type of consult) were developed and tested for preferences. Risk groups were predefined based on medical characteristics (size of the tumor and number of lymph nodes infected) and age. Sawtooth Software and SPSS were used to process and analyze the data.

Results show that patients have strongest preference for 5-year follow-up, twice a year, performed by the surgeon in a face-to-face setting. However, 3-year follow-up and follow-up by a Nurse Practitioner (NP) are also accepted by part of the respondents. The latter is particularly interesting, because only approximately 10% of the patient had actual experiences with a NP at the time of measurement, while approximately 25% showed preference for follow-up by a NP. Just 1-year follow-up, as well as follow-up by telephone, was least preferred. Analyses per attribute level showed no significant differences between the risk groups and preferences. However, logistic regression analyses showed weak significant differences and a sign of relationship: the lower the risk group, the higher the preference for expensive follow-up. This is a notable conclusion that goes against our hypothesis and requires further research. No relationship between coping style and preferences, nor number of years in follow-up and preferences were found.

Previous studies show various reasons for preferences, in which the current follow-up plays an important role. To have new policies accepted by patients, providing adequate information to patients is important, because misperceptions about the effectiveness of follow-up are widely spread among the population.



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1 INTRODUCTION

Breast cancer follow-up is a well-discussed topic. Many discussions have been conducted and are ongoing about the medical effectiveness, about the best way to offer follow-up, and about the role of the patient. This study especially focuses on that last point of interest.

This chapter is the introductory chapter. Paragraph 1.1 gives a short introduction and background to the subject. To gain insight in the concept of follow-up, paragraph 1.2 describes the reasons why follow-up is offered to cancer patients and the national and local guidelines for follow-up are described in 1.3. Paragraph 1.4 describes the medical effectiveness of follow-up. Many studies show that there is hardly evidence for effectiveness, and this paragraph describes studies explaining this. Paragraph 1.5 subsequently defines the problem description, which states that besides low cost-effectiveness evidence, patient preferences are uncertain. In paragraph 1.6 the research questions and study hypotheses are given, and the chapter is concluded with the scientific importance of this study in paragraph 1.7, which draws comparisons with other studies investigating the same topic.

Various medical terms are introduced in this chapter. They are summarized and further defined in Appendix 1: Glossary.

1.1 Background

In the Netherlands about 12 500 women are diagnosed with breast cancer annually (making up for more than 33% of female cancer patients) and approximately 3500 women die every year of breast cancer (Visser and Van Noord 2005). Only 80 men are annually diagnosed with breast cancer, making this type of cancer especially applicable to women. About one in every eight women will be diagnosed with breast cancer during her lifetime (Kankerbestrijding 2007). The risk of cancer increases with age, and because of the demographic ageing of the Dutch population the amount of patients with breast cancer is increasing. This is also caused by the fact that the effectiveness of treatments has been improved, which lead to an increase of the survival rate (Health Council of the Netherlands, 2007). The 5-year survival rate is approximately 88% (depending on various medical characteristics of the patient, and received treatment) (Thurfjell and Lindgren 1996). Because of the expected increase of patients due to these reasons, costs are rising (Grunfeld, Fitzpatrick et al. 1999). The limited capacity of health care makes this trend a very relevant point of interest in Dutch healthcare and it is crucial correct choices are made. It is an international trend that with these important choices patient opinions are more often taken into account as well, besides medical based medicine (Coulter 1997). This shift of paradigm leads to the importance for policy makers of new follow-up guidelines to have knowledge about patient satisfaction, opinion and preferences, and is more extensively explained in paragraph 1.5: Problem Description.



The Centre for Mammacare annually receives about 500 patients with suspected breast cancer. Approximately 250 of these patients are diagnosed positively. After positive diagnosis the clinical part of the treatment starts in which either mastectomy (removal of the breast) or breast-conserving therapy is performed, optionally with supplementary treatments like radiotherapy and/or chemotherapy, depending on diagnosis. After these primary treatments the surveillance strategy starts, typically provided by the health care institution where the patient received treatment. The patient annually returns to the hospital for a check-up. Follow-up is defined as the subsequent examination of a patient for the purpose of monitoring earlier relapses. Follow-up has five aims, described in the next paragraph.

The follow-up consults vary in time span and frequency per year, depending on national and/or local valid guidelines. In The Netherlands, the nationally recommended procedures for breast cancer follow-up are described by the Institute of Quality in Health Care. In addition to these guidelines, the Centre for Mammacare follows locally agreed guidelines, which are more extensive in time span and frequency per year than the national guidelines. Further information on the guidelines can be found in paragraph 1.3.

1.2 Reasons for follow-up

Various reasons exist why follow-up is offered (Jacobs et al. 2001; Wiggers 2001; Hiranamek 2004; Kimman et al. 2007a).

1. Detection of loco-regional recurrence

Breast cancer patients have a certain risk of recurrence, depending on primary diagnosis. A loco-regional recurrence is cancer that occurs in the same breast as the first tumor. Some patients have higher risk of recurrence than other patients. The risk depends on various factors, such as age, tumor size and lymph nodal status. The peak hazard of recurrence occurs in the interval of 1 to 2 years. After this period the hazard decreases slowly, with a mean hazard of recurrence of 4,3% per year in 5 to 12 years post surgery (Saphner, Tormey and Gray 1996). When a local recurrence is diagnosed, the patient is first checked for metastases, a transfer of cancer from one organ or part of the body to another not directly connected to it. When metastases are not present, curative treatment is possible.

2. Detection of second primary tumors

Women with breast cancer have a higher risk for a second primary tumor than women who have not had breast cancer: approximately 0,6% risk per year (Gao, Fisher et al. 2003). A second primary tumor is a tumor that occurs in the other breast than the one of the first tumor. Because of this higher risk, surgeons perform follow-up in order to detect second primary tumors in an earlier stage.



3. *Evaluation of primary and adjuvant therapies*

During follow-up, the surgeon inspects the results of the therapy. Especially in the first year after curative treatment, postoperative morbidities exist that need to be treated such as monitoring the healing of the wound and psychosocial problems.

4. *Psychosocial support*

Breast cancer has a great physical, psychological and social impact (Ferrell, Hassey-Dow and Grant 1995). Fallowfield and Baum (1989) conclude that many women experience anxiety and distress. Follow-up can help relieving this distress, therefore influencing the quality of life. A follow-up consult gives women the reassurance no recurrence or second primary tumor has developed, and some women appreciate this reassurance (Allen 2002). A more recent study found a reduced rate of cancer-related worries associated with follow-up (Lash at al., 2005). At the same time, these consults are the cause of stress. 70% of women experience distress at follow-up (Paradiso et al. 1995).

5. *Collecting data for research*

Medical research often takes place in the form of clinical trials. These trials need data to measure variables. Follow-up provides an opportunity to record data for research (Hiramanek 2004).

It is important to realize that patients who develop distant metastases are essentially incurable (Shapira 1993). Distant metastases in breast cancer mostly occur in the lungs, liver or bones. Cancer that occurs in the lymph nodes however, can be treated most of the times. It is important to understand this difference. Because of the incurable character of distant metastases, diagnosing these distant metastases is not one of the aims of follow-up. Discovering these incurable metastases when the patient has not yet developed symptoms has a large psychological impact and leads to a decreased quality of life.

1.3 *Current guidelines for follow-up*

In the Netherlands the Institute of Quality in Healthcare (Kwaliteitsinstituut voor de Gezondheidszorg, CBO) publishes national guidelines for the follow-up for breast cancer patients. The CBO tries to improve patient care in the Dutch health care system, focusing on less complications, shorter waiting times for surgeries, and better cooperation between patient and health care provider, disciplines, departments and hospitals.

In its 2005 report, in cooperation with the Vereniging van Integrale Kankercentra, CBO recommends to have consults that include history taking and physical examination 4 times in the first year of follow-up, twice in the next year, and once a year thereafter. No particular time span is recommended, but indicated is that in normal circumstances this should not be

² http://www.cbo.nl/algemeen/default_view



longer than 5 years, unless the patient has the BRCA 1/2 gene mutation, which heightens the chance of breast cancer. Furthermore they recommend a mammography once a year until the age of 60, and once in 2 years thereafter. Patients and their general practitioner should know whom to contact when symptoms arise.

In addition to the national guidelines, regional guidelines exist that apply to the Centre for Mammacare. These guidelines are formulated by ONCON, the Oncological Network Surgeons East Netherlands (Oncologisch Netwerk Chirurgen Oost Nederland). Their guidelines can be consulted in the next table. The main goal of this network is to optimize the oncological surgery for cancer patients². The differences between the national and local guidelines can be found in the frequency and time span of the consults. Since the Centre for Mammacare follows the local guidelines, these guidelines were taken as a basis for this study.

Women < 60 years	Years 0-5	Years 6-10	Years >10*
History + PE	2x	1x	1x
Mammography	1x	1x	1x
Women ≥ 60 years	Years 0-5	Years 6-10	Years >10*
History + PE	2x	1x	1x
Mammography	once in 2 years	once in 2 years	once in 2 years
PE = Physical Examination			
* Optional when considered appropriate			

Table 1 Current follow-up scheme Centre for Mammacare, frequency per year (Source: MST)

1.4 Effectiveness of follow-up

Breast cancer patients frequently return to the hospital for their follow-up visit. These follow-up services can be divided into two groups, according to intensity. Limited follow-up includes annual history taking, physical examination and a mammography (annually or once in 2 years). In addition to these elements, intensive follow-up also includes chest X-ray, blood analysis and bone scintigraphy (bone scan). The total time span of the follow-up, as well as the frequency per year can also vary between the two types of follow-up services. Typically a surgeon provides the service in both types, in which the patient comes to the hospital for a face-to-face consult. In the Netherlands, limited follow-up is normally offered, because intensive follow-up does not prove to be medically efficient (see further).

²http://www.ikcnet.nl/1/ST/werkgroepen/oncologisch_netwerk_chirurgie_oost_nederland/index.php



In the past 20 years many studies have been performed that studied the effectiveness of follow-up services. Collins, Bekker et al. employed a systematic review of these studies. All previous studies that reported empirical data of patients attending a routine follow-up service after treatment for breast cancer were included (in English, from 1989 to 2001) and frequency tables were used to summarize the study characteristics. From the selected studies, a systematic review of 38 articles that met previous defined conditions was performed about the effectiveness of follow-up services (Collins, Bekker et al. 2004). After reviewing these 38 studies, Collins et al. conclude that no scientific evidence exists that justifies intensive follow-up for patients who have been treated for breast cancer. A minimal approach (defined earlier in this paragraph) is as effective as intensive follow-up in terms of survival, timeliness of recurrences detection, and quality of life.

A study that shows similar results, and was not included in the review of Collins et al., is a study by Jacobs, Dijk et al. (2001). In their study the authors applied a simulation model to evaluate the impact of different follow-up strategies, using a five-state Markov chain model. Medical aspects such as life expectancy and the percentage of the patients who died from breast cancer were studied. In the simulation, the output of standard follow-up (defined as physical examination and history taking (three-monthly in the first year, six-monthly in the second to sixth year and annually thereafter) and an annual mammography) was compared to the output of no follow-up at all, in 4 different age cohorts: 40, 50, 60 and 70 years. The conclusion of this study reaches even further than the conclusion of Collins et al., saying that in the most beneficial situation the gain in years of life for a woman aged 40 is only 73 days, and even less for a woman aged 60: 37 days.

Two studies that were reviewed by Collins et al. and are considered to definite support that intensive follow-up is unnecessary (te Boekhorst, Peer et al. 2001), are the studies of the GIVIO-investigators and Roselli Del Turco et al., both published in the Journal of the American Medical Association. The GIVIO-investigators performed a randomized clinical trial in 26 Italian hospitals in which 1320 women were assigned to one of two groups of follow-up that varied in intensity, and concluded that routine use of intensive follow-up methods should be discouraged (GIVIO-Investigators 1994). In the study of Roselli del Turco et al. a randomized clinical trial allocating 1243 patients who had been treated for breast cancer to two alternative follow-up protocols was performed: intensive and limited follow-up. The conclusion of this study is that a periodic chest X-ray and bone scan do allow earlier detection of metastases, but has no impact on prognosis. The final conclusion is that intensive follow-up (defined previously in this paragraph) should not be recommended as a routine policy (Roselli Del Turco, Palli et al. 1994).

The conclusion that earlier detection of a relapse does not have effect on prognosis or on the improvement of survival not only questions the effectiveness of intensive follow-up, but also the effectiveness of limited follow-up. This is underlined by te Boekhorst et al., who, in their analysis of 270 patients, found no significant differences in survival after recurrence between patients in the asymptomatic stage (the stage in which symptoms are not yet possible to detect by the patient herself and can only be discovered by follow-up visits) and patients in the symptomatic stage (the stage in which the patient herself can detect



symptoms of a recurrence, which means that these recurrences can be discovered without any follow-up service at all) (te Boekhorst, Peer et al. 2001). Despite the fact that 66% of the recurrences were detected during a routine follow-up visit, the authors conclude that the survival does not improve, and conclude that routine follow-up hardly affects the course of loco-regional recurrence (a relapse in the same breast).

This conclusion corresponds to the conclusion of the study by Jacobs et al., earlier discussed, and the conclusion of Loong et al., who reviewed 490 patients and also comes to the conclusion that detection and treatment of local recurrence in the asymptomatic stage do not have beneficial effects on overall survival (Loong et al. 1998).

In this paragraph the most important of many studies were mentioned that allocates insignificant efficiency to even limited follow-up. In summary, it can be concluded that two reasons exist why even limited follow-up is not medically efficient: only a minority of the recurrences is found in the asymptomatic stage, and the life expectancy of those women who do get diagnosed earlier during a follow-up visit does not increase significantly. Many more than the above mentioned studies conclude the same (e.g. Telaro et al. 2007; Tolaney and Winer 2007; Tondini, Fenaroli et al. 2007; Kimman, Voogd et al. 2007a).

1.5 Problem description

The previous paragraph showed that for many years studies have come up with the same conclusions over and over again, generally assigning little medical effectiveness to neither extensive nor limited follow-up. One may wonder, despite the results of these studies, why are the follow-up schemes still as long and intensive as they are today? Although the national guidelines show a trend of decrease of length and frequency, the Centre for Mammacare wants to finally cut through this tradition by introducing a more individualistic approach, with the underlying goal to increase the efficiency and effectiveness of follow-up. Although studies assign little medical effectiveness of follow-up in general, these conclusions do not apply to the whole patient population, since all patients have different characteristics. The current follow-up leaves little room for individualizing follow-up. A more individualistic approach only assigns an intensive follow-up to patients who actually need it, e.g. because of medical or psychosocial circumstances. This not only improves the quality of life for the patients in the follow-up (Allen 2002), but also for new patients, since more time becomes available for this group. Breast cancer has a tremendous influence on one's life, and therefore a high quality of care is important (Fallowfield, Hall et al. 1990). Literature suggests that, although medical reasons might be absent when calculating the efficiency of follow-up, other reasons exist why these services are desired by the patients. Patients appreciate information on long-term effects of diagnosis and treatment, and the possibility to discuss prevention of breast cancer hereditary factors and changes in the untreated breast. A study investigating the relationship between anxiety and preferences for follow-up concludes that women with higher scores on measurements of anxiety or depression have a stronger preference for intensive follow-up, showing that psychological effects are



important (de Bock, Bonnema et al. 2004). To conceptualize psychological effects, one of the concepts that is used in literature is coping style; the way people deal with their disease and the role information has in this process (Phipps and Zinn 1986).

Not only does the Centre for Mammacare wants to offer more individualistic follow-up in the interest of the patient, but also for other reasons. At this moment, according to one surgeon of the Centre for Mammacare, consulting follow-up patients takes so much time that it starts to affect the ability of surgeons to treat new patients. Another reason is that costs for follow-up services are significant, and rising because of the increase of the patient population (Grunfeld, Fitzpatrick et al. 1999). Therefore, this study is part of a broader two-section study. The other section investigated the cost-effectiveness of different follow-up scenarios, concluding that the Centre for Mammacare can cut back costs up to 30% by offering less follow-up services to patients who do not need this (see "Individualized breast cancer follow-up", Master thesis of J.J. van Elteren of the University of Twente, 2008).

In this study the focus also lies on offering more individualistic follow-up, but corresponding to the preferences of patients. The opinion of patients becomes more important in health care. It has been claimed that there is an international paradigm shift of shared decision-making replacing the old paradigm of 'the doctor knows best' (Coulter 1997). Many studies have investigated this new approach. However, a clear, uniform definition does not yet exist (Moumjid et al. 2007). Terms such as informed decision making, partnership, patient involvement and patient centered care are used, all as synonyms for shared decision making (idem). All definitions contain the characteristic that describes that decisions are shared by the doctor and patient. Haynes, Devereaux et al. (2002a) describe a model in which different aspects are taken into account when medical decisions have to be made. In their study they focus on patients with hypertension, but their model can be applied to other medical fields as well. Although the authors themselves recognize several shortcomings of the model, their model provides a useful approach in medical decision making. Four components play a major role when it comes to medical decision making: the clinical state and circumstances of the patient; research evidence; patients' preferences and actions; and finally clinical expertise (basic skills and experience). The model focuses on the individual patient in an individual consult, in which a shared decision has to be made about an individual treatment. However, this approach can be uplifted to a more general model, in which patients and their preferences and opinions are involved when new policy is created. As the authors state "evidence does not make decisions, people do" (Haynes, Devereaux et al. 2002a). It is clear that medical decision making is no longer based solely on effectiveness and medical experiences, but that patient preferences and wishes should certainly be taken into account as well.

Previous studies have been conducted in order to explore the preferences and perceptions of women who are in follow-up after breast cancer treatment (Pennery and Mallet 2000; Allen 2002; Renton, Twelves et al. 2002; Bock, Bonnema et al. 2004, Grunfeld, Fitzpatrick et al. 1999). However, the conclusions of these studies are ambiguous. One of the largest studies that focused primarily on preferences is that of Renton, Twelves et al. (2002), who questioned 134 women and concluded that patients appreciate intensive follow-up services



because of the reassuring effect. On the other hand, these visits cause anxiety, as Allen (2002) states: "Required attendance produces anxiety in women who were otherwise living free from anxiety about breast cancer recurrence. This anxiety appeared to create a need to attend in order to gain reassurance of continued well-being".

These facts taken into account, the problem formulation is:

Although cost-effectiveness modeling studies conclude that breast cancer follow-up services can be limited resulting in decreasing costs, these studies do not take into account patient preferences.

The main goal of this study is to measure patient preferences for predefined follow-up scenarios, and to investigate whether differences between predefined risk groups exists (see paragraph 3.1). The results of this study can influence the quality of the consults in terms of consensus to patient preferences en desires.

1.6 Research Questions and study hypotheses

The main research question is derived directly from the problem formulation:

Which of the proposed breast cancer follow-up scenarios do patients prefer, and do differences in preferences exist between patient groups?

The sub-questions that help answering the main question are:

- 1) Which of the investigated aspects of follow-up do patients value most important?*

The preferences of the patient population of the Centre for Mammacare are investigated by looking at the most valued aspects of follow-up. The investigated aspects are Total Time Span, Frequency per Year and Type of Consult, terms that were already mentioned in the introductory chapter. These aspects are called 'attributes', and motivation for the choice of these attributes is outlined in Chapter 3. When we know which aspects patients value most important, the Centre for Mammacare is able to focus on this/these aspects when new policy for follow-up services is determined.

We hypothesize that the attribute Total Time Span is valued most important by breast cancer patients, and that there will be no difference between follow-up by a surgeon or a NP (Nurse Practitioner, explained later). A common psychological phenomenon in health care is cognitive dissonance reduction, which means that patients who have experiences with a treatment generally show stronger preference for that treatment than other patients or health care providers (Stiggelbout et al. 2001). Since the patients of the Centre for Mammacare receive more follow-up in terms of years than the proposed follow-up services (10 years vs. proposed 5 years maximum), it is expected that the time span of the follow-up will have much influence on preferences.



The second part of the hypothesis is derived from a small study performed by Pennery and Mallet (2000), who on a small scale asked women about their preferences, concluding that the majority of the women would agree to receive part of all of their care from a NP. The same conclusion comes from a study in 2002, which found that 64% of the 134 questioned women would have been satisfied with receiving care from the NP (Renton et al. 2002). High patient satisfaction in women followed-up by a specialist nurse was also seen by Koinberg et al., who randomly assigned 264 women to follow-up by a specialist, or by a nurse (2004).

2) Do differences in preferences for breast cancer follow-up scenarios exist between predefined risk groups, and if so, what are these differences?

The main question asks whether differences between patients groups exist when it comes to preferences for follow-up. The first division that is made is division of patients in risk groups. These risk groups are predefined by using Dutch statistics on risks and prevalence of recurrences of breast cancer focusing on tumor size, number of infected lymph nodes and age, and are described in paragraph 2.4. It is interesting to see whether the different risk groups have different preferences for follow-up services. When different preferences are found, will this lead to different recommendations, which automatically leads to care with an individual approach.

Hypothesized is that women from the high risk group show more preference for more expensive follow-up services than women from the low risk group, and that the medium risk group shows preference for average expensive services. It is expected that being assigned to the high-risk group causes more desirability for frequent and long follow-up visits than being assigned to the low risk group, because the impact to the quality of life might be larger. This factor has not yet been studied by previous literature. No differences between the risk groups are expected when it comes to physician-led or nurse-led follow-up, according to the same reasons mentioned before.

3) Is there a relation between preferences and coping style of the patients?

An important aspect of the ability to cope with a specific disease is the desire for information (Phipps and Zinn, 1986). To measure coping style, the Threatening Medical Situation Inventory classification is used. This is the second way in which patients are divided. This instrument measures cognitive confrontation or avoidance in medical situations. People are classified into two groups. The first group is Monitors (M): they have the tendency to search for information and focus on medical threats. The second group is Blunters (B): they have the tendency to avoid information (Muris, van Zuuren and de Vries 1994; van Zuuren et al. 1996; Nordin et al. 2002). We hypothesize that Monitors have stronger preference for more follow-up than Blunters, because they focus on medical threats and need information.

If a relation between preferences and coping style is found, then this relation should be considered and taken into account as a second factor when offering new follow-up services, besides the defined risk groups. However, because this study mainly focuses on risk groups, coping style is less extensively explained and analyzed.



4) *Do the preferences of patients change when the time to primary treatment increases?*

Typically a patient diagnosed positively with breast cancer in the Center for Mammacare receives 10 years of follow-up services after treatment. It is interesting to see whether the opinion (i.e. preferences for certain aspects of follow-up) of patients changes over time (de Bock et al. 2004). We expect that women at the end of their follow-up scheme are more objective, and less driven by emotions caused by the traumatic experience of breast cancer than women in the first years of follow-up, since the time to the primary treatment increases. When this is true, then more support exists for less intensive follow-up, at least when it comes to the total time span of follow-up.

1.7 Scientific importance

Some studies have been conducted in order to explore the preferences and perceptions of women who receive follow-up services after breast cancer treatment (Pennery and Mallet 2000; Allen 2002; Renton, Twelves and Yuille 2002; Bock et al. 2004). Most of these studies compare the current follow-up scheme with only one alternative, such as follow-up by a Nurse Practitioner or General Practitioner (Grunfeld et al. 1999; Kimman et al. 2007b). In this study, the current follow-up scheme is compared with different alternative scenarios that are plausible for the Center for Mammacare.

A recent study compares different scenarios as well, in which various studies were consulted as the basis for theoretical comparison (Kimman et al. 2007a). However, when studies are consulted and included into a comparison, methodological comparison problems might occur, e.g. differences in trial settings, cohorts and selection criteria. In this study, the perceptions of women for different proposed scenarios (in 1 clinical setting) are investigated. By comparing these different scenarios and by using one clinical setting, differences become clearer without methodological comparison biases.

At the moment Kimman et al. (2007b) continue their research by testing more scenarios in 1 clinical setting as well (although from 7 hospitals and 2 radiotherapy clinics). They use 4 different scenarios: 1) Standard follow-up; 2) Nurse-led telephone follow-up; 3) Scenario 1, with an educational group program. 4) Scenario 2, with an educational group program. Data is collected at baseline, and at 3, 6, 12 and 18 months after treatment. 320 women were randomly assigned to one of the groups, creating groups of 80 participants per scenario. The study focuses on cancer specific quality of life measured by the EORTC QLQ-C30, and on perceived feelings of control, anxiety, patients' satisfaction with follow-up, and costs. Summarized can be said that Kimman et al. are testing these 4 scenarios in a real-life clinical trial setting. At baseline these women were assigned to one of the four categories, and their experiences will be measured over time. The results are expected in 2009.

Although in this study different scenarios are tested in the same clinical setting as well, these scenarios are tested hypothetically. By testing hypothetically, we are able to test more



scenarios. In the above described trial women are asked about their experiences and opinion for their own assigned scheme (randomly assigned), whereas we ask the women their opinion about all the proposed scenarios in which we do not include their current follow-up scheme as one of the alternatives. In doing so, the focus of investigation is on the differences in preferences between the scenarios that differ from their own.

Research shows that the need for information of cancer patients is high before treatment, and decreases over time (Mesters et al. 2001). It is interesting to investigate, as Bock et al. already mention in their discussion about the needs of breast cancer patients in a routine follow-up program (2004), whether the needs and preferences of these patients change over time when the interval to their primary treatment is increasing. We expect that women at the end of their follow-up scheme are more objective, and less led by emotions than women in the first phases, resulting in preference for less demanding follow-up schemes. This would justify a less intensive follow-up scenario. However, no evidence has been found yet, so firm expectations cannot be given on beforehand.

One of the unique factors of this study is that the preferences of breast cancer patients are measured with a Discrete Choice Experiment (explained in the next chapter), in which patients are classified in different ways to investigate differences. DCE is more and more used in health care because of its promising results (Sculpher et al. 2004). If differences are found, follow-up services can be individualized to different categories of patients, making the service more adequately for that patient. This study can help making decisions about new follow-up policies, based on preferences as a whole, and preferences based on differences in patient groups. This can increase patient satisfaction and quality of life, since the proposed follow-up is more optimal for the patients' needs.

Summarized, the scientific contribution of this research is that patients are classified into different risk groups and differences are investigated, which might result in more individualistic follow-up. Various scenarios are proposed to the patients. A unique feature of this study is that a discrete choice experiment is used, an upcoming and promising technique for health care studies.



2 METHODOLOGY

This chapter describes the methodology of the study. In paragraph 2.1 the data collection procedure is described. Paragraph 2.1 describes the methodological instruments used to measure quality of life, coping style and preferences. Then the descriptives of the respondents are described in 2.3; 2.4 describes the risk group classification and the chapter is concluded with the statistical analyses in 2.5.

2.1 Data collection

The research questions were investigated by questioning patients who have been treated for breast cancer and who currently receive follow-up services at the Center for Mammacare. A paper questionnaire seemed the most appropriate way to approach respondents, since respondents come to a general facility (Centre for Mammacare), creating a good opportunity for obtaining data. Data collection was performed from January 2008 until March 2008, in which January was used for pilot-testing the questionnaire (40 patients were used in this pilot test).

When checking in, the assistant handed over the questionnaire, asking the patient on behalf of the surgeon to fill out the questionnaire in the waiting area of the hospital. When having their consult, patients gave the questionnaire to the surgeon or nurse practitioner who registered the tumor size and the number of infected lymph nodes of the patient on the first page of the questionnaire, which he or she retrieved from the medical file. No other personal data were copied from the medical file. The questionnaire was semi-structured, and the introductory text gave patients information about the study objectives and importance of respondents' participation, the medical consequences of the scenarios that were described, explanation and an example of the choice set task, the approximate time needed to complete the questionnaire and an assurance of confidential responses.

Many women feel anxious before the consult, but relieved after (Renton et al., 2002). Since waiting in the waiting area is an anxious period for patients (Fallowfield and Baum, 1989), the patient was also asked whether she has filled out the questionnaire before or after the consult with the specialist, in order to obtain a insight of the balance between these two groups of patients.

Patients who in the past had been diagnosed with breast cancer and who had breast-conserving treatment or mastectomy with curative intent, and who at the moment of measurement applied for follow-up services were invited to fill out the questionnaire. Patients excluded were those who could not physically or mentally participate and those who did not master the Dutch language at an appropriate level. Patients who had no chance of curative treatment were also excluded, since this group does not enter the follow-up process. Men with breast cancer were also invited to participate; however, during the data collection period no men were consulted.



2.2 Instruments

Various methodological instruments were used to measure quality of life, coping style and preferences. These instruments are described in the next sub-paragraphs. In addition to these instruments, basic questions were used to determine age, amount of education, living situation, work situation, marital situation and sex.

2.2.1 Quality of Life

For the measurement of the quality of life 2 measurements were used. The first is the European Quality of Life Instrument 5 Dimensions (EQ-5D) of the EuroQol Group. This instrument has been extensively validated and been shown to be a sensitive and internally consistent instrument. It is considered to be reliable in the general population and various patient groups (Dorman et al. 1997; Schrag et al. 2000). It consists of questions with 3 levels on 5 dimensions of health (mobility, self-care, usual activities, pain/discomfort and anxiety/depression), and a visual analogue scale with a self-rated health status on a vertical graduated scale (0-100). It is an instrument that is easy to complete. The scores of the 5 dimensions are scored on a 3-point scale. These 5 scores are then serialized. This index corresponds with a health profile (e.g. 12323). This score is then recalculated with a norm table to one single score per respondent. This single score is the utility, which is used for further analyses.

The second instrument is the Short Form 12 (SF-12) which consists of 12 items that evaluate eight health domains related to quality of life: bodily pain, general health, mental health, physical function, role-physical, role-emotional, social function and vitality. All dimensions are scored on a 5-point scale, in which some of the dimensions are scored using multiple questions. After recalibration of some of the questions to make calculations more easily, each dimension receives a raw scale score. Finally the scores are transformed to a 100-point scale with the formula (Ware et al. 2003):

$$\text{Transformed scale} = \left[\frac{\text{Actual raw score} - \text{lowest possible raw score}}{\text{Possible raw score range}} \right] \times 100$$

This transformation converts the lowest and highest scores to respectively 0 and 100. The scores between these scores represent the percentage of the total possible score that was achieved.

This instrument gives an overview of the quality of life of the respondents on more dimensions than the EQ-5D, and is used for the descriptives. Table 2 on the next page shows the possible raw scores used for the transformation.



Scales	Lowest and highest possible raw scores	Possible raw score range
Physical Functioning	2,6	4
Role physical	2,10	8
Bodily Pain	1,5	4
General Health	1,5	4
Vitality	1,5	4
Social Functioning	1,5	4
Role Emotional	2,10	8
Mental Health	2,10	8

Table 2 SF-12 scale items aggregated

2.2.2 Coping Style

Coping style is measured with the TMSI classification (Threatening Medical Situation Inventory), which divides people in Monitors (information seekers) and Blunters (information avoiders) (Muris, van Zuuren and de Vries 1994). The TMSI describes 4 medical scenarios of which respondents are asked to imagine him/herself in these situations: 1) vague, suspicious headache; 2) being diagnosed as hypertensive; 3) choosing for uncertain heart surgery; 4) and a sudden appendicitis operation. In order to ensure the whole range of potential medical stressors is covered, these 4 scenarios diverge with respect to two important stress parameters: controllability and predictability (Nordin et al. 2002). See table 3 for an overview.

Scenario	Predictability	Controllability
1. Vague, suspicious headache complaints	-	-
2. Being diagnosed as hypertensive	+	++
3. Choosing for uncertain heart surgery	-	+
4. A sudden appendicitis operation	+	--

Table 3 Predictability and Controllability of the 4 TMSI-scenarios (Source: van Zuuren et al. 1996)

The scenarios are followed by three monitoring and three blunting alternatives, in random order, to be answered on a 5-point Likert scale (1= "Not at all applicable to me" to 5= "Strongly applicable to me"). The total Monitoring and Total Blunting scores are obtained by summing up the relevant items, with a range for both scales of 12-60 (1 point for "Not at all applicable to me" to 5 points for "Strongly applicable to me"). To categorize the patients, the sum scores are used by subtracting the total blunting score from the total monitoring score. Then respondents are categorized as Monitors if they score above the median of the sum score, and as Blunters if the score below the median of the sum score (Miller 1987).



2.2.3 Discrete Choice Experiment

To elicit the preferences of the patients a conjoint analysis (CA) is used, an analysis to elicit patients' view on health care which was developed during the 1990s (Ryan and Farrar 2000). The conjoint analysis has 3 methods to elicit preferences: ranking (in which the respondent should rank the proposed scenarios); rating (in which the respondent is asked to rate every scenario from e.g. 1-5); and discrete choice experiment (in which the responses are discrete, e.g. preference for scenario A or preference for scenario B (idem)). In literature the discrete choice experiment (DCE) is also known as choice based CA, stated preference or stated preference discrete choice modeling (Ryan et al. 2001b). Because this method resembles real life decisions best, discrete choice experiments are preferred in health care (Ryan and Farrar 2000; Ryan et al. 2001a). This is also confirmed by Sculpher et al. who state that their study about the preferences of patients with prostate cancer provides evidence that the discrete choice experiment can be applied in health care, with success (2004). Because of these promising results, the technique has been increasingly used in health care programs. Studies have also shown that "few difficulties have been reported when answering choice-based CA questions [...]" (Kjær 2005).

The technique is based on the idea that every service can be described by its characteristics, which are called attributes (Ryan et al. 2001a; Peacock et al. 2006), and that the valuation of a service of an individual depends on the level of these characteristics (Ryan and Farrar 2000). These levels of characteristics are called attribute levels. Respondents are presented with a number of choices and are for each asked to choose their preferred one. These choices are described in terms of attributes and attribute levels. The output data provides information on the relative importance of the attributes (Sculpher et al. 2004).

The technique has shown high levels of internal validity (Peacock et al. 2006). A technique with high internal validity is a technique in which the (causal) correlations that are found by that technique are acceptable (Swanborn 1987). This is also concluded by Ryan et al. (2001b) after consulting various studies. However, some respondents are not willing to trade, showing non-compensating behavior. To guarantee internal consistency, a dominant option can be added, i.e. an option that is obviously considered being superior to the other when the attributes are compared. The respondent would therefore be expected to choose this scenario, and should show higher weight. If it is not possible to define a dominate alternative because no level is clearly dominate, it is also possible to include the same choice set twice, in order to examine consistency (Kjær 2005).

Although a limited number of studies have investigated the external validity (or criterion validity) of the technique, making this an interesting field for further research, those who did provided promising results (Ryan 2004; Peacock et al. 2006). A technique with high external validity is a technique that results in conclusions that can be generalized to the population that was studied, concluding that respondents would decide the same in real life (Swanborn 1987). Telsler and Zweifel performed a validity research by testing the technique in an investigation of a hip protector that could reduce the risk of fracture of the femur in an



elderly population, concluding that **the research** showed a strong evidence that the **discrete choice experiment** has external validity (2005).

The **determination of the various attributes, attribute levels and scenarios** is explained in Chapter 3, in which the **DCE model of this study** is described.

2.3 Descriptives of respondents

125 respondents were **included in analyses**, with a response of **approximately 85%**. The mean age of the respondents is 60,6 with a minimum of 36 and a maximum of 94.

All participants were female. This is **not unusual**, since in 2006 the Centre for Mammacare only saw 2 male breast cancer patients (Gosselt 2006). In this report the terms 'patients' and 'women' are used interchangeably, in which both cases all **participating respondents** are meant.

The variable 'education level' has been recoded into 3 categories: Low for people with "lager onderwijs", "lager voortgezet onderwijs" or "lager beroepsonderwijs". Intermediate for people with "middelbaar voortgezet onderwijs" or "middelbaar beroepsonderwijs", and High for people with "hoger voortgezet onderwijs", "voorbereidend wetenschappelijk onderwijs", "hoger beroepsonderwijs" or "universitair onderwijs". Almost half of the respondents have a low education (42,6%); about one third has an intermediate education (31,1%) and 23,0% has a high education.

About a quarter of the respondents lives alone (24,0%); 73,6% lives with a partner, possibly with children. None of the respondents lives with her parents, and only one respondent lives in a living community.

Almost one third of the respondents claims to be employed (31,4%); another third to do housekeeping (29,8%), and almost one third to be retired (29,8%). Only one respondent is unemployed (0,8%), and 5,8% is disabled.

The next table also shows the 8 domains of the 5F-12 Quality of Life score (physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, mental health). Notable is that the transformed score (on a 0-100 scale) are the same for most of the domains, except for physical role and general health: they score lower than the other domains.

The EQ-5D Quality of Life scale shows a mean utility score of 0,8174, and a mean VAS-score of 75,51 (on a scale of 1 to 100). This means that respondents generally assign a 7,5 on a ten-point scale to their general quality of life.



Variable	n	Percentage (%)
Age (n=119)		
Mean	60,64	(Std. dev. 11,35)
Minimum	36	Maximum 94
Sex (n=125)		
Female	125	100,0
Male	0	0,0
Education (n=122)		
Low	52	42,6
Intermediate	38	31,1
High	28	23,0
Other	4	3,3
Living situation (n=121)		
Alone	29	24,0
With partner (possibly with children)	89	73,6
Living community	1	0,8
Other	2	1,6
Work Situation (n=121)		
Employed	38	31,4
Housekeeping	36	29,8
Unemployed	1	0,8
Disabled	7	5,8
Retired	36	29,8
Other	3	2,5
Quality of Life SF-12		
Scales	Mean (SD)	Transformed score
Physical Functioning (n=122)	5 (1)	75
Role physical (n=18)	7 (2)	62,5
Bodily Pain (n=123)	4 (1)	75
General Health (n=124)	3 (1)	50
Vitality (n=117)	4 (1)	75
Social Functioning (n=123)	4 (1)	75
Role Emotional (n=118)	8 (2)	75
Mental Health (n=116)	8 (1)	75
Quality of Life EQ 5D (n=123)		
Mean Utility score	0,8174	(Std. dev. 0,1931)
Mean VAS-score	75,51	(Std. dev. 15,24)

Table 4 Descriptives of respondents



2.4 Risk group classification

Patients are classified into groups according to characteristics. These characteristics are partly based on the TNM Classification of Malignant Tumors, a validated classification for cancers (Gusterson 2003). This is a cancer staging system for describing the extent of cancer and is widely used in oncology. The basic model describes the T (Tumor in cm), N (Number of lymph nodes infected) and M (whether metastases are present or not).

The first variable is lymph node status. When diagnosing the patient with breast cancer, the number of infected lymph nodes is determined. The more lymph nodes are positive, the worse the patients' prognosis. A regular division of patients into lymph node status groups is 0 nodes positive, 1-3 nodes positive and >3 nodes positive (Saphner, Tormey and Gray, 1996).

The second variable that is a major determinant of risk of recurrence is tumor size. The tumor size is also determined during diagnosis. A regular division of patients in tumor size groups is 0.1-1.0 cm, 1.1-3.0 cm and > 3.0 cm (Saphner, Tormey and Gray, 1996). For statistical reasons these were modified to 0.1-1.0 cm, 1.1-2.9 cm and ≥ 3.0 cm.

The third variable of the TNM classification, metastases (M), was not included, since patients with metastases are essentially incurable (see paragraph 1.2) and do not enter the follow-up process.

A variable that do was included is age. Age is not a very strong predictor of recurrence of breast cancer, except with patients younger than 35. For this group age significantly increases risk of recurrence, placing these patients in the highest risk group (Bollet et al. 2007). A summary of the defined risk groups is outlined in table 5. 118 respondents were included in the analyses in which differences between risk groups were investigated: 31 from the Low Risk category, 63 from the Medium Risk category, and 26 from the High Risk category.

Risk Group	Characteristics
Low Risk (n=31)	0 lymph nodes positive 0.1 – 1.0 cm tumor size
Medium Risk (n=63)	1-3 lymph nodes positive 1.1 – 2.9 cm tumor size
High Risk (n=26)	>3 lymph nodes positive ≥ 3 cm tumor size <35 years old

Table 5 Characteristics of the Risk Groups



2.5 Statistical analyses

2.5.1 Preferences

Preferences are measured using the DCE model described in Chapter 3. The utilities (a measurement of the relative satisfaction or desirability for consumption of goods) for every attribute and their corresponding levels are used to calculate the importance of the different attributes. In this analysis, 125 respondents were included. Respondents with 3 or more missing values (i.e. $\geq 25\%$ of the choice sets was missing) were excluded from further analyses. To test for consistency the same choice set was added twice, since no clear dominant choice set could be defined. 7 respondents were not consistent with their answers. However, because their number was so small, they were included in analyses nevertheless.

First the respondent answers to the choice sets were manually entered in Excel, coding the answers as 1 for choice A, and 2 for choice B. Missing answers were coded as 0. This file was used by the Sawtooth Software CBC/Web v6.0 module to prepare the files for further calculations and to calculate the utilities. This tool is a separate program from the SSI Web system. This component assesses the relative impact of each attribute level by counting the alternatives chosen by the respondent (Sawtooth Software 2007). The complete enumeration approach was used to design the model, meaning that all possible concepts are considered and those are chosen that produce the most nearly orthogonal design for each respondent. It also makes that each attribute level is equally likely to occur and that the same attribute level does not occur twice in one choiceset. The SSI Web system determines the impact of each level by counting the proportion of times the levels are chosen. This is done by the CBC's module "count".

The utilities per attribute level for all respondents were calculated using the Sawtooth Software Market Research Tools (SMRT) module. The SMRT platform imports data from the CBC/Web module and with the LOGIT function utilities were calculated. The Sawtooth Software Hierarchical Bayes module is software for estimating individual part-worths and was used to calculate individual utilities. The highest utility per attribute shows the most preferred level for that attribute. In Excel this highest utility per attribute was extracted. Combining the 3 highest utilities levels for each of the 3 attributes created the preferred follow-up scenario per respondent. These results were imported in SPSS by creating 3 new variables in the dataset, one variable for each attribute. Cross tables were used to investigate differences between risk groups and preferred attribute by using each of these 3 new variables. First the variables were tested for normal distribution with a histogram. Then a Kruskal-Wallis test for non-parametric tests with more than 2 groups was used to test for statistically significant differences between the 3 risk groups. Furthermore 2 of the three risk groups were combined and tested for statistically significant differences with the third group by using a Mann-Whitney test, a non-parametric test for two groups. These tests were also used to determine whether differences exist in relation with coping style, and with the number of years respondents received follow-up. In the latter the number of years in follow-



up was divided into 3 groups: 0-5 years follow-up, 6-10 years follow up, and more than 10 years follow-up.

The importance of the 3 attributes were calculated by taking, per attribute, the maximum and minimum utility and calculate the difference between both, and divide this difference by the total sum of differences of all attributes. In formula:

$$\frac{X_i}{\sum_{i=1}^3 X_i} * 100$$

$i = 1, 2, 3$

$X_1 = MAX(time) - MIN(time)$

$X_2 = MAX(freq) - MIN(freq)$

$X_3 = MAX(type) - MIN(type)$

Finally Excel was used to calculate the probability a level was chosen when presented in one of the choice tasks. This is done by taking the exponent of each utility within an attribute, and then of each level divide this exponent by the sum of all exponents of the other levels within that attribute. In formula:

$$u = \sum b_j$$

$$p = \frac{\exp(u)}{\sum \exp(u_j)}$$

In these equations, b stands for the part-worth for each individual. In this model, we assume a logit model for each individual, where the utility of each alternative is the sum of the part-worth of its attribute levels, and the respondents' probability of choosing each alternative is equal to its utility divided by the sum of utilities for the alternatives in that choice set.

2.5.2 Logistic regression model

To investigate whether differences between risk groups and the total preference (i.e. all three attributes combined) exist, a regression model was used.

To use this model, first the scenarios were weighted, so that the three attributes together make up for 1 scenario. Every follow-up scenario ($3 * 2 * 3 = 18$ scenarios in total) was weighted by multiplying each level with their corresponding economic value in Euros, derived from the table 6. These economic values are based on the hourly wage of a surgeon (€ 132,50 (Orde van Medisch Specialisten, 2007)) and the nurse practitioner (€ 23,00 (NVZ Vereniging van Ziekenhuizen, 2006)). Since the function of the economic value is to give the various scenarios different weights, rather than to estimate actual costs of the different scenarios, additional costs like administrative costs were not taken into account. This means



that the scenario “five years, twice a year, by the surgeon” receives a weight of $5 \times 2 \times 22,08 = \text{€ } 220,80$. This new created variable was called Total Costs and represents all 18 scenarios, calculated in the total costs of those scenarios. These scenarios are shown in table 7.

Type of consult	Time per consult	Costs per consult
Surgeon – visit in hospital	10 minutes	€ 22,08
Nurse Practitioner – visit in hospital	20 minutes	€ 7,66
Nurse Practitioner - telephone	10 minutes	€ 3,83

Table 6 Time and Costs per Type of Consult

Scenario	Frequency (1)	Total Years (2)	Type of consult – costs (3)	Total Costs (1*2*3)
1	Once a year	1	NP – by telephone € 3,83	3,83
2	Once a year	1	NP – visit in hospital € 7,66	7,66
3	Twice a year	1	NP – by telephone - € 3,83	7,66
4	Once a year	3	NP – by telephone € 3,83	11,49
5	Twice a year	1	NP – visit in hospital - € 7,66	15,32
6	Once a year	5	NP – by telephone € 3,83	19,15
7	Once a year	1	Surgeon – visit in hospital : € 22,08	22,08
8	Once a year	3	NP – visit in hospital - € 7,66	22,98
9	Twice a year	3	NP – by telephone € 3,83	22,98
10	Once a year	5	NP – visit in hospital - € 7,66	38,30
11	Twice a year	5	NP – by telephone - € 3,83	38,30
12	Twice a year	1	Surgeon – visit in hospital : € 22,08	44,16
13	Twice a year	3	NP – visit in hospital - € 7,66	45,96
14	Once a year	3	Surgeon – visit in hospital : € 22,08	66,24
15	Twice a year	5	NP – visit in hospital - € 7,66	76,60
16	Once a year	5	Surgeon – visit in hospital : € 22,08	110,40
17	Twice a year	3	Surgeon – visit in hospital : € 22,08	132,48
18	Twice a year	5	Surgeon – visit in hospital : € 22,08	220,80

Table 7 Total Costs of all scenarios

NP = Nurse Practitioner

Scenarios 2 and 3, 8 and 9, and 10 and 11 have the same Total Costs. This is because in these scenarios the NP provides the follow-up services. A visit in the hospital (NP) takes twice as much time as a consult by telephone (NP), and is therefore twice as expensive. However, the variance of frequency (once or twice a year) makes that these scenarios have the same costs. This is not a problem for the calculation, because both scenarios involve the NP, creating no difference for the hospital.



Because **the variable Total Costs has no normal distribution (Mean=132,55; Std.Dev.=72,763; N=125)**, a **logistic regression model** was used for this analysis. The **independent variable Total Costs was dichotomized**, with a cut-off point at 110 Euros: **all scenarios below 110 Euros were marked as scenarios with low costs (coded as 0); all scenarios above 110 Euros were marked as high costs (coded as 1)**. A cut-off point of 110EUR was used because this division yields in 2 approximate equal numbers of respondents in both groups. Then the **logistic regression analysis of SPSS** was used to calculate odds ratios, in which the **primary goal** was to investigate the relationship between risk group and preferences.

Furthermore **different variables** were entered into the model to check for variances in the odds ratio of the risk groups. These variables were first explored for outliers, skewness and normal distribution. Number of years in follow-up and coping style proved to influence the odds ratio of the variable risk group the most and were added to the models.



3 DESIGN OF THE DISCRETE CHOICE EXPERIMENT

To define scenarios that create the discrete choice experiment the stepped approach of Ryan and Farrar (2000) was used, who describe these steps when undertaking a conjoint analysis. These steps show how the scenarios were defined. Although the choices we presented to the women are hypothetical, this allows us to have complete control over the experimental design. Furthermore it ensures statistical robustness (Ubach et al. 2003).

Step 1: Identifying the characteristics

As mentioned before, in the discrete choice experiment design characteristics of scenarios are called attributes. No golden standard exist about the number of scenarios: some studies claim a maximum of 5 or 6; others 8 (Ryan et al. 2001b; Kjær 2005). Neither is there consensus about how the attributes should be chosen (Kjær 2005). According to Bennett and Blamey, attributes should be relevant to the requirements of policy makers, as well as to the patients (2001). These authors advise to obtain as much information as possible from different sources. Through a review of literature we created an overview of the current and previous studies about different scenarios for follow-up for breast cancer and other types of cancer (prostate cancer: Sculpher et al. 2004) and which attributes were used in those studies.

Discussions with surgeons and a Nurse Practitioner of the Centre for Mammacare made clear the problem definition and needs of the staff and the Centre for Mammacare. Using these 2 approaches and their corresponding sources together, eventually different attributes that construct the proposed scenarios were identified. These attributes are: Total Time Span in Years; Frequency per Year, and Type of Consult.

Kjær (2005) reminds researchers who are using the discrete choice experiment design that 2 problems related to attributes can occur: attributes can be mutually or causally dependent. Mutually dependent attributes are dependent in one way or the other; causally dependent attributes show a causal relationship. When considering the defined attributes, we find no signs of dependence whatsoever.

Step 2: identifying levels of the characteristics

The levels of the characteristics of the scenarios are called attribute levels. For every attribute we assign plausible attribute levels, based on literature and discussions with staff of the Centre for Mammacare. In this process the national and local guidelines were particularly taken into account, since the Centre for Mammacare strives after a high quality of care in which national guidelines are covered.

Although the current time span for follow-up in the Centre for Mammacare is 10 years, according to the local guidelines, we only offer follow-up scenarios with a time-span of maximum 5 years, according to the national guidelines. Another reason for this is that by doing so we reduce the total number of possible scenarios. This choice is also based on



previous studies that indicate that less intensive follow-up is as medically effective as more intensive follow-up, as discussed in chapter 1. When we propose scenarios of no more than 5 years, this limitation applies to the consult (i.e. history taking, physical examination) as well for the mammography. When patients no longer apply for follow-up services, they are recommended to take part in the national breast cancer prevention program, which means that a mammography is taken once in two years for women with the age from 50 until and included 75.

Follow-up consults in the first year have more applications than in the years thereafter. The consequences of the surgery and post-morbidity (e.g. psychosocial problems, chronic fatigue) are monitored in the first year (Wiggers 2001; Hiranek 2004). However, after the first year everything is close to normal. This first year of follow-up is unquestioned because of the extra applications and reasons for the consults in this year. Therefore, when proposing different follow-up scenarios for different risk groups of breast cancer patients, the minimal follow-up length is 1 year.

The national guidelines recommend a consult 4 times in the first year of follow-up, twice in the next year, and once a year thereafter. In this study the levels are once, or twice a year. When a scenario with a frequency of once a year is proposed, this means that there is one consult per year in which the results of the mammography are discussed and the history taking and physical examination is performed. When we propose a scenario with a frequency of twice a year, in only one of these consults the results of the mammography is discussed; in both physical examination and history taking are taking place. When a woman has an age >60, the current guidelines are followed, e.g. a mammography once in two years. The variance of the attribute 'frequency per year' lies in the frequency of the consult (history taking and physical examination); we do not propose different frequencies for the mammography.

The proposed scenarios need to be plausible for the Centre for Mammacare. When focusing on type of consult, we selected 3 attribute levels: Surgeon – visit in hospital, NP – visit in hospital, NP - telephone. A NP is a Nurse Practitioner, a nurse who has completed an advanced nursing education, typically a master's degree. These levels are a combination of type of physician (surgeon or NP) and type of consult (visit in hospital or by telephone), in which the combinations are chosen according to plausibility. Because of a lack of time and due to financial reasons, the combination "Surgeon - telephone" is not plausible. For non-complicated cases, the telephone is a suitable alternative. In such a case the Nurse Practitioner is as capable as the surgeon, but cheaper for the hospital. Therefore the combination "Surgeon - telephone" is not offered as one of the scenarios.

The attributes and their corresponding levels are summarized in table 8. The possible scenarios are shown in Figure 1, in which the time span shows the total time span of the follow-up (including the first year).



Attribute	Attribute levels
Total time span in years	1 year
	3 years
	5 years
Frequency per year	Once a year
	Twice a year
Type of consult	Surgeon – visit in hospital
	NP* - visit in hospital
	NP* - by telephone

Table 8 Attributes and assigned attribute levels

*NP = Nurse Practitioner

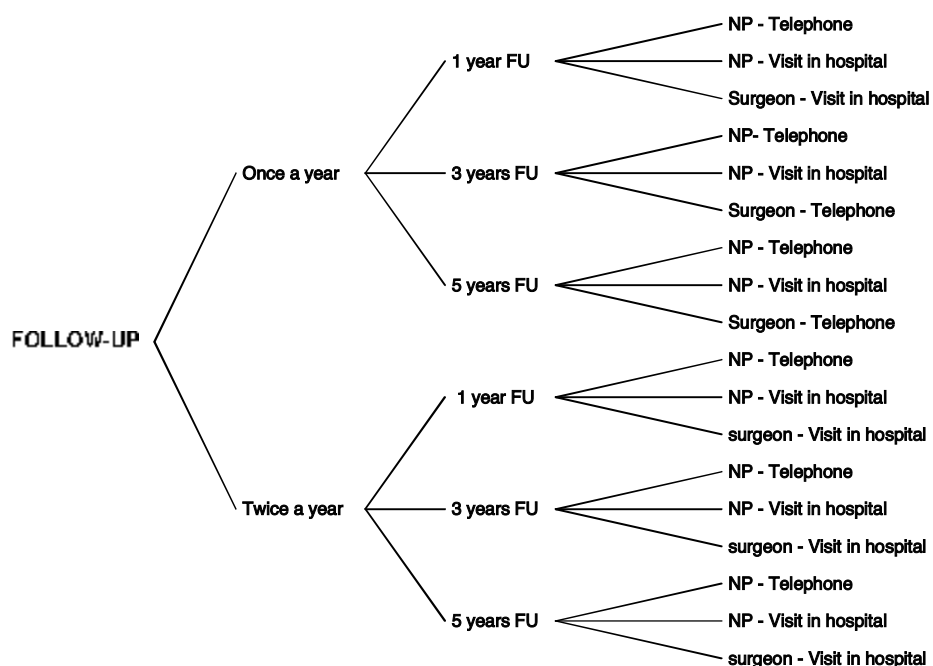


Figure 1 Defined scenarios

Step 3: Choice of scenarios

When deciding which scenarios will be used in the questionnaire, two designs exist: full factorial design and fractional factorial design (Kjær 2005). In the first design, all the possible scenarios are used. This can only be done in designs with a limited number of attributes and



attribute levels. However, many designs produce many possible scenarios, which makes that the researchers need to select a number of them to take part in the research. This design is called a fractional factorial design, and can be done manually or with computer software. In such a design the properties of the full factorial design are maintained in the best way possible. However, all fractional designs have some loss of statistical information, which sometimes can be significant (idem).

To ensure a theoretically maximum efficiency, 4 principles are agreed on to maximize this so called D-efficiency (Zwerina, Huber and Kuhfeld 1996). The attributes that construct the different scenarios should have minimum overlap, should be statistically independent (orthogonal), should occur an equal number of times (level balance) and the utilities of alternatives should be equal. The problem with the latter principle is that this demands that the researchers have knowledge about the respondents' preferences. The authors state that for most designs it is impossible to satisfy all these principles, also because some of these principles might conflict with each other (Kjær 2005). Computer programs exist to maximize D-efficiency.

The total number of possible scenarios in our research is 18 (see Figure 1), which we see as a manageable level for the respondents. Therefore we presented all these scenarios, using computer software of Sawtooth Software to maximize D-efficiency. This creates the advantage that no scenario needs to be excluded, and no exclusion bias occurs. However, by selecting these scenarios (i.e. attributes and attribute levels) we already excluded some possibilities in order to use only plausible scenarios for the Centre for Mammacare. This is in line with the conclusions of Bateman et al., who stated that although orthogonality is desirable, plausibility and realism might be reasons to depart from this when this is supported with analysis of the statistical properties of the design (Bateman et al. 2002).

An example of a choice set is presented in figure 2.

Figure 2 Example of Choice set (actual questionnaire is in Dutch)

	Scenario 1	Scenario 2
Time span	1 year	5 years
Frequency	Once per year	Twice per year
Type of consult	NP: by telephone	Surgeon: visit in hospital

Which do you prefer? Prefer 1 Prefer 2

(tick only one)



Step 4: Establishing preferences

The study population is the group of women who come to the Centre for Mammacare in Oldenzaal and Enschede (The Netherlands) for breast cancer follow-up in February and March 2008. A rule-of thumb for determining the minimum sample size formulated by Johnson (Orme 2006):

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

N = number of respondents

T = number of tasks (choice sets)

A = number of scenarios per task

C = number of analysis cells (equal to the largest number of levels for the largest attribute)

The number of tasks in the questionnaire is 12, in which 2 scenarios per task are asked. The attribute with the most levels has 3 levels. According to the equation, this makes a minimum number of respondents of 63. Since we divide the sample into different risk groups, the sample size is somewhat bigger: 125 women.

Step 5: Statistics and data analysis

Statistical packages of Sawtooth Software (SSI Web 6.2.0, SMRT v4.16.0 and CBC HB 4.6.0) and SPSS 12.0 are used to organize and analyze the data, as explained in chapter 2: Methodology. Results are presented in the next chapter.



4 RESULTS

4.1 *Important aspects of follow-up*

The first research question is: “Which of the investigated aspects of follow-up do patients value most important?”

First the importance of the 3 attributes and attribute levels are outlined and differences between those are investigated. Then the scenarios are tested for dominant criteria.

4.1.1 Importance of the different aspects and levels

Of the total preference ($n=100$), 43,2% has been determined by Total Time Span of the consults, 49,8% by Type of Consult, and only 7,0% by Frequency per Year. This means that, when respondents make their choices in the choice sets, they decide which scenario to choose by mainly determining their choice based on Total Time Span and Type of Consult. Our hypothesis that Total Time Span is the most important attribute is not correct, although it is one of the two main attributes. Frequency per Year, however, is far less important when choosing, and hardly affects the choice. This means that in this design Frequency per Year is not a strong indicator for preferences. Apparently the respondents do not care whether they have a follow-up visit once or twice a year; they value the other attributes more important (this influence can positive as well as negative) when making their choice.

When considering these results, it is important to realize that the framing of the attribute levels might not be the same. When two levels are close to each other, these levels might not show high differences in preferences, because to the respondents they might look the same.

We now know, with the caution of different framing of the attribute levels in mind, that the attributes Total Time Span and Type of Consult are most important when respondents make their choice, and that Frequency per Year hardly has influence on the choice. Now it is interesting to see which levels within these 3 attributes are valued most important by looking at the highest utility per attribute. These utilities are visually presented in figure 3, and table 9 shows the values of the utilities per attribute level, in which the highest level per attribute has been marked bold.

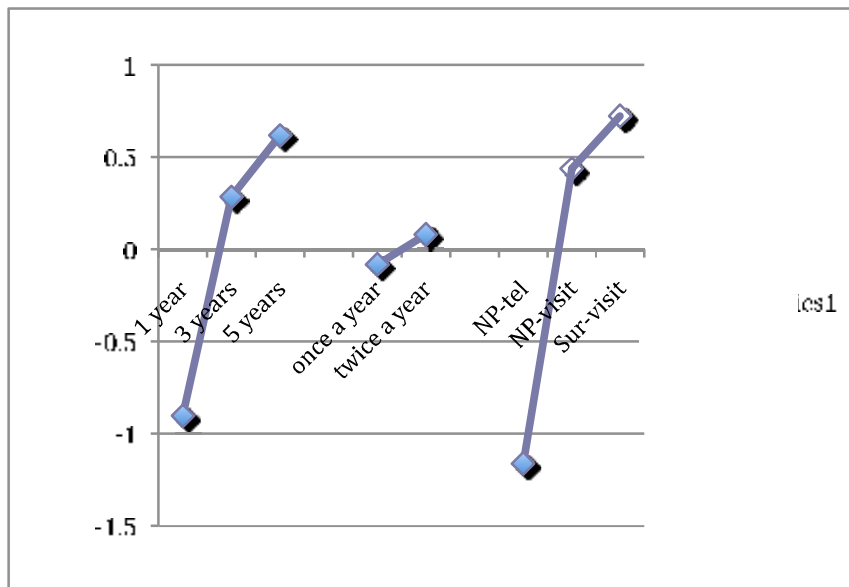


Figure 3 Utilities per attribute level. (Importance per attribute: Total time Span 0,4320; Frequency per Year 0,0704; Type of Consult 0,4976)

Figure 3 shows the utilities per attribute level. The figure clearly shows that the difference between once a year and twice a year is indeed small. For detailed information on the actual utility data, see Table 9. It also shows that the difference between 1 year follow up and 3 years follow-up is far greater than between 3 years and 5 years. 1-year of follow-up has a strong negative utility compared to the other levels, meaning that it is least desired. The same is true for the attribute Type of Consult: the distance between NP – by telephone and NP – visit in hospital is far greater than between Nurse Practitioner – visit in hospital and Surgeon – visit in hospital. Clearly a telephonic consult is least appreciated, but whether the NP or the surgeon facilitates the consult is of far less importance, as long as the consult takes place in a face-to-face setting.

Effect	Std. Error	Level
-0.92457	0.06123	Total time 1 year
0.30710	0.05504	Total time 3 years
0.61747	0.06287	Total time 5 years
0.09520	0.03500	Frequency: once a year
0.09520	0.03500	Frequency: twice a year
-1.17134	0.06479	NP* – by telephone
0.43932	0.05234	NP* – visit in hospital
0.73202	0.06556	Surgeon – visit in hospital

Table 9 Utilities per attribute level

NP = Nurse practitioner



Table 9 shows the utilities per attribute level. Utilities are presented as interval data, meaning that nothing can be said about the proportion between the utilities. However, the largest utility shows the most preferred level; the smallest utility the least preferred level. The utilities per attribute together sum up zero. A rule of thumb is that the standard errors should be around 0,05 when measuring main effects (Orme 2007).

When looking at the first attribute, Total Time Span, the maximum time span that was offered in the questionnaire is the most preferred: 5 years (effect = 0,61747), 1 year follow up is least preferred (0,92457) and 3 years is intermediate preferred (0,30710).

The second attribute, Frequency per Year, does not have much influence on preference, as was shown before. However, if this attribute is taken into account, twice a year (effect = 0,09520) is preferred over once a year (-0,09520). Notice that the utilities together sum up as zero: for that reason the utilities within an attribute with only 2 levels are one another's opposite.

The third attribute, Type of Consult, shows that the most preferred level is Surgeon – visit in hospital (0,73202). Second most preferred is NP – visit in hospital (0,43932). Least preferred is NP – by telephone (-1,17134).

When we sum up these results, the most preferred scenario for the studied population contains the attribute levels 5 years, twice a year, performed by the Surgeon in the hospital. In other words, the most intensive offered scenario in this study has been proven to be the most preferred. However, support exists for 3-year follow-up, and face-to-face consults with the NP. The latter conclusion is what we hypostasized in paragraph 1.6., although weaker than our hypothesis.

4.1.2 Choosing levels when presented

The previous paragraph shows the importance of each attribute, and the most preferred level within each attribute. The next table shows the probability a level was chosen when presented in one of the sets of the choice set, and the frequency it was chosen.

Total Time Span				
	1 year	3 years	5 years	Total
Probability	0,0865	0,2888	0,6247	1
Frequency n (%)	6 (4,8)	31 (24,8)	88 (70,4)	125 (100)

Frequency per Year			
	Once a year	Twice a year	Total
Probability	0,4418	0,5582	1
Frequency n (%)	41 (32,8)	84 (67,2)	125 (100)



Type of Consult				
	NP–visit in hospital	NP – by telephone	Surgeon–visit in hospital	Total
Probability	0,3794	0,0321	0,5886	1
Frequency n (%)	31 (24,8)	2 (1,6)	92 (73,6)	125 (100)

Table 10 Probability and Frequency of attribute levels

Table 10 shows that no dominant criteria exist within each attribute and that only 6 respondents have highest preference for only one year follow-up services, and only 2 respondents have highest preference for consults by telephone.

Paragraph 4.2.1 showed that although a 5 year follow up plan was most preferred, differences in utilities between 3-year follow up and 5 year follow-up are not very great. The same conclusion counted for a face-to-face consult by the NP or surgeon. However, table 10 shows that although utilities might be close to one another, 70,4% of the respondents show most preference for 5-year follow-up, and 73,6% for consults with the surgeon. This clearly shows that although support for the other levels exists, these are clearly ‘second-best’ choices.

4.2 Differences in preferences between risk groups

We now know the importance of the different attributes, and the most preferred corresponding levels. The next question is whether differences in preferences exist between the predefined risk groups. The research question is:

“Do differences in preferences for breast cancer follow-up scenarios exist between predefined risk groups, and if so, what are these differences?”

To answer this research question, 3 analyses are made for the risk groups: one for Total Time Span, one for Frequency per year, and one for Type of Consult. These three attributes together create the total preference. The reason why these attributes are analyzed separately, is to investigate differences between these attributes and risk groups.

4.2.1 Total Time Span

First the attribute Total Time Span is explored, using a cross table.

Total Time Span	Risk Group		
	Low Risk	Medium	High Risk
1 year	2 (6,5)	1 (1,6)	3 (11,5)
3 years	6 (19,4)	16 (25,4)	6 (23,1)
5 years	23 (74,2)	46 (73,0)	17 (65,4)

Table 11 Cross Tabulation Total Time Span [n (%)]



Table 11 shows the results of the cross table for Risk Group and the attribute Total Time Span, with 3 levels: 1 year, 3 years and 5 years. The table shows that all risk groups have highest preference for the maximum level: 5 years (74,2; 73,0; and 65,4% resp. for low, medium and high risk group). Interesting to see is that 1-year follow-up is hardly preferred in none of the risk groups. Remember that our hypothesis is that the higher the risk group, the more preference for longer follow-up. To test whether differences between risk groups and their preferred number of years of follow-up exist, we use the Kruskal-Wallis test. This is used for non-parametric tests with more than 3 groups. This test yields $P = 0,976 > 0,05$. If we combine Low Risk and Medium Risk in one group, and High Risk in the second group, and test this for significant differences with the Mann Whitney test, this does not yield any significant results either ($P = 0,323 > 0,05$); neither with Low Risk as group 1, and Medium and High Risk as group 2 ($P = 0,778 > 0,05$).

With these results, we conclude that no differences between the three predefined risk groups, nor when two of these risk groups are combined as one, exist in relationship with preference for Total Time Span. We reject our hypothesis.

It is worth noticing that patients show a resp. 19,4%, 25,4% and 23,1% preference for only 3 years of follow-up. It is up to the policy makers of follow-up services whether a satisfaction rate of approximately 22% is acceptable (average of low and medium risk is 22,6%) if this leads to follow-up of 3 years instead of 5 years, resulting in lower costs.

4.2.2 Frequency per year

Now the differences between Risk Group and Frequency per year are investigated, in which Frequency per year has 2 levels: once a year, and twice a year. Remember from paragraph 2.1 that frequency per year has only a minor influence on preference. For reasons of completeness, this attribute is calculated.

Frequency per Year	Risk Group		
	Low Risk	Medium Risk	High Risk
Once a year	7 (22,6)	21 (33,3)	10 (38,5)
Twice a year	24 (77,4)	42 (66,7)	16 (61,5)

Table 12 Cross Tabulation Frequency per Year [n (%)]

Table 12 shows the results of the cross table of Risk Group and the attribute Frequency per year. The table shows that all risk groups have highest preference for the maximum level: twice a year (77,4; 66,7 and 61,5% resp. for low, medium and high risk group). Remember that our hypothesis is that the higher the risk group, the more preference for more intense follow-up. The Kruskal-Wallis results in $P = 0,406 > 0,05$, which shows no significant differences between the three risk groups; neither does the combination Low Risk and



Medium Risk in 1 group (Mann Whitney $P = 0,402 > 0,05$); nor Medium and High risk combined (Mann Whitney $P = 0,209 > 0,05$).

We conclude that no significant statistical differences exist between the three predefined risk groups in relationship with preference for Frequency per Year, nor do differences exist when two groups are combined as one. We reject our hypothesis.

4.2.3 Type of Consult

The last analysis investigates the differences between Risk Group and Type of Consult, in which Type of Consult has 3 levels: Nurse Practitioner – visit in hospital, Nurse Practitioner – by telephone, Surgeon – visit in hospital.

Type of Consult	Risk Group		
	Low Risk	Medium Risk	High Risk
NP – by telephone	0 (0,0)	1 (1,6)	1 (3,8)
NP – visit in hospital	6 (19,4)	17 (27,0)	7 (26,9)
Surgeon – visit in hospital	25 (80,6)	45 (71,4)	18 (69,2)

Table 13 Cross Tabulation Type of Consult [n (%)]

Table 13 shows the results of the cross table of Risk Group and the Type of Consult. The table shows that all risk groups have highest preference for the maximum level (i.e. the most expensive type of consult): Surgeon – visit in hospital. (80,6 71,4 and 70,8% resp. for low, medium and high risk group). Our hypothesis is that the higher the risk group, the more preference for more expensive follow up. The Kruskal Wallis test yields a result of $P = 0,590 > 0,05$; the Mann Whitney results in $P = 0,642 > 0,05$, and $P = 0,310 > 0,05$ (for resp. when Low and Medium are combined in 1 group, and when Medium and High are combined in one group). None of the tests show any significant differences between the risk groups and their preferred Type of Consult. We cannot confirm our hypothesis.

4.3 Logistic Regression Model

In the previous sub paragraphs differences between groups and the attributes were analyzed separately. No significant differences were found in either of the attributes. In this paragraph a regression model is used to test whether differences between risk groups and the total preference (i.e. all three attributes combined) exists and if confounding variables exist.

We take Risk Group as the most important variable, since this is the principle variable of this study. In this analysis, High Risk was taken as the reference category.



Variable	Model 1	Model 2	Model 3
Low vs. High Risk Group	2,444 [0,820-7,285]	2,667 [0,883-8,056]	2,564 [1,009-12,585]*
Medium vs. High Risk Group	1,739 [0,690-4,382]	1,902 [0,742-4,876]	2,002 [0,725-5,528]
Number of Years in FU (LCG)		0,896 [0,327-2,450]	0,920 [0,304-2,788]
Coping Style			1,198 [0,520-2,760]

Table 14 Results from Logistic Regression (ϕ [95% CI]) * =sig. on 0,05 level

The table above shows the results of the logistic regression model. In Model 1 we find an ϕ for Risk Group 1 (Low Risk) of 2,444 and 95% CI [0,820-7,285] (no significance: $p = 0,109 > 0,05$). This means that patients in from the low risk category have a 2,444 higher chance of having preference for high costs follow-up than high-risk patients. Patients from Risk Group 2 (Medium Risk) have a 1,739 higher chance of having preference for high costs follow-up (95% CI [0,690 – 4,382], no significance: $p = 0,241 > 0,05$) than high-risk patients. These results show that the higher the risk category, the less chance of preference for high costs follow-up. These results are confirmed by the table below, which shows a cross tabulation of Risk group and preference for follow-up (dichotomous, cut-off point 110EUR). These results do not confirm our hypothesis which states that the higher the risk category, the more preference for high costs follow up. On the contrary, these results show an opposite effect (although not statistically significant).

Total Costs	Risk Group		
	Low Risk	Medium Risk	High Risk
Low Costs	9 (29,0)	23 (36,5)	13 (50,0)
High Costs	22 (71,0)	40 (63,5)	11 (50,0)

Table 15 Cross Tabulation total Costs [n (%)]

After correcting the model for various variables (age, number of years a patient already had received follow-up, the Monitors and Blunters TMSI coping style scale, and quality of life), we find that number of years in follow-up and coping style have greatest impact on the model. All variables were first explored for outliers, skewness and normal distribution. We first add number of years in follow-up (logarithmic transformed) to the model (Model 2) and find an odds ratio of Risk Group 1 (Low Risk) of 2,667 with 95% CI [0,883-8,056] (no significance: $p = 0,082 > 0,05$). This means that patients in from the low risk category have an approximately 2,7 times higher chance of having preference for high costs follow up than high risk patients. Patients from Risk Group 2 (Medium Risk) have a 1,9 higher chance of having preference for high costs follow up [95% CI [0,742-4,876]; no significance: $p = 0,181 > 0,05$). Number of years hardly has any influence: its odds ratio is 0,896 [95% CI [0,327



2,450]). Number of years is not a confounding variable; the odds ratio of Risk Group only increases slightly.

Then we add coping style to the model (Model 3) and find an odds ratio of Risk Group 1 (Low Risk) of 3,564 with 95% CI [1,009 – 12,585] (significance: $p = 0,048 < 0,05$). This means that patients in from the low risk category have an approximately 3,5 times higher chance of having preference for high costs follow up. Patients from Risk Group 2 (Medium Risk) have a 2,002 higher chance of having preference for high costs follow up (95% CI [0,725 – 5,528]; no significance: $p = 0,180 > 0,05$). The other variables have hardly any influence: their odds ratio lies between 0,9 and 1,2. Although the inclusion of coping style makes that the differences between low-risk patients and high-risk patients becomes (weakly) statistically significant, we cannot confirm firmly that coping style is not a confounding variable; the odds ratio of Risk Group hardly changes.

We cannot confirm our hypothesis that the higher the risk category, the higher preference for high costs follow up. Signs even show an opposite direction, saying that the low risk category has higher preference for high costs follow up than the high risk category. This finding is significant when the low and high risk groups are compared. This is also true for the medium-risk category, although this finding is not statistically significant. We see that number of years in follow-up has no influence on preference; neither has coping style (Monitors or Blunters).

4.4 Relation between preferences and coping style

The third research question is: “Is there a relation between preferences and coping style of the patients?”

In this analysis, the dichotomous variable Total Costs with a cut-off point of 110EUR was used.

Costs	Coping Style	
	Blunters	Monitors
Low Costs	19 (36,5)	21 (41,2)
High Costs	33 (63,5)	30 (58,8)

Table 16 Cross tabulation Coping style (CO-point 110EUR) [n (%)]

Table 16 shows the cross tabulation of the coping style (Monitors or Blunters) and the total costs variable, which represents preference. Notice that the total number of respondents is somewhat lower, because some respondents did not complete this part of the questionnaire completely. The table shows hardly any differences between blunters and monitors and



their preferences. This is confirmed by a Mann Whitney test, that yields $p = 0,631 > 0,05$. No statistical differences between coping style and preferences were found. We cannot confirm our hypothesis that Monitors have stronger preference for expensive follow-up than Blunters.

4.5 Change of opinion over time

The last research question is: "Do the preferences of the patients change over time?" Again a cut off point of 110EUR was used to divide the total costs (=preferences) into two groups.

Costs	Number of years in FU		
	0-5 years	6-10 years	>10 years
Low Costs	26 (38,8)	15 (39,5)	4 (26,7)
High Costs	41 (61,2)	23 (60,5)	11 (73,3)

Table 17 Cross Tabulation Number of years in FU (CO-point 110EUR) [n (%)]

Table 17 shows the results. We hardly find any differences between the 3 clusters of number of years in follow up and the preferences for low or high costs follow up. This is confirmed by a Kruskal-Wallis test (number of years in follow up has no normal distribution), that yields a $p = 0,652 > 0,05$. No statistical significant differences can be found between the number of years in follow-up and the preferences for low or high costs follow-up. The expectation that women at the end of their follow-up are more objective cannot be confirmed.



5 CONCLUSIONS

With an increase of the number of patients it is important to make correct choices regarding new follow up policies. This study can contribute to making those decisions when patient preferences are taken into account. Although cost effectiveness studies conclude differently, in this study breast cancer patients showed highest preference for the most intensive follow-up scenario offered: follow-up services for 5 years, with 2 consults per year, performed by the surgeon in a face-to-face consult. This scenario was the most expensive offered scenario for the Centre for Mammacare. Further analyses show that patients least prefer consults by telephone, or only 1 year of follow-up services. However, the differences in preferences between 3 or 5 years of follow-up services are not very large: both levels show a positive preference utility. This is also true for the differences between the NP and surgeon: as long as the consult takes place at the hospital rather than by telephone, patients do not show large differences in preferences between these two levels. These two findings are important, because they show that a certain amount of support exists from breast cancer patients for decreasing breast cancer follow up. Another important finding is that the preference utilities between one and two consults per year are close together. This means that patients do not find it of that importance whether they receive follow up services once or twice a year. This important finding leads to a decrease of costs with 50%. This finding might have medical consequences. Engel et al. (2003) found in their study that a 10mm tumor can double in volume in 4 months, making this a 12,6mm tumor. In this case, further metastases may be initialized in 2,6% of the cases. This finding shows that a decrease of the frequency of follow-up from twice a year to once a year allows the tumor to grow for more time before the next consult. However, as was mentioned in paragraph 1.4, although women might be diagnosed positively earlier, their life expectancy does not increase significantly (Telaro et al. 2007; Tolaney and Winer 2007; Tondini, Fenaroli et al. 2007; Kimman, Voogd et al. 2007a).

The above mentioned findings show a certain support for limited follow-up, but it is important to realize that the most preferred scenario is still the most intensive scenario. Although 3 years of follow-up has a positive utility, still 72% of the patients prefers 5-year follow-up most, versus 24% for 3-year follow-up. The same is true for the differences between NP en surgeon and a face-to-face consult: although the utilities are close together, still 74% prefers the surgeon, and 25% the NP. However, at the time of measurement approximately 10% of the patients had actual experience with the NP, because a NP was not introduced in the Centre for Mammacare until 2006. It is interesting to see that only 10% of the patients have actual experience with a NP, but approximately 25% prefers follow up by the NP. This creates opportunities to extend the services by the NP. Since the NP has 20 minutes available for a consult, as opposed to the 10 minutes of the surgeon, it is expected that patients appreciate it when enough time is reserved for them, as previous research already showed (Pennery & Mallet 2000).

It is important to realize that valid medical arguments for certain follow up should always be the basis on which decision makers make new guidelines for follow up. If medical arguments exist for a certain amount of follow up services, these arguments should not be



overruled by results of a preference study. Within the medical framework, variance exists in which the preferences of the patients can play a role. As was mentioned in the previous paragraph, decreasing frequency per year from twice a year to once a year hardly shows differences in preferences, but decreases costs significantly. If the Center for Mammacare wants to decrease follow-up even further, than the NP could take over more consults from the surgeon. Because wages of NP's are lower, this will decrease costs as well, despite the fact that a consult of a NP takes twice as much time as that of a surgeon.

The last conclusion is that the hypothesis that high risk patients have more preference for expensive follow up than low risk patients cannot be confirmed. Signs even show the opposite conclusion. The fact that hardly significant differences between this risk groups were found implies that the misperception that follow-up is medical effective is widely spread, or that all patients feel comfortable having follow-up visits, regardless the risk group. Another reason might be that patients are not aware of the risk group they belong to, and that breast cancer has such an impact on one's life, that it is not important in which risk group a patients belongs: the overall impact is the same to all patients. Although some signs were found indicating that low-risk patient prefer more expensive follow-up than high-risk patients, more research is needed in order to validate this finding. Therefore, this means that on the basis of preferences, this study cannot provide hard evidence that different patients groups prefer different follow up scenarios.



6 DISCUSSION & LIMITATIONS

Previous literature found underlying reasons for the preferences of cancer patients for follow up. These reasons might influence current preferences and will be discussed in 6.1. Paragraph 6.2 describes the importance of adequate information for patients for the acceptance of new follow up policies. In paragraph 6.3 some limitations of this study are explained.

6.1 *Reasons for preferences*

Many studies assign little to no evidence for medical effectiveness for follow up. However, results of this study show that patients prefer extensive follow up services most. The emphasis of this study lies not in the reasons why patients prefer the follow up they prefer. However, from literature various reasons can be found for this discrepancy. The first reason is that patients who have experienced a treatment generally show stronger preference for that treatment in terms of trade-off scores than patients who did not. This phenomenon is called cognitive dissonance reduction (Stigglebout 2001). Patients tend to make their preferences agree with decisions that were made for them previously (O'Conner 1987). One of the reasons that patients prefer the maximum level of 5 years of follow-up, combined with follow-up performed by the surgeon, might be due to the fact that these levels come closest to their current follow-up service, showing that they have stronger preference for the treatment they have experienced previously or are experiencing at the moment of measurement.

When the respondents were diagnosed positively for breast cancer (many) years ago, they then were told to have follow-up services for 10 years (according to the locally agreed and followed guidelines of Oncoline), performed by the surgeon. At that moment patient information claimed that to be the right amount of follow-up. Guidelines have changed and new insights have been found around the effectiveness of follow-up, but the perception of the patient has not changed. Patients believe what was told back then to be correct, and determine their preferences based on this knowledge. So not only does the current treatment influences the opinion in terms of cognitive dissonance reduction, also the information that came with that follow up service influences the opinion and preferences.

However, the most important reason why patients prefer intensive follow-up has been shown by previous studies. These studies show that follow-up visits give certainty and comfort to the patient that everything "is okay". At the end of the questionnaire of this study space was available for additional comments if applicable. Although not many patients used this opportunity, of those who did more than half of them wrote comments about the strong wish to have follow up services for many years. "Although I'm nervous during visits, I really hope that the follow up will continue as it is! It gives a lot of rest between the visits!" and "After 9 years I would still appreciate annually follow up visits by the surgeon" are examples of additional comments. Although the choices these respondents made in the



questionnaire between the different follow up scenarios already showed clear preferences for the most intensive scenario, it appears that these women wanted to strongly emphasize how important the follow-up visits are to them, and how much they appreciate these visits. As de Bock (2004) already states, "Patients needs and preferences are in contrast with the available evidence in the literature on the value of diagnostic tests for the detection of asymptomatic metastases. This finding stresses the point that patients need to be educated about the effectiveness of follow-up examinations." But if follow-up has such an important psychological function in the sense of comfort and relief, then the more reasons exist why the NP should provide more follow-up services in the future. The NP, as stated before, has more time available, time in which not only the physical part of the disease treatment can receive attention, but also the psychological part. The psychological aspects of preferences for follow up are an interesting topic for further investigation.

6.2 Providing information to patients

Besides the trend of medical decision making another trend is visible in health: risk communication. Risk communication is important with breast cancer, because the treatments are complex, and all have their own risks and benefits (Nekhlyudov & Partridge 2003). Also previous studies have shown that patients want information (Degner et al. 1997). A last reason why providing adequate information to patients is important is because this leads to a better acceptance of new (reduced) follow up policies (Kimman et al. 2007a). According to Nekhlyudov & Partridge (2003) effective risk communication involves non-persuasive communication and exchange of information between patient and specialist. Furthermore the information needs of the patient should be assessed. Before the follow-up services start, the patient should be informed about the service that is offered to her, and most importantly, why this service is offered the way it is. It should become clear to patients why it is possible that different patients receive different follow-up services, based on medical conditions, and therefore why their own follow-up might differ from that of e.g. family members or neighbors. It should also be clear to the patient that after the follow-up, she again participates in the national breast cancer examination program.

Next to the fact that patients want information, it has been shown that misperception exists among breast cancer patients about the disease, and risks and benefits of treatments (Ravdin et al. 1998). This is not only true for women with invasive breast cancer, but also for women with non-invasive breast cancer, i.e. ductal carcinoma *in situ* (DCIS) (Bluman et al. 2001). Women overestimate the actual risk of e.g. early relapse. This fact emphasizes that complete, understandable information for the patient is not only desirable for patients, but also necessary because misperceptions exist.

Previous studies have shown that physicians' recommendations have a significant influence on medical decisions, and can pull people away from decisions they believed were best (Gurmankin et al. 2002). Patients value the opinion of the physician as very important. When this fact, in combination with medical decision making and effective risk communication, is used in follow-up consults, follow-up services can be offered that are not



only more medically efficient, but that also are in agreement with the patients' wishes and preferences.

6.3 Limitations

In this paragraph some limitations of this study are explained.

Although weak statistical significant differences were found between risk groups, logistic regression did show signs of a relationship: the higher the risk group, the lower the preference for high costs follow-up. This is striking in two ways. Firstly, our hypothesis states an opposite relationship. Secondly, when the groups are compared on attribute level (comparisons between the risk groups for every attribute) no significant differences were found. This striking result might be due to the distribution of the risk groups: the low risk category represents approximately 25% of the respondents, the medium risk 57%, and the high risk only 18% of the respondents. Because the groups are not equally distributed, this might lead to untrue conclusions. This study therefore has weak power to confirm this finding. However, it is an interesting topic for further research.

Patients were asked to fill-out the questionnaire while waiting in the waiting area of the hospital. Waiting in the waiting area can be an anxious period for patients (Fallowfield and Baum, 1989). This anxiety could influence the answers the patient gives and the opinion she has. It is imaginable that anxiety creates higher preference for less follow up visits, because this anxiety is created because of the waiting for this consult. However, the opposite is also imaginable: women feel relieved after the consult (Renton et al. 2002), and therefore might have higher preference for more follow up consults. Either way can anxiety bias the respondents answers. An attempt to at least recognize this bias has been done by asking the respondents whether they have filled out the questionnaire before, or after the consult with their physician. 56,5% of the respondents had filled-out the questionnaire before the consult; 43,5% after the consult. Because these two groups are approximately equal, the anxiety bias might have been decreased. However, it is an interesting topic to investigate how much influence the consults have on patients' emotions, and how this influences preferences.

Another note is that in many studies using a conjoint based analysis, the factor willingness to-pay is included. This factor describes how much a respondent is willing to give up in order to get the benefit (Kjær 2005). In the design of this study it was decided not to include this factor, and therefore excluding a trade-off for the respondents. Excluding a trade-off is an important limitation of this study, because patients can choose whatever they prefer, without having to trade-off in terms of e.g. costs. This would mean that a more expensive scenario would result in extra costs for the patient. Such a trade-off was excluded because of two reasons. The first reason is that the simplicity of the model offered to the respondents was an important factor. During the pilot-testing period many respondents indicated that a too extended model was too complicated to understand. The second reason is that the willingness to pay factor is especially used in the United States, where the health



care system is based on a system of payment by the patients. In such a system it is applicable to ask patients about their willingness to pay for a certain treatment, since they are used to this concept. However, Dutch patients are not used to this concept, because the Dutch health care system is a system based on insurance payment. Asking patients about something that is not plausible in the nearby future was not considered to be appropriate.

This study is part of a two section study. The other section studied the cost effectiveness of the different follow up scenarios in which costs were measured in time, and effectiveness in medical effectiveness. A last note is that these two sections were studied separately. However, they can be connected by using the utilities for follow up scenarios from this study that were used to measure preferences. These utilities can be connected to costs utilities of the different scenarios in relation to the effectiveness on the quality of life of these scenarios. When these utilities are connected, one could investigate which scenario creates the maximum quality of life gain (assuming that this is related to preferences), related to the costs of that scenario. Consequently this leads to the conclusion that the introduction of a certain scenario leads to a certain increase or decrease of the quality of life, or visa versa: to improve quality of life certain scenarios should be introduced. An optimal situation can then be calculated. This is an aspect that was not extensively investigated by this study and is an interesting topic for further research.



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8 APPENDICES

Appendix I Glossary

Term	Description
Adjuvant Therapy	Use of chemotherapy or radiotherapy in addition to surgical procedures in the treatment of cancer
Asymptomatic state	The stage in which the patient does not experience noticeable symptoms
Bone scintigraphy	Bone scan to evaluate the skeletal system
BRCA 1/2 gene mutation	Breast cancer gene, indication of breast cancer
Breast Conserving Therapy	Treatment in which the lump and a rim of surrounding tissue is removed, followed by additional treatments like radiotherapy
Contra lateral tumor	Second primary tumor in the opposite breast
Distant metastases	Metastases with breast cancer occur mostly in the bones, lungs and liver, incurable
Ductal Carcinoma in Situ (DCIS)	Non-invasive type of cancer that does not spread to other parts, but stays inside the milk duct. Referred to as stage 0 cancer: non life-threatening.
Follow up	Surveillance strategy after primary treatment
Loco regional recurrence	Tumor that occurs in the same breast or same side as the first primary tumor
Lymph node status	Important parameter for patient prognosis. Refers to the number of positive lymph nodes
Mammography	An X-ray of the female breast
Mastectomy	Partial or complete removal of the breast
Metastases	Transfer of cancer from one organ or part of the body to another not directly connected with it
ONCON	Oncological Network Surgeons East Netherlands (Oncologisch Netwerk Chirurgen Oost Nederland)
Primary metastases	Distant metastases caused by the primary tumor
Primary treatment	Treatment related to the primary tumor



Second primary tumor	Occurs in the contra lateral (=opposite) breast than the first primary tumor, unrelated to primary tumor
Secondary metastases	Distant metastases caused by a loco regional recurrence or a second primary tumor
Symptomatic stage	The stage in which the patient does experience noticeable symptoms



Bestemd voor de specialist:

<i>T size in cm.</i>	<input type="text"/>
<i>Number of positive lymph nodes</i>	<input type="text"/>

Uitleg voor patiënt

Het ziekenhuis probeert de kwaliteit van de zorg steeds verbeteren, en wil daarom graag weten wat uw behoefte is aan nacontroles na behandeling van borstkanker. Met deze informatie wil het ziekenhuis de zorg meer aanpassen op uw wensen. Onderzoekers twijfelen eraan of de jarenlange nacontroles medisch gezien wel zin hebben. Het is daarom belangrijk dat u deze vragenlijst invult, omdat het ziekenhuis graag wil weten of u deze nacontroles toch op prijs stelt.

Deze vragenlijst bestaat uit 36 vragen en kost ongeveer 10 minuten om in te vullen. Overal staat uitgelegd hoe u de vragen moet beantwoorden. Vul deze vragenlijst alstublieft in de wachtkamer in, zonder overleg met anderen: het gaat tenslotte om uw eigen mening en ervaringen.

Heeft u alle vragen ingevuld, geef de vragenlijst dan tijdens uw bezoek aan uw specialist. Bent u nog niet helemaal klaar met invullen als u door uw specialist geroepen wordt, vul de vragenlijst dan alstublieft na uw bezoek alsnog verder in. U kunt de vragenlijst daarna aan de secretaresse geven.

Uw specialist zal tijdens uw bezoek 2 medische gegevens opschrijven: de grootte van de tumor die u had, en het aantal lymfeklieren dat geïnfecteerd was. Verder worden er geen persoonsgegevens gebruikt: de vragenlijst is volledig anoniem en vertrouwelijk. Uw specialist zal de antwoorden die u gegeven heeft niet lezen.

Vraag 1 begint op de achterkant van deze pagina. Met uw hulp wordt de zorg verbeterd! Bedankt voor uw medewerking.

1. In welk jaar bent u **behandeld** voor borstkanker?

2. In welk jaar bent u **geboren**?

3. Wat is uw geslacht?

- Vrouw
 Man

4. Wat is uw hoogst **afgeronde** opleiding? (één vakje aankruisen)

- Lager Onderwijs
 Lager Voorgezet Onderwijs (LAVO, VGLO)
 Lager Beroepsonderwijs (LHNO, Huishoudschool, LTS, LDS)
 Middelbaar Voortgezet Onderwijs (MAVO, MMO, MULO)
 Middelbaar Beroepsonderwijs (MEAO, MTS)
 Hoger Voortgezet Onderwijs (HAVO)
 Voorbereidend Wetenschappelijk Onderwijs (VWO, HBS, Gymnasium)
 Hoger Beroepsonderwijs (HBO, HTS, HEAO)
 Universitair Onderwijs (Universiteit, Technische Hogeschool)
 Anders

5. Hoe is uw **woonsituatie**? (één vakje aankruisen)

- Ik woon alleen
 Ik woon met partner (en eventueel kinderen)
 Ik woon met mijn ouders
 Ik woon in een woongroep
 Anders

6. Hoe is uw **werksituatie**? (één vakje aankruisen)

- Betaald werk
 Huishouden
 Werkeloos
 Arbeidsongeschikt
 Gepensioneerd
 Student(e)
 Anders

7. Komt borstkanker veel bij u in de familie voor?

- Ja, erg veel
- Nee, niet zo veel
- Helemaal niet
- Weet ik niet

UITLEG: Zet bij de volgende vragen een kruisje in het hokje voor de zin die het best past bij uw eigen situatie vandaag.

8. Mobiliteit

- Ik heb geen problemen met lopen
- Ik heb enige problemen met lopen
- Ik ben bedlegerig

9. Zelfzorg

- Ik heb geen problemen om mijzelf te wassen of aan te kleden
- Ik heb enige problemen om mijzelf te wassen of aan te kleden
- Ik ben niet in staat mijzelf te wassen of aan te kleden

10. Dagelijkse bezigheden (*bijvoorbeeld werk, studie, huishouden, gezins- en vrijetijdsactiviteiten*)

- Ik heb geen problemen met mijn dagelijkse activiteiten
- Ik heb enige problemen met mijn dagelijkse activiteiten
- Ik ben niet in staat mijn dagelijkse bezigheden uit te voeren

11. Pijn/klachten

- Ik heb geen pijn of andere klachten
- Ik heb matige pijn of andere klachten
- Ik heb zeer ernstige pijn of andere klachten

12. Stemming

- Ik ben niet angstig of somber
- Ik ben matig angstig of somber
- Ik ben erg angstig of somber

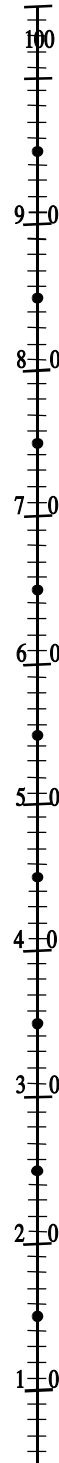
Vraag 13

Om mensen te helpen bij het aangeven hoe goed of hoe slecht een gezondheidstoestand is, hebben we een meetschaal (te vergelijken met een thermometer) gemaakt. Op de meetschaal hiernaast betekent "100" de beste gezondheidstoestand die u zich kunt voorstellen, en "0" de slechtste gezondheidstoestand die u zich kunt voorstellen.

We willen u vragen op deze meetschaal aan te geven hoe goed of hoe slecht volgens u uw eigen gezondheidstoestand vandaag is. Trek een lijn van het hokje hieronder naar het punt op de meetschaal dat volgens u aangeeft hoe goed of hoe slecht uw gezondheidstoestand vandaag is.

**Uw
gezondheidstoestand**

Best
voorstelbare
gezondheidstoestand



Slechtst
voorstelbare
gezondheidstoestand

UITLEG: Bij de volgende vragen wordt elke keer een situatie beschreven. Probeer de situatie voor te stellen en kruis dan bij elke stelling (a t/m f) het hokje aan dat het best bij u past. De situaties hebben niets te maken met uw persoonlijke omstandigheden en zijn willekeurig gekozen.

Vraag 14

Stel, u hebt al een tijd last van hoofdpijn en duizeligheid. U bent bij de huisarts en deze vertelt u dat hij het niet helemaal vertrouwt en dat u naar de specialist moet voor een nogal vervelend onderzoek.

Geef uw mening over de volgende stellingen door het juiste hokje erachter aan te kruisen:

- a. Ik neem mij voor de specialist zoveel mogelijk te vragen
- b. Ik denk dat het allemaal wel mee zal vallen
- c. Ik besluit eerst nog bij andere instanties en dokters te informeren
- d. Ik neem mij voor te gaan lezen over hoofdpijn en duizeligheid
- e. Ik probeer voorlopig zo min mogelijk aan vervelende dingen te denken
- f. Ik maak me niet druk: zo'n onderzoek is minder erg

Helemaal niet op mij van toepassing	Niet erg op mij van toepassing	Enigszins op mij van toepassing	Nogal op mij van toepassing	Zeër op mij van toepassing
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Vraag 15

Stel, u werkt hard en bent veel te zwaar. Uw huisarts heeft al vaker gezegd dat dit onverstandig is. U bent bij hem en hij constateert een te hoge bloeddruk.

Geef uw mening over de volgende stellingen door het juiste hokje erachter aan te kruisen:

- a. Ik kijk mee op het apparaat om te zien of hij zich niet vergist
- b. Ik maak me niet al te druk
- c. Ik besluit gewoon door te leven
- d. Ik vraag uitgebreid naar de verdere gevolgen en risico's
- e. Ik denk bij mezelf: "er zijn ergere kwalen"
- f. Ik neem me voor veel te lezen over een hoge bloeddruk.

Helemaal niet op mij van toepassing	Niet erg op mij van toepassing	Enigszins op mij van toepassing	Nogal op mij van toepassing	Zeër op mij van toepassing
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Vraag 16

Stel, u hebt last van uw hart. U bent bij de specialist en hij adviseert een operatie. Hij vertelt dat u er vier maanden op moet wachten en dat niet zeker is of de operatie echt zal helpen.

Geef uw mening over de volgende stellingen door het juiste hokje erachter aan te kruisen:

- a. Ik ga ervan uit dat de operatie bij mij wel zal helpen
- b. Ik besluit me zoveel mogelijk in hartoperaties te gaan verdiepen
- c. Ik neem me voor de komende maanden zoveel mogelijk plezierige en nuttige dingen te gaan doen
- d. Ik ga onderzoeken of er een kans is dat de operatie nadelig uitpakt
- e. Ik ga contact zoeken met andere patiënten met hetzelfde probleem, voor informatie
- f. Ik denk: "het zal allemaal wel meevallen"

Helemaal niet op mij van toepassing	Niet erg op mij van toepassing	Enigszins op mij van toepassing	Nogal op mij van toepassing	Zeer op mij van toepassing
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Vraag 17

Stel, u gaat met niet al te ernstig lijkende darmklachten naar de dokter. Hij constateert een acute blindedarmonsteking en zegt dat u zo snel mogelijk geopereerd moet worden.

Geef uw mening over de volgende stellingen door het juiste hokje erachter aan te kruisen:

- a. Ik wil precies van hem weten wat ze met me gaan doen
- b. Ik besluit me nog even te ontspannen voor het zover is
- c. Ik vraag me af wat er allemaal mis kan gaan
- d. Ik maak me zo min mogelijk druk
- e. Ik denk: "het zal allemaal wel meevallen"
- f. Ik probeer snel nog iemand te bellen die mij iets over deze operatie kan vertellen

Helemaal niet op mij van toepassing	Niet erg op mij van toepassing	Enigszins op mij van toepassing	Nogal op mij van toepassing	Zeer op mij van toepassing
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

UITLEG: Het ziekenhuis gaat de nacontroles voor borstkanker veranderen. Daarom wil het ziekenhuis graag weten hoe u dit het liefst heeft. Hierbij kijkt het ziekenhuis naar 3 dingen:

1. Totaal aantal jaren van de nacontroles

Het ziekenhuis wil de nacontroles in totaal 1 jaar, 3 jaren of 5 jaren aanbieden. Minimaal 1 jaar is nodig, omdat dan gekeken wordt of bijvoorbeeld de wond van de operatie goed geneest. Meer dan 5 jaren is niet nodig, blijkt uit onderzoek. Na de jaren van nacontroles doet u weer mee met de landelijke bevolkingsonderzoeken.

2. Hoe vaak per jaar

Het ziekenhuis wil 1x of 2x per jaar een consult aanbieden. Vaker dan 2x per jaar is niet nodig, blijkt uit onderzoek.

3. Wat voor soort bezoek

Nu gaat u nog elke keer naar het ziekenhuis voor een nacontrole, maar dit kan ook per telefoon. U wordt dan geleerd hoe u zichzelf thuis kunt onderzoeken, en wordt thuis gebeld met de vraag of u klachten heeft. Heeft u al eerder klachten, dan kunt u zelf het ziekenhuis bellen om alsnog snel een afspraak in het ziekenhuis te maken.

Nu wordt u gecontroleerd door de chirurg. Het ziekenhuis wil dit ook laten doen een Nurse Practitioner (NP). Zij is goed opgeleid om een aantal taken van de chirurg over te nemen, waaronder bijvoorbeeld de nacontroles.

Bij de volgende vragen worden steeds twee mogelijkheden gegeven, die elke keer weer anders zijn. Kruis bij elke vraag aan welke mogelijkheid u het liefst heeft: **A of B**.

Voorbeeld:

	<div style="border: 1px solid black; padding: 5px; width: fit-content;">Totaal 5 jaren 1x per jaar NP – telefonisch</div>			<div style="border: 1px solid black; padding: 5px; width: fit-content;">Totaal 1 jaar 2x per jaar Chirurg – bezoek in ziekenhuis</div>	
Kies:	A	<input checked="" type="checkbox"/>	OF	B	<input type="checkbox"/>

A betekent in dit voorbeeld: na de operatie nog 5 jaren lang nacontroles, 1x per jaar, door de Nurse Practitioner, waarbij zij u opbelt om te vragen of alles goed is.

B betekent in dit voorbeeld: na de operatie nog 1 jaar nacontroles, 2x per jaar, door de chirurg, waarbij u naar het ziekenhuis gaat voor de nacontrole.

Kruis bij vraag 18 t/m 22 aan welke mogelijkheid u het liefst heeft: A of B.

Vraag 18

Totaal 5 jaren
1x per jaar
NP – bezoek in ziekenhuis

Totaal 1 jaar
2x per jaar
NP - telefonisch

Kies:

A

OF

B

Vraag 19

Totaal 1 jaar
1x per jaar
NP – bezoek in ziekenhuis

Totaal 3 jaren
2x per jaar
Chirurg – bezoek in ziekenhuis

Kies:

A

OF

B

Vraag 20

Totaal 3 jaren
1x per jaar
NP - telefonisch

Totaal 5 jaren
2x per jaar
Chirurg – bezoek in ziekenhuis

Kies:

A

OF

B

Vraag 21

Totaal 3 jaren
2x per jaar
NP – bezoek in ziekenhuis

Totaal 1 jaar
1x per jaar
Chirurg – bezoek in ziekenhuis

Kies:

A

OF

B

Vraag 22

Totaal 5 jaren
1x per jaar
NP - telefonisch

Totaal 1 jaar
2x per jaar
NP – bezoek in ziekenhuis

Kies:

A

OF

B

Kruis bij vraag 23 t/m 27 aan welke mogelijkheid u het liefst heeft: A of B.

Vraag 23

Totaal 5 jaren
2x per jaar
NP - telefonisch

Totaal 3 jaren
1x per jaar
Chirurg – bezoek in ziekenhuis

Kies: A

OF B

Vraag 24

Totaal 3 jaren
2x per jaar
NP– bezoek in ziekenhuis

Totaal 1 jaar
1x per jaar
Chirurg – bezoek in ziekenhuis

Kies: A

OF B

Vraag 25

Totaal 3 jaren
1x per jaar
NP– bezoek in ziekenhuis

Totaal 5 jaren
2x per jaar
NP - telefonisch

Kies: A

OF B

Vraag 26

Totaal 5 jaren
2x per jaar
Chirurg – bezoek in ziekenhuis

Totaal 1 jaar
1x per jaar
NP - telefonisch

Kies: A

OF B

Vraag 27

Totaal 5 jaren
1x per jaar
NP– bezoek in ziekenhuis

Totaal 1 jaar
2x per jaar
Chirurg – bezoek in ziekenhuis

Kies: A

OF B

Kruis bij vraag 28 t/m 30 aan welke mogelijkheid u het liefst heeft: A of B.

Vraag 28

Totaal 3 jaren
1x per jaar
NP - telefonisch

Totaal 1 jaar
2x per jaar
NP – bezoek in ziekenhuis

Kies: A

OF B

Vraag 29

Totaal 3 jaren
2x per jaar
NP - telefonisch

Totaal 5 jaren
1x per jaar
Chirurg – bezoek in ziekenhuis

Kies: A

OF B

Vraag 30

Totaal 1 jaar
1x per jaar
NP – bezoek in ziekenhuis

Totaal 3 jaren
2x per jaar
Chirurg – bezoek in ziekenhuis

Kies: A

OF B

UITLEG: De laatste vragen gaan over uw gezondheid. Als u niet zeker weet hoe u de vraag moet beantwoorden, geef dan het best passende antwoord. Geef steeds één antwoord per vraag.

31. Wat vindt u, **over het algemeen**, van uw gezondheid? (één hokje aankruisen)

Mijn gezondheid omschrijf ik zelf als...

- | | |
|--------------------------|------------|
| <input type="checkbox"/> | Uitstekend |
| <input type="checkbox"/> | Zeer goed |
| <input type="checkbox"/> | Goed |
| <input type="checkbox"/> | Matig |
| <input type="checkbox"/> | Slecht |

32. De volgende vragen gaan over de dagelijkse bezigheden. Wordt u **op dit moment** beperkt door uw gezondheid bij deze bezigheden? Zo ja in welke mate?

	Ernstig beperkt	Een beetje beperkt	Helemaal niet beperkt
a) Tijdens matige inspanning zoals stofzuigen of fietsen word ik...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Bij het lopen van een paar trappen word ik...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

33. Had u, ten gevolge van uw lichamelijke gezondheid, **de afgelopen 4 weken één** van de volgende problemen bij uw werk of andere bezigheden?

	Altijd	Meestal	Soms	Zelden	Nooit
a) Ik heb <i>minder bereikt</i> dan ik zou willen...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Ik was beperkt in het <i>soort werk</i> of het soort bezigheden...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

34. Had u, ten gevolge van een emotioneel probleem (bijv. doordat u zich depressief of angstig voelde), **de afgelopen 4 weken één** van de volgende problemen bij uw werk of andere dagelijkse bezigheden?

	Altijd	Meestal	Soms	Zelden	Nooit
a) Ik heb <i>minder bereikt</i> dan ik zou willen...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Ik was beperkt in het <i>soort werk</i> of het soort bezigheden...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

35. In welke mate heeft pijn u **de afgelopen 4 weken** belemmerd bij uw normale werkzaamheden (zowel werk buitenshuis als huishoudelijk werk)?

Pijn belemmerde mij de afgelopen 4 weken...

<input type="checkbox"/>	Helemaal niet
<input type="checkbox"/>	Een klein beetje
<input type="checkbox"/>	Nogal
<input type="checkbox"/>	Veel
<input type="checkbox"/>	Heel erg veel

36. Deze vragen gaan over hoe u zich **de afgelopen 4 weken** heeft gevoeld. Wilt u bij elke vraag het antwoord aankruisen dat het beste aansluit bij hoe u zich heeft gevoeld.

Hoe vaak gedurende de afgelopen 4 weken....

	Altijd	Meestal	Soms	Zelden	Nooit
a) voelde u zich kalm en rustig?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) voelde u zich energiek?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) voelde u zich neerslachtig en somber?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

37. Hoe vaak hebben uw lichamelijke gezondheid of emotionele problemen gedurende de **afgelopen 4 weken** uw sociale activiteiten (zoals bezoek aan vrienden of naaste familieleden) belemmerd?

Mijn lichamelijke gezondheid en emotionele problemen belemmerden mij de afgelopen 4 weken...

- Voortdurend
- Meestal
- Soms
- Zelden
- Nooit

38. Dit is de laatste vraag. Wanneer heeft u deze vragenlijst helemaal afgemaakt?

- Ik was **voor** mijn bezoek aan de specialist al helemaal klaar met invullen
- Ik heb **na** mijn bezoek aan de specialist deze vragenlijst nog afgemaakt

Bedankt voor het invullen van deze vragenlijst! Geef deze vragenlijst alstublieft aan uw specialist tijdens uw bezoek zodat de medische gegevens genoteerd kunnen worden, of na uw bezoek bij de specialist aan de secretaresse wanneer u de vragenlijst voor het bezoek nog niet helemaal af had en deze later nog heeft afgemaakt.

Heeft u opmerkingen na aanleiding van deze vragenlijst? Hieronder is ruimte om uw opmerkingen op te schrijven. Voor dringende vragen kunt u contact opnemen met de onderzoeker Timon Sibma: 053 489 2709.

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