Breast cancer follow-up: from the perspective of health professionals and patients

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Increased breast cancer incidence and better survival have raised the number of patients requiring follow-up care. Despite guidelines, there is controversy about appropriate breast cancer follow-up. Therefore, semi-structured interviews were conducted in two hospitals with 23 patients and 18 health professionals [HPs] in order to explore opinions and preferences about the purpose, the duration and frequency of breast cancer follow-up and which examinations should be done, by whom. The transcripts were inductively analysed and coded into pre-identified themes. Patients were followed more intensively than guidelines recommend. HPs mentioned three major reasons; patient preferences, each discipline wanting to observe the patient, and financial incentives. For patients and HPs the most important purpose of follow-up was early detection of new malignancies. A highly valued aspect of follow-up mentioned by HPs was the psychosocial support, which was rarely mentioned by patients. Patient’s expectations about the benefits of follow-up and additional examinations were sometimes unrealistic. Patients and HPs were positive about nurse practitioner-led follow-up, but less positive about general practitioner-led follow-up. Important barriers to current guideline adherence were revealed and should be taken into account by implementing new individualised guidelines. Furthermore, patients should be better informed about the benefits of follow-up to prevent unrealistic expectations.

Keywords: breast cancer, follow-up, preferences, guidelines, patient, health professional.

INTRODUCTION

More than 13,000 women are diagnosed annually with breast cancer in the Netherlands [Comprehensive Cancer Centre the Netherlands [IKNL] 2011]. The 5-year relative survival of breast cancer patients increased over the years, from 77% for patients diagnosed in 1989–1993 to 86% for patients diagnosed in 2003–2008. This leads to an increasing number of patients requiring follow-up care. The primary purpose of follow-up is the early detection of loco-regional recurrences or a second primary tumour, in order to start immediate potentially curative therapy and
prolong survival [National Breast Cancer Consideration Netherlands (NABON) 2008]. Other reasons for providing follow-up care are detecting side-effects of treatment and providing psychosocial support.

Since 1999 evidence-based follow-up guidelines exist in the Netherlands, although compliance with these guidelines is not obligatory. As a result, follow-up practices vary between hospitals in the Netherlands and patients attend the hospital for follow-up visits more often than guidelines recommend (Grandjean et al. 2012). Due to the doubtful benefits of routine follow-up visits and the increasing burden for health professionals (HPs), the debate about the frequency and duration of follow-up is ongoing. Who should provide follow-up care and which diagnostic tests should be performed? (te Boekhorst et al. 2001; Jacobs et al. 2001; De Bock et al. 2004a). Several studies investigating patient preferences have shown that patients tend to have a strong preference for intensive follow-up by a specialist (Adewuyi-Dalton et al. 1998; De Bock et al. 2004b). However, little is known about the opinions and preferences of HPs. Previous reports show that HPs are likely to follow a large group of patients longer and more intensive than guidelines advise and many different HPs are involved in follow-up (Donnelly et al. 2001; van Hezewijk et al. 2011a). In optimising breast cancer follow-up and understanding the heterogeneity in compliance, it is important to gain insight into the attitudes, experiences and preferences of HPs and patients. After all, their opinions will strongly influence the adherence to the guidelines. Therefore, the present qualitative study was conducted, to explore the opinions and preferences of both HPs and patients about the current follow-up guideline and different aspects of follow-up, including the purpose of follow-up, the duration and frequency, which examinations should be done and by whom.

MATERIALS AND METHODS

Semi-structured interviews were conducted with breast cancer patients and with HPs involved in breast cancer follow-up at two top clinical teaching hospitals in the Netherlands. Both hospitals have mammot care centres, in which multidisciplinary teams perform the diagnostic examinations, treatment and follow-up of patients with a breast lesion. In 2009, 432 women were diagnosed with breast cancer in both hospitals. Depending on the treatment, the follow-up in these hospitals was performed by one or more HPs: a surgeon, a medical oncologist, a radiation oncologist or a nurse practitioner (NP).

Participants

In 2009, patients at different ages and with different time intervals since diagnosis, who fulfilled the inclusion criteria were asked to participate in the study. In total 26 curatively treated breast cancer patients were asked to participate. The following inclusion criteria were applied: [1] patients had not suffered an earlier tumour and were free of loco-regional recurrences or metastases; [2] patients were physically and emotionally able to participate; and [3] patients had sufficient knowledge of the Dutch language. All patients received a letter from their surgeon with detailed information about the study. After a week, patients were called and invited to participate. Three patients refused to participate. In the end 10 and 13 patients from each hospital took part in the study. The median age of the patients was 51 years (range 43.9–80.6 years) and the median time after diagnosis was 2.5 years (range 0.3–5.6 years). All patients were treated surgically (70% mastectomy), 50% received adjuvant chemotherapy and 50% received adjuvant radiotherapy. Endocrine therapy was given to 14 patients (64%) at time of the study inclusion.

Health professionals (n = 20) were selected on the basis of their involvement in the treatment and follow-up of the patient and their field of interest. They were informed by letter and asked to participate by phone. Two HPs (one medical oncologist and one surgeon) refused to participate. In total 18 HPs agreed to participate in the study: five surgeons, two medical oncologists, three radiation oncologists, one gynaecologist, five NPs and two general practitioners (GPs). The NPs had a masters degree in Advanced Nursing Practice or an in-hospital training to become a mammot care specialist. The medical specialists all followed a specialisation in oncology. The years of experience ranged from 2 to 26 years. Two-thirds of the HPs were men.

Follow-up guidelines

In the Netherlands, national guidelines for breast cancer care have existed since 1999. During the study period the 2008 NABON guideline (NABON 2008) was available, suggesting a standard follow-up schedule lasting of 5 years for all breast cancer patients. Patients should visit the hospital every 3 months in the first year, every 6 months in the second year and annually during the subsequent 3 years. During these visits a physical examination is performed, supported by an annual mammogram. The annual follow-up continues until the age of 60, patients older than 60 are referred to the GP or to the national screening programme. In the national screening programme, women
between 50 and 75 years old undergo a standard biennial screening mammogram. It should be made clear to the patient and the GP who co-ordinates the follow-up, this could be the NP, surgeon, medical oncologist or radiation oncologist.

Data collection

Semi-structured, face to face, interviews were conducted by the same person ABGK (who was trained to do semi-structured interviews). Interviews were audio taped after consent of the participant. Patients were interviewed at their homes, and the interviews lasted between 30 and 90 min. Each patient interview started with some general questions about how breast cancer was detected, how it was treated, how follow-up was organised and how satisfied they were with the current follow-up. HPs were interviewed at the hospital or their practice. For the HPs the interview started by asking how follow-up was organised and what specific contribution they had in it. Subsequently, both patients and HPs were asked to reflect freely about the following issues: purpose of follow-up, preferred duration and frequency, preferred diagnostic examinations and involved HPs.

Ethical considerations

According to local regulations in the Netherlands [Medical Research Involving Human Subjects Act [WMO]], the study did not need approval of the ethical review board, only non-intervention studies with high burden for patients have to be reviewed. The following precautions were taken to protect the participants. Participants were informed about the purpose of the research, the procedure and how data will be used. Furthermore, patients were informed that participation was completely voluntary and that their decision about participation did not have any consequences for treatment and follow-up care. Patients were also informed that none, neither their doctors, will be informed about the participation in the study and content of the interviews. The field notes and transcripts did not contain personal identifiers and were kept locked or password protected. Data were only shared with the three investigators.

Data analysis

The audiotapes were transcribed verbatim. All three investigators separately read all transcripts to familiarise themselves with the data. The principle investigator (ABGK) selected all citations that were relevant to the research questions, and coded these into five pre-identified themes:

1. Implementation of the current follow-up guidelines;
2. Main purpose of follow-up;
3. Preferred frequency and duration;
4. Which examinations should be conducted;
5. Who should perform the follow-up care.

Next, the citations within each theme were further analysed and arranged into subcategories by three investigators [ABGK, CHCD and SS] independently, using an inductive process, meaning that themes and categories arise from the data (Patton 1990). During this phase the coders met on several occasions to discuss their findings. Differences were discussed until consensus was reached on the final subcategories [as presented in the results section]. Finally, one coder (ABGK) examined the raw data again to ensure the robustness of the analytical process and to confirm that all data were indeed reflected in the coding. Although the qualitative nature of the study does not allow for any conclusions regarding the numbers of HPs that held a particular opinion, the frequencies of the number of citations within each subcategory was used to assist in determining their importance in our interpretation of the answers of the interview questions.

RESULTS

The results describe the perceptions of HPs and patients regarding the current follow-up practice and opinions and preferences regarding diverse follow-up items: the purpose of follow-up, frequency and duration, which diagnostic examinations should be used and who should perform follow-up visits.

Perceptions regarding the current follow-up

The interviews started by asking in general how the current follow-up was organised and how satisfied patients were with current follow-up. Almost all HPs mentioned that current follow-up guidelines were used. However, subsequently about half of the HPs indicated that patients often were followed longer and more frequently than recommended. Several reasons for more intensive follow-up emerged from the interviews. The first reason that emerged from the data was that HPs felt that patients prefer a more intensive or longer follow-up, and HPs complied with their requests. This was illustrated by a NP in the following quote:

For the patient, the follow-up visits are very important, therefore it is hard to end the follow-up period.

[HP: nurse practitioner]

The second reason was that some HPs indicated that each involved discipline [surgeon, radiation oncologist...
and medical oncologist) wants to follow the patient themselves. Because they want to monitor side-effects relevant for their own specialty. A radiation oncologist said:

Patients are examined for late treatment effects. In order to know what the treatment will cause in future patients. [HP: radiation oncologist]

The final reason was that financial incentives for longer follow-up periods appeared to play a role in continuing the follow-up. The following extract illustrates this point:

Because of budgetary reasons patients are seen for 10 years instead of 5 years. [HP: surgeon]

Patients were generally satisfied about how the follow-up was organised and particularly about the accessibility of the HPs. Patients agree that follow-up is often more intense than recommended by the guideline. Some patients indicated that they were seen every year by a surgeon or NP, a radiation oncologist and a medical oncologist. Therefore visited the hospital up to three times a year, whereas one visit should have been sufficient. Moreover some patients were dissatisfied about the many different faces they have seen during the follow-up period, as illustrated by the following citation:

Sometimes it isn’t possible, but I prefer to see the same doctor during the follow-up period. Than you don’t need to tell your story again and again. Sometimes I asked myself whether they read my dossier before the follow-up visit.

Opinions and preferences regarding different follow-up items

What should be the main purpose of follow-up!

Table 1 shows an overview of the mentioned goals of the follow-up according to the HPs and patients.

For almost all HPs, the most important goal of follow-up was the early detection of a recurrence or a second primary tumour. Yet some HPs questioned whether early detection of recurrence is a realistic goal:

You catch almost nothing, those patients come in between the regular visits. It’s more about the social talk. [HP: surgeon]

Furthermore, HPs mentioned that psychosocial support becomes a more and more important purpose of follow-up. Patients, however, rarely mentioned psychosocial support as follow-up goal in itself.

For patients one of the main purposes of follow-up were examination of the breast. Hardly none of the patients explicitly mentioned early detection of recurrences. Another important purpose for patients was reassurance and guidance.

I think it is reassuring, after the follow-up visit you are less tense for the next year. Although, a month later you can have problems again, you are never sure about that. [Patient]

It was noted by HPs that the views of patients regarding ‘reassurance’ were sometimes unrealistic. As some patients seemed to think that they could not get breast cancer, as long as they were in the follow-up programme, which is illustrated by the following citation:

I prefer follow-up visits as long as possible, 2 times a year. As they just make a mammogram every half year, than you can be sure that you never get it again. Of course, I know that you can get the disease elsewhere, but at least no longer in the breast.

Half of the HPs mentioned to experience a discrepancy between the expectations of the patient and the ability of the HPs. This was illustrated by the following point:

We tell the patient that we see no signs of disease, the patient interprets that as: I am healed. [HP: gynaecologist]

Monitoring long-term side-effects of radiation therapy was particularly important for the radiation oncologist. The medical oncologist evaluated the effects of endocrine therapy in order to adapt therapy if necessary. They also keep patients in follow-up because of participation in a clinical trial. The NPs were mainly concerned about the wounds and the effects of the resection of lymph nodes.

Table 1. Follow-up goals: reported by health professionals and patients

<table>
<thead>
<tr>
<th>Often mentioned</th>
<th>Health professionals</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Early detection of recurrences and second tumours</td>
<td>• Examination of the breast</td>
<td></td>
</tr>
<tr>
<td>• Psychosocial support</td>
<td>• Reassurance</td>
<td></td>
</tr>
<tr>
<td>• Guidance, information and referral</td>
<td>• Guidance of patients; answering questions</td>
<td></td>
</tr>
<tr>
<td>Occasionally mentioned</td>
<td>• Evaluation of treatment and treatment side-effects</td>
<td></td>
</tr>
<tr>
<td>• Evaluation of treatment and treatment side-effects</td>
<td>• Evaluation of treatment and treatment side-effects</td>
<td></td>
</tr>
<tr>
<td>• Early detection of metastases</td>
<td>• Psychosocial support</td>
<td></td>
</tr>
<tr>
<td>• Clinical trials; building own database</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
What should be the frequency and duration of follow-up?

In Table 2 we present arguments for the duration and frequency of follow-up, categorised into less intensive than, more intensive than, or according to the current guidelines.

About half of the HPs indicated that the frequency and duration of follow-up could be tailored depending on patient and tumour characteristics (such as age at diagnosis, stage and positive lymph nodes), as a result, the follow-up could be shorter and less frequent for some patients. Most patients were, however, uncomfortable with the idea that follow-up could become shorter than 5 years. Many patients preferred an even longer follow-up period (until lifelong) than currently offered. Reasons for this were: anxiety for recurrent distant metastases, the need for guidance and reassurance, or the fact that the national screening programme only starts at age 50. Only a few patients indicated that the duration of follow-up could be shortened. Also about a third of the HPs felt that follow-up should be continued after 5 years for certain patients. They mentioned several reasons for this, including: patients’ expectations, the ongoing increased risk of a second primary tumour, the duration of hormonal treatment and financial reasons.

It appeared from the interviews that some patients took 5 years literally to mean that follow-up should be continued after 5 years. It finally should be noted that it makes no sense specialist sees a patient less often than once a year.

According to current guidelines (5 years)
- Because the guidelines are scientifically based
- Because, after a while, patient’s life should return to normal
- Because patients can always contact the hospital, even after 5 years
- For low risk patients (low tumour stage, elderly patients)
- Because the usefulness of follow-up is not proven
- Because 2–3 years is sufficient for psychosocial and recurrence control
- Because follow-up visits evoke anxiety for the patient
- Because patients expect more and feel abandoned if follow-up ends
- Because there still can be problems after 5 years (second primary tumours)
- Because the duration of hormonal treatment is often longer
- Because of financial benefits
- For high-risk patients (node-positive patients)
- For younger patients, because screening starts at the age of 50
- Because that is the standard (then you are free of cancer)
- Because you can return to the national screening programme
- Because it is no longer necessary
- Because you can call yourself if something is wrong
- Because it requires a lot of healthcare time
- Because of the anxiety of a metastasis
- For younger patients, because screening starts at the age of 50
- Because it is pleasurable and gives reassurance and you don’t have to return to the national screening programme
- The doctor decides

Table 2. Opinions about the duration of follow-up and frequency of visits of health professionals and patients

<table>
<thead>
<tr>
<th>Duration of follow-up</th>
<th>Health professionals</th>
<th>Patients</th>
</tr>
</thead>
</table>
| According to current guidelines (5 years) | - Because at the beginning there is a need for regular control and information  
- Because in the years the probability of a recurrence is the highest | - Because at first there is a need for security and the possibility to ask questions  
- Because in the course of time your life can return to normal and if there are problems you can always call  
- Because visits become less frequent and you know you are getting better | |
| Shorter than guidelines (<5 years) | - For older patients, a minimum number of visits is desirable  
- Because an annual fixed control visit with additional visits based on complaints would be sufficient | - Particularly in the first years, it is very tough  
- As long as it is possible to stay under control for a long time | |
| Longer than guidelines (>5 years) | - For patients treated by different disciplines; when a specialist sees a patient less often than once a year it makes no sense | - Because waiting for 1 year takes too long | |
| Other | - Because it depends on the patient, no fixed number of years | |

*Current guidelines prescribe every 3 months in the first year, every 6 months in the second year and annually during the subsequent 3 years.
the question about required duration of follow-up was difficult for some patients, as they felt that the doctors are the experts and they should decide how long the follow-up should take.

Regarding the preferred frequency of visits, almost all patients and HPs agreed with the recommended frequency according the guidelines. More frequent visits at the begin-
ing of the follow-up period was experienced to be pleasant by most patients, because there is a lot uncertainty short after the treatment period. Three HPs mentioned that less frequent visits should be sufficient, especially for older patients. Also, a few patients mentioned that they prefer less frequent visits, because it was too much or with the consequence that they could stay under control for a longer period.

Almost a quarter of the HPs and patients questioned the value of physical examinations. Experience is needed and even experienced HPs cannot find everything by physical examinations. About a third of the patients were disappointed that additional tests, such as blood tests or a total body scan, were not performed. They felt that you could never be sure that something is wrong elsewhere, without a total body scan. Only a few patients were aware that total body scans do not add value, or they did not want to search for trouble. HPs recognised the demand for additional blood tests and scans from patients. But they were not convinced about the additional value, and stressed the importance of good education.

Who should perform the follow-up visits!

Table 4 presents an overview of the opinions of HPs and patients on the perceived advantages and disadvantages of the different follow-up care providers. No more than a quarter of the women had most confidence in the surgeon. Other patients indicated that they saw no extra value in a check-up by the surgeon. NPs indicated that surgeons are responsible for follow-up care and makes care policy; however, other disciplines could perform the follow-up care.

In general NPs were seen as a valuable addition to the surgical department by both patients and HPs. Reasons included that NPs were easily accessible to the patient; had more time for the patient; were more socially empathic to the patient; saved time for the specialists and

Table 3. Opinions about which diagnostic examinations should be performed of health professionals and patients

<table>
<thead>
<tr>
<th>Diagnostic examinations</th>
<th>Health professionals</th>
<th>Patients</th>
</tr>
</thead>
</table>
| **Mammography**         | + * This is the most important control  
                        | + After 5 years women could take part in the national screening programme  
                        | - Patients have to wait too long for the outcome | + * This is the most important control  
                        | + After 5 years women could take part in the national screening programme | - It is unpleasant  
                        | - Sometimes cancer cannot be detected by a mammogram | |
| **Physical examination** | + For women with a lobular tumour  
                        | - Expertise is needed for physical examination  
                        | - You cannot find everything with a physical examination | + When nothing is seen on the mammogram  
                        | - It is not possible to find everything with physical examination | - Seems unnecessary, when mammograms are made |
| **Additional examinations** (body scan, MRI, blood tests) | + MRI for young patients  
                        | + MRI, when the tumour is not visible on a mammogram  
                        | - Blood tests and body scans: almost impossible to find metastasis  
                        | - Early detection of metastases does not affect your life expectancy | + MRI, when there is nothing to see on the mammogram  
                        | + You remain uncertain, if no total body check or blood tests are done | - If a blood test is useful, they would have used it  
                        | - Early detection of metastases does not affect your life expectancy | - No need to search for trouble: If you don’t know, it will not hurt |

*+*: advantage of the diagnostic examination; -: disadvantage of the diagnostic examination.

MRI, magnetic resonance imaging.
Table 4. Health professionals’ and patients’ opinions about the advantages and disadvantages of various follow-up care providers

<table>
<thead>
<tr>
<th>Care provider</th>
<th>Health professionals</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgeon</td>
<td>+ The surgeon is always responsible</td>
<td>+ The surgeon is trained/specialised</td>
</tr>
<tr>
<td></td>
<td>+ For more complex patients</td>
<td>+ More confidence in the surgeon than in other disciplines</td>
</tr>
<tr>
<td></td>
<td>− The surgeon makes care policy, but implementation can be done by another caregiver, e.g. a nurse practitioner</td>
<td>− It is an expensive waste of time</td>
</tr>
<tr>
<td></td>
<td>Nurse practitioner</td>
<td>− The surgeon does the surgery, not the follow-up</td>
</tr>
<tr>
<td></td>
<td>+ They can save time for the specialist</td>
<td>+ They have more time for the patient</td>
</tr>
<tr>
<td></td>
<td>+ They have more time for the patient than the specialist</td>
<td>+ They are as good as the surgeon</td>
</tr>
<tr>
<td></td>
<td>+ They are easily accessible and can trace psychosocial problems earlier</td>
<td>+ They have more empathy</td>
</tr>
<tr>
<td></td>
<td>+ Cheaper care</td>
<td>+ They act as coach for questions and problems</td>
</tr>
<tr>
<td></td>
<td>− They should always be supervised by the specialist</td>
<td>− Doubt whether they have enough experience</td>
</tr>
<tr>
<td></td>
<td>− They are inclined to do more diagnostics</td>
<td>− They are not specialised enough</td>
</tr>
<tr>
<td>Radiation oncologist</td>
<td>+ For the control of long-term radiation effects</td>
<td>+ They do more extensive physical examinations</td>
</tr>
<tr>
<td></td>
<td>+ They know how the patient was treated with radiotherapy</td>
<td>− The reason for the involvement of a radiation oncologist is unknown</td>
</tr>
<tr>
<td></td>
<td>+ More frequent contact with the patients during treatment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>− The reason for involvement of a radiation oncologist is unknown</td>
<td></td>
</tr>
<tr>
<td>Medical oncologist</td>
<td>+ For patients participating in trials</td>
<td></td>
</tr>
<tr>
<td></td>
<td>+ For the control of endocrine treatment effects</td>
<td></td>
</tr>
<tr>
<td></td>
<td>− Not all perform a physical examination</td>
<td></td>
</tr>
<tr>
<td>General practitioner</td>
<td>+ It is cheaper care</td>
<td>+ For support for psychosocial problems</td>
</tr>
<tr>
<td></td>
<td>− They have not enough expertise, which quickly creates commotion</td>
<td>+ When hospital follow-up is ended</td>
</tr>
<tr>
<td></td>
<td>− They do not see enough breast cancer patients to guarantee good care</td>
<td>+ Then you are not required to go to the hospital anymore</td>
</tr>
<tr>
<td></td>
<td>− This is asking too much of the general practitioners</td>
<td>− The general practitioner is too busy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>− They refer you to the hospital anyway</td>
</tr>
<tr>
<td></td>
<td></td>
<td>− They are not specialised enough</td>
</tr>
</tbody>
</table>

*: advantage of the particular care provider; −: disadvantage of the particular care provider.

were cheaper than specialists. However, some surgeons in particular doubted the usefulness of the NPs, and questioned whether NPs would recognise recurrence of the disease. They were concerned about the efficiency because more diagnostic examinations might be performed by a NP and because the patient was often seen by the surgeon as well.

Opinions about the GP were divided. Initially, patients saw no role for the GP during follow-up. However, when hospital follow-up ends, they want to return to the GP. Other patients saw no reason to go to the hospital when no mammogram will be performed. HPs doubted if GPs have enough time to see breast cancer patients, whether they have enough experience and as a result might request diagnostic examinations too often. Both GPs stressed that they would like to take part in follow-up, but that the patient’s preference would be important here.

From the interviews it appeared that currently, different disciplines were often involved in the follow-up. Primary, patients are under control by the surgeon or NP. Radiation and medical oncologists found it important to see the patient during follow-up because of the treatment effects. Patients and HPs did not always fully understand why patients were seen by different care providers. Patients and HPs mentioned both advantages and disadvantages of this. The most frequently mentioned advantage of seeing different HPs was the second opinion. A disadvantage was the lack of continuity, that is, seeing the same HP. Another disadvantage was the insufficient communication between the different disciplines. Which sometimes resulted in inadequate sharing of information with the patient and in lack of co-ordination. A few surgeons and NPs mentioned that they could take over the follow-up care of the radiation and medical oncologists.

**DISCUSSION**

To our knowledge, this is one of the first studies on breast cancer follow-up identifying a broad overview of opinions and preferences of both HPs and patients on breast cancer follow-up. Due to the qualitative and explorative design of the study new insights were revealed.

**Purpose of follow-up**

Health professionals mentioned that psychosocial support becomes a more and more important aspect of follow-up.
care. The same findings were reported in a Dutch study about professionals’ opinion on follow-up by van Hezewijk et al. (2011a). In this study 83% of the HPs mentioned detecting psychological problems as a purpose of follow-up. Remarkably, the present study showed that only a few patients mentioned psychosocial support as an important goal of follow-up. In agreement with results from a study of Beaver and Luker (2005) patients are satisfied with examination of the breast and with reassurance of the HP that everything is still gone. Furthermore van Hezewijk et al. (2011b) showed that consultation by a psychologist or social worker was less valued by breast cancer patients. A reason could be that the available time for psychosocial support during a routine follow-up visit is limited and therefore not always appropriate [Pennery & Mallet 2000; Allen 2002; Beaver et al. 2009]. Although HPs mentioned that psychosocial support becomes a more important aspect, in daily practice control visits are still focused on physical symptoms, which could retain patients to talk about other problems. Since 2012 the NABON guideline is revised, advising to make a personal follow-up care plan with the patient during the first year of follow-up (NABON 2012). The personal follow-up care plan describes the physical and psychological impact of the disease and treatment, how frequent the patient should receive a follow-up visit and which diagnostic tests should be performed during these visits. The introduction of the personal follow-up care plan could help recognising psychosocial problems in an early stage, so that the patient can be referred to specialists.

In our study HPs doubted the primary goal of follow-up early detection of recurrences. Their doubts are supported by literature: in a meta-analysis was found that 41% of recurrences had been diagnosed outside routine visits or routine tests (De Bock et al. 2004a). A few HPs mentioned that early detection of metastases is a goal of follow-up. Van Hezewijk et al. (2011a) showed that six out of 10 HPs still indicate that detecting metastases is a follow-up goal. This is remarkable since previous studies have shown that early detection of metastases gives no improvement in survival or quality of life (Joseph et al. 1998).

Several misconceptions about follow-up persist among patients, underlining the need for better patient education. For example, some patients believe that follow-up care can prevent new malignancies, others expected blood tests and total body scans, believing that finding metastases in an early stage can improve prognosis. Indeed, a recent study by Montgomery et al. (2008) has shown that education can eliminate misunderstandings. And could influence women’s preference for the nature of follow-up (regular mammograms versus more intense follow-up).

However, van Hezewijk et al. (2011b) saw no differences in expectations about additional investigations between a written informed group and a non-informed group. An explanation could be that the written information was not well understood. Given the improved survival of cancer patients and the involvement of many disciplines for treatment and follow-up care, there is need for better co-ordination and information sharing. In response, the revised NABON guideline developed the personal follow-up care plan describing treatment and follow-up care to the patient and involvement of the patients HP. However, it is still unknown how often these plans are implemented. A study performed with American cancer survivors showed that approximately one-third reported receiving cancer treatment summaries and 44% reported receiving written follow-up care instructions (Sabatino et al. 2013).

Frequency and duration

The results of the present study presume that current follow-up is more intensive in terms of frequency and duration than the guidelines recommend. Patients preferred prolonged and frequent follow-up and found it hard to end follow-up. These findings agree with earlier studies, who concluded that more than half of the patients questioned preferred lifetime follow-up (De Bock et al. 2004b; van Hezewijk et al. 2011b). Our study showed that this preference is one of the main reasons why HPs keep patients under observation for a longer period than that stated in the guideline. This is also illustrated in the study of Beaver and Luker (2005), on request of the patient, HPs prolong follow-up care. However it is known that when follow-up schedules change, patients adjust to the new system and appreciate it. An earlier clinical trial showed that a less frequent follow-up schedule is well appreciated by breast cancer patients (Gulliford et al. 1997). However this is a small study with a possible bias in patient selection. Patients selected for this study were of older age, had positive tumour characteristics and had a positive attitude towards less intensive follow-up. Other trials evaluated reduced follow-up strategies by nurse-led telephone follow-up (Beaver et al. 2009, Kimman et al. 2011) and point-of-need access to specialist care (Sheppard et al. 2009), and found that most patients were satisfied with these alternative strategies.

A second reason why more frequent follow-up visits were offered than recommended was that each discipline wanted to observe the results of their therapy. These findings agree with the results from van Hezewijk et al. (2011a) who found that the co-ordination of follow-up was
most often done by multiple specialists and ongoing hormone therapy was a reason for longer follow-up. Geurts et al. (2012) showed that follow-up frequency increased with the number of medical disciplines involved in routine follow-up.

Finally, financial incentives were thought as playing an important role. According to the Dutch guidelines patients older than 60 years can be referred to the GP or the national screening programme after 5 years of in-hospital follow-up (NABON 2008). In the national screening programme a standard biennial mammogram will be performed, patients who will visit the GP should still make a biennial mammogram at the hospital. However, according to the current Dutch reimbursement schemes, surgical and radiation departments receive a yearly reimbursement for each patient who visits the department. A phone call about the outcome of the mammogram does not suffice and therefore departments continue inviting patients for follow-up visits.

All these reasons together ensure that many patients are seen too frequently, by different disciplines, and for a long period. Recently, the American Society of Clinical Oncology (ASCO) performed a systemic review for the update of the 2006 guideline for breast cancer follow-up (Khatcheressian et al. 2013). They did not found enough evidence to change the guideline. Examinations should be performed every 3–6 months for the first 3 years, every 6–12 months for years 4 and 5, and annually thereafter. On the other hand, the revised NABON guideline advise an annual follow-up visit combined with a mammogram for the first 5 years of follow-up, because for early detection of relapse a mammogram is more effective than only clinical follow-up (NABON 2012).

Considering the above mentioned results, we do not expect that the revised follow-up guideline in the Netherlands automatically will be implemented in clinical practice. The revised guideline requires changes in patients’ behaviour, better collaboration among clinical disciplines and changes in the organisation of follow-up care.

Follow-up care provider

The number of patients attending breast cancer follow-up is increasing. Costs have increased and a shortage of personnel has occurred (Grunfeld et al. 1999). Furthermore, patients were dissatisfied about the many different faces they sometimes see during the follow-up period. This raises questions about whether follow-up can be optimised. In literature, there is continued interest in GP-led follow-up care. Grunfeld et al. (2006) showed that GP-led care is as effective as specialist care, while being considerably cheaper than hospital care. The results of our study showed limited support for GP-led care. Both patients and HPs were concerned about the lack of experience of the GP. They also felt that GPs are too busy and will refer the patient to the hospital anyway. In the study of van Hezewijk et al. (2011a) the HPs agree that the GP should play a minor role in follow-up, only 8% indicated that the GP should always be involved. However it is known that when patients are informed about the usual care, they have a preference for what they know best (Salkeld et al. 2000). Patients and HPs are unfamiliar with follow-up care provided by a GP. Follow-up care provided by a NP is well implemented, and highly appreciated by both HPs and patients. NPs would be cheaper than specialists and be time-saving for the specialist. McCaughan and McSorley (2007) concluded in their qualitative study that doctors were enthusiastic about nurse-led follow-up care because it would free valuable time for medical consultants. From literature it is known that nurse-led follow-up is as effective as specialist care in terms of detection of cancer recurrence (Koinberg et al. 2002), and that nurses are more likely to detect psychological distress in breast cancer patients (Sheppard 2007). Pennery and Mallet (2000) found that 54% of the patients preferred a breast cancer nurse (more supportive) and 38% a surgeon (most qualified, most up to date knowledge). In the present study disadvantages of nurse-led follow-up were also mentioned: some HPs emphasised that a NP should always be supervised by a specialist, which takes extra time, and some HPs were worried that NPs would be inclined to do more diagnostics. Koinberg et al. (2004) indeed revealed a higher rate of mammograms among NPs, but requests for other imaging and laboratory evaluations were similar to that of specialists.

Study limitations

Some limitations have to be discussed. Although we felt that we have reached data saturation [no new information was being obtained during the three final interviews], and as a result the overview of relevant issues and opinions is likely to be complete, we should take the small sample size of our study into account and results should be interpreted with caution. Furthermore, the study took place in two hospitals in the eastern part of the Netherlands. The findings therefore may not be representative to other hospitals. However, due to the qualitative and explorative design of the study new insights were revealed. This is of great importance, because it enables changing the follow-up, thus tackling the increasing burden due to increasing incidence and survival.
CONCLUSION

This study gave inside into barriers for the implementation of adjusted follow-up schedules. Beside patient preferences also the collaboration of involved specialists play an important role even as the financial incentives. Implementation of new follow-up schedules might be more successful when taking these barriers into account. The implementation should therefore be active through education of both the HP and the patients.

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