

Follow-Up for Breast Cancer – the Patients' View

Hans-Joachim Stemmler^a Petra Stieber^b Dorit Lässig^a Ingo Bauerfeind^c Peter Fasching^d
Matthias Beckmann^d Margrit Glattes^e Ursula Goldmann-Posch^f Verena Hoffmann^a
Volker Heinemann^a

^a Medizinische Klinik und Poliklinik III,

^b Institut für Klinische Chemie,

^c Klinik und Poliklinik für Frauenheilkunde und Geburtshilfe, Klinikum der LMU München, Standort Großhadern, München

^d Frauenklinik des Universitätsklinikums Erlangen,

^e AOK Rheinland, Düsseldorf,

^f Vorstand Mamazone e.V., Augsburg, Germany

Key Words

Breast cancer · Follow-up · Guidelines

Summary

Background: International and national guidelines (S3 guideline) for the surveillance of post-treatment breast cancer patients recommend a clinical follow-up including routine history and physical examination and regular mammograms. The practice of a clinical follow-up has been often discussed, but has been proven not to be inferior when compared to an intensified follow-up in randomized trials. **Patients and Methods:** The present manuscript reports the patients' view on the basis of a survey including 2000 patients with a history of breast cancer. **Results:** A total of 452 patients (22.6%) answered the questionnaire. The median age was 62 years (range 23–85 years). More than 80% of the patients were disease-free at the time of the survey. The need for surveillance was affirmed by the majority of patients (>95%), and one third stated that there was a need for more technical efforts during follow-up. In contrast to the follow-up guidelines, the results of the present survey indicated that most of the regularly scheduled follow-up visits were expanded using extensive laboratory and imaging procedures. **Conclusion:** This survey shows that the majority of physicians obviously do not accept the present follow-up guidelines. A new surveillance study investigating the efficacy of an intensified surveillance based on the improved possibilities of modern diagnostics and endocrine, immunotherapeutic, chemotherapeutic and interventional treatment options is warranted.

Schlüsselwörter

Mammakarzinom · Nachsorge · Richtlinien

Zusammenfassung

Hintergrund: Internationale und nationale Leitlinien (S3-Leitlinie) empfehlen eine rein symptomorientierte Nachsorge, die hinsichtlich der apparativen Diagnostik allein durch eine regelmäßige Mammographie erweitert wird. Allerdings stößt diese Praxis, die in randomisierten Untersuchungen einer intensivierten Nachsorge gleichwertig war, bei den Betroffenen immer wieder auf Unverständnis. **Patientinnen und Methoden:** Die vorliegende Untersuchung zeigt die Sichtweise der Betroffenen basierend auf den Ergebnissen einer Umfrage bei 2000 Patientinnen mit anamnestisch bekanntem Mammakarzinom. **Ergebnisse:** Insgesamt beantworteten 452 Patientinnen (22,6%) den Fragebogen. Das mediane Alter der Befragten betrug 62 Jahre (23–85 Jahre). Mehr als 80% der Patientinnen waren zum Befragungszeitpunkt krankheitsfrei. Die Notwendigkeit der Nachsorge wurde von der Mehrheit der Patientinnen bejaht (>95%), allerdings wünschten knapp ein Drittel der Befragten eine mehr apparativ ausgerichtete Nachsorge. Im Gegensatz zu den Richtlinien zeigt diese Umfrage, dass die gegenwärtig durchgeführten Nachsorgeuntersuchungen mit teils ausgiebigen Laboruntersuchungen und bildgebenden Verfahren erweitert werden. **Schlussfolgerung:** Diese Umfrage offenbart eine klare Diskrepanz zwischen den Empfehlungen und den tatsächlich durchgeführten Nachsorgeuntersuchungen. Eine neue Nachsorgestudie, die den Nutzen einer intensivierten Nachsorge vor dem Hintergrund innovativer Diagnostik- und Therapieverfahren (z.B. Endokrinologie, Immuntherapie, Chemotherapie) untersucht, ist notwendig.

Introduction

The majority of newly diagnosed metastases in patients with breast cancer are discovered between the intervals of regularly scheduled clinical visits. Randomized trials have shown no superiority of an intensified surveillance including chest X-ray, bone scans, ultrasound or computed tomography in asymptomatic patients when compared to a clinical follow-up including routine history and physical examination and regularly scheduled mammograms. Routine examination for metastatic spread is therefore not recommended in clinically asymptomatic patients. The statement number 50 of the German S3 Guideline concluded: Laboratory and intensified machine-aided tests are only recommended for patients with a history or with symptoms of recurrence or metastatic spread (level of evidence 1a, grade of recommendation B).

The majority of breast cancer recurrences occur during the first decade after primary therapy, particularly during years 2–5. However, a much later occurrence is possible [1–4]. Recommendations regarding surveillance for relapse of disease are based on international and national guidelines. It has often been discussed whether an intensified follow-up, including various laboratory and imaging tests, really improves outcome. Although intensified surveillance may detect asymptomatic disease recurrence, 2 major randomized trials and a Cochrane review have concluded that there is no survival benefit from more intensive surveillance during post-treatment follow-up [5–7]. In contrast, 70% of the patients recruited into these trials stated that they wanted to continue regular clinical visits, even when they are asymptomatic.

The cost of intensive surveillance was addressed in a report comparing the ‘minimalist approach’ to follow-up of breast cancer survivors to the ‘maximalist approach’. The estimated cost of the maximalist approach was 5 times that of the minimalist approach (USD 5,735.– vs. USD 1,025.–). The authors projected that a universal minimalist policy would save nearly USD 812 million by 1995 [8]. The present investigation was performed to analyze the patients’ view on the issue of surveillance after diagnosis of breast cancer.

Patients and Methods

A questionnaire was sent to 2,000 patients with a history of breast cancer in Rheinland-Pfalz. The questionnaire used for the present survey included 29 questions with a total of 58 variables. The complete questionnaire is accessible on the homepage of our institution (http://med3.klinikum.uni-muenchen.de/ycms/Studien_80.htm).

Differences between patient groups were analyzed using the χ^2 -test (Chi-square test).

Results

A total of 452 patients (22.6%) answered to the questionnaire and provided the basis for the present evaluation. Nearly one

Table 1. Tests for surveillance offered to the patients

Tests	Patients, %		p value (χ^2 -test)
	Self-help group	Non-organized	
Laboratory tests	88.2	82.5	ns
Tumor marker tests	79.5	56.0	<0.0001
Chest X-ray	55.9	52.0	ns
Ultrasound	81.9	85.5	ns
Bone scan	47.2	35.7	0.02
CT scan	33.8	29.5	ns
PET-CT scan	9.4	12.0	ns
Mammography	86.6	89.2	ns
Physical examination	90.6	85.5	ns
Routine history	93.7	92.9	ns

ns = Not significant; CT = computed tomography; PET = positron emission tomography.

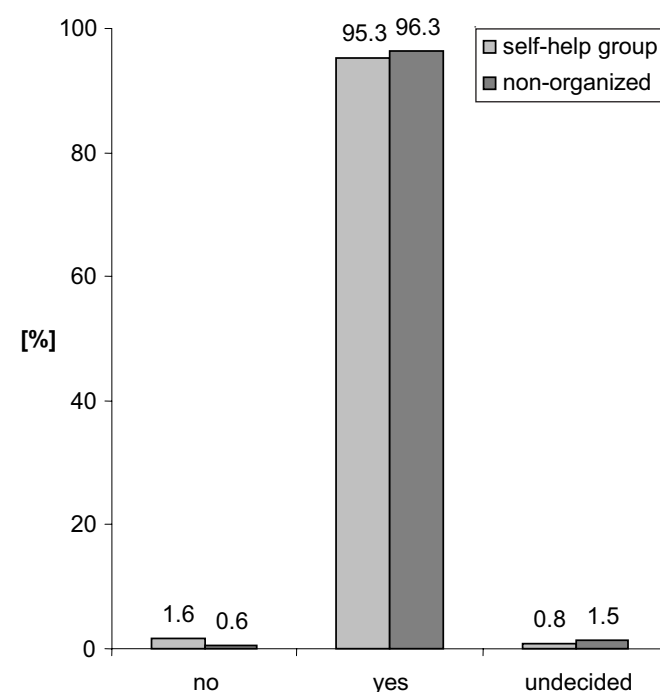


Fig. 1. Is there a need for surveillance after therapy?

third of the patients were organized members of a self-help group (28.1%). The median age was 62 years (range 23–85 years). More than 80% of the surveyed patients were disease-free at the time of the survey, with the percentage being slightly lower in the organized patient group (70%).

The need for surveillance after therapy was affirmed by the majority of the patients (fig. 1). When asked about follow-up tests and examinations regularly offered in the past, most patients named ultrasound and expansive laboratory tests. There was a significant difference regarding the frequency of tumor

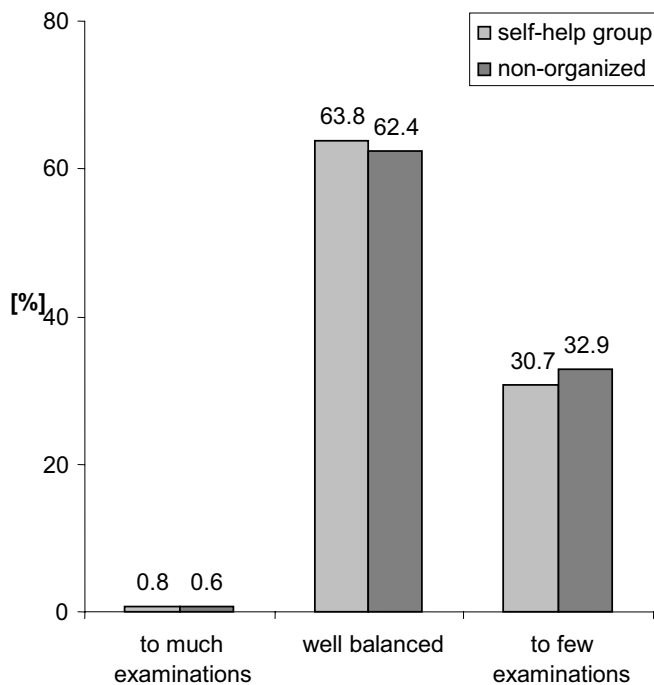


Fig. 2. Is the intensity of the present surveillance adequate?

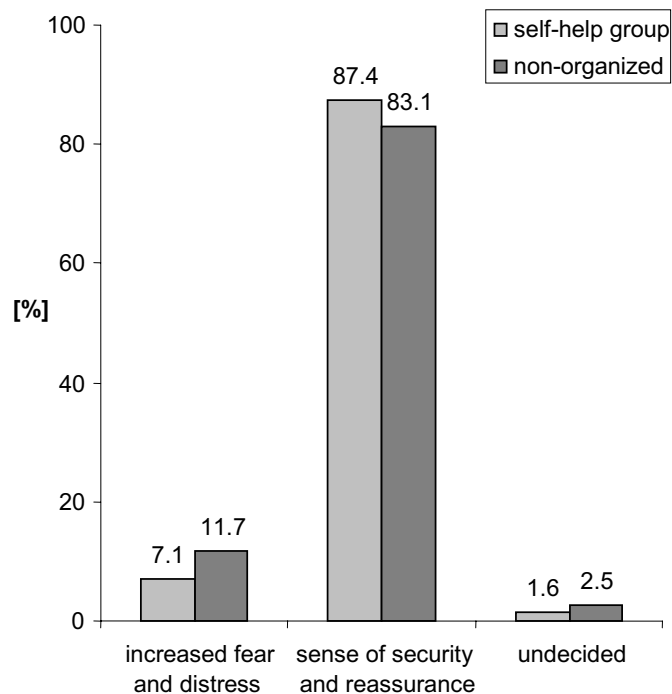


Fig. 4. Intensification of surveillance leads to ...?

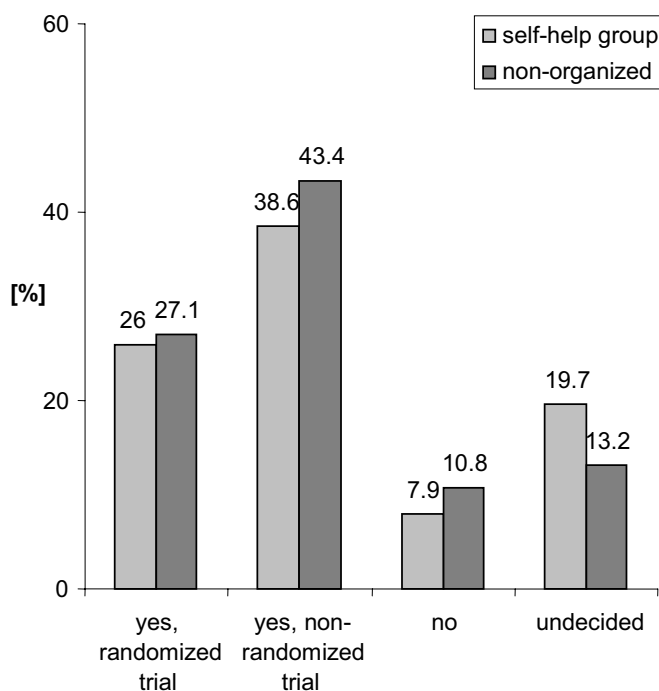


Fig. 3. Would you accept participation on a surveillance study?

marker tests and bone scans which were both offered more frequently to members of the self-help group (table 1). Two thirds of patients accept the increased effort of an intensified surveillance, and one third answered that there is a need for more technical examinations during follow-up (fig. 2). The

majority of patients would participate in a surveillance study, but only few would accept participation in a randomized setting (fig. 3). The expectations of an intensified follow-up included an increased sense of security and reassurance and, interestingly, a decrease in fear or distress (fig. 4). Moreover, 95% of the consulted patients (94% of self-help group) would want to be informed earlier of recurrent disease if such an early diagnosis improves the clinical outcome. And the majority believes that early diagnosis of recurrence, even early diagnosis of metastatic spread, will improve survival (97%; 94% of the organized patients).

Discussion

Except for routine history, physical examination and regularly scheduled mammograms, there are no strong recommendations to implement more intensive surveillance tests for asymptomatic patients after primary treatment of breast cancer. Although an intensified follow-up may detect asymptomatic disease recurrence, randomized trials have shown no survival benefit from more intensive surveillance during post-treatment follow-up [5–7]. Despite these evidence-based recommendations, a majority of post-treatment breast cancer patients recruited on these trials declared that they want to continue regular clinical visits even when they are asymptomatic.

It is justified to query the relevance of the above mentioned trials. Cocconi et al. [9] already demonstrated that the nega-

tive outcome of those trials was predictable. Major criticism concerns the largely palliative treatment approach, the absence of multimodal strategies and the limited options of endocrine or chemotherapeutic therapies [9]. Considerable changes in the endocrine treatment and surgical and interventional radiology procedures (radiofrequency ablation, laser-induced thermotherapy, selective intrahepatic radiotherapy) have been made in the last decade. It has been demonstrated that an aggressive surgical approach improves the outcome of selected patients with oligometastatic breast cancer [10]. These highly selected patients, the majority of whom is diagnosed in an asymptomatic stage, may benefit from an intensified follow-up. Moreover, it is critical to evaluate the impact of newer surveillance strategies and the early onset of modern endocrine treatment, such as aromatase inhibitors, on survival. The present non-representative investigation was initiated to evaluate the patients' view on the matter. The results can be summarized in 3 major categories. Firstly, the expectations of an intensified follow-up include an increased sense of security and reassurance but interestingly not an increase in fear or

distress as often stated in more emotional debates. Additionally, one third of the patients wish for more technical efforts in their surveillance, which was also found in a Dutch study by De Bock et al. [11]. Secondly, the majority of physicians obviously do not accept the present follow-up guidelines, as regularly scheduled follow-up visits were expanded using extensive laboratory and imaging tests as demonstrated in table 1. Interestingly, there is a significant difference in the frequency of tumor marker testing and bone scans performed in organized patients as compared to those who are not organized in self-help groups. Thirdly, there is a large discrepancy between the present evidence-based facts and the expectations of the afflicted patients, since the majority of them believe in the positive impact of early diagnosis of recurrence on survival. It is time to initiate a new surveillance study which investigating the efficacy of an intensified surveillance based on the improved possibilities of modern diagnostics and endocrine, immunotherapeutic, chemotherapeutic and interventional treatment options. Not only physicians but also the patients are prepared to re-analyze this important field of oncological activity.

References

- 1 Burstein HJ, Winer EP: Primary care for survivors of breast cancer. *N Engl J Med* 2000;343:1086–1094.
- 2 Emens LA, Davidson NE: The follow-up of breast cancer. *Semin Oncol* 2003;30:338–348.
- 3 Jatoi I, Tsimelzon A, Weiss H, et al: Hazard rates of recurrence following diagnosis of primary breast cancer. *Breast Cancer Res Treat* 2005;89:173–178.
- 4 Kattlove H, Winn RJ: Ongoing care of patients after primary treatment for their cancer. *CA Cancer J Clin* 2003;53:172–196.
- 5 Palli D, Russo A, Saieva C, et al: Intensive vs. clinical follow-up after treatment of primary breast cancer: 10-year update of a randomized trial. National Research Council Project on Breast Cancer Follow-up. *JAMA* 1999;281:1586.
- 6 Rojas MP, Telaro E, Russo A, et al: Follow-up strategies for women treated for early breast cancer. *Cochrane Database Syst Rev* 2000;CD001768.
- 7 Rosselli Del Turco M, Palli D, Cariddi A, et al: Intensive diagnostic follow-up after treatment of primary breast cancer. A randomized trial. National Research Council Project on Breast Cancer follow-up. *JAMA* 1994;271:1593–1597.
- 8 Schapira DV, Urban N: A minimalist policy for breast cancer surveillance. *JAMA* 1991;265:380–382.
- 9 Cocconi G: Follow-up of patients with breast cancer. *JAMA* 1994; 272: 1657; author reply 1658–1659.
- 10 Vlastos G, Smith DL, Singletary SE, et al: Long-term survival after an aggressive surgical approach in patients with breast cancer hepatic metastases. *Ann Surg Oncol* 2004;11:869–874.
- 11 De Bock GH, Bonnema J, Zwaan RE, et al: Patient's needs and preferences in routine follow-up after treatment for breast cancer. *Br J Cancer* 2004;90:1144–1150.