

Effectiveness of Routine and Spontaneous Follow-up Visits for Breast Cancer

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Abstract—*The effectiveness of routine (initiated by the health services) and spontaneous (initiated by the patient) follow-up visits were compared based on a 5 year follow-up of all (551) breast cancer patients residing in one of the Finnish central hospital districts and diagnosed in 1977–1980. There were altogether 8248 visits, i.e. 4.6 per follow-up woman year, of which 2.7 visits were based on the recommended follow-up schedule. Recurrence (252) was detected in 14.7% of spontaneous visits which was five times more often than at the regular visit. False positive clinical diagnosis (63) was three times more frequent for spontaneous than for regular visits. The follow-up system should probably not be based solely on detecting of recurrences of the disease only but aspects related to the patient's quality of life may be decisive.*

INTRODUCTION

BREAST CANCER is the most common malignancy among the 2.5 million Finnish women. In 1980 the number of prevalent cases of breast cancer was 12,610 (0.6% of the adult female population) and according to predictions for the year 2000 it will be 44,000 (2.5% of the adult female population) [1]. Therefore follow-up visits for breast cancer consume a substantial amount of the resources of health services at present and will do so even more in the future.

There is a general recommendation by the National Board of Health in Finland and an agreement between the specialized cancer clinics to have a follow-up visit every 3 months during the 1st year after primary treatment and every 4 months during the 2nd year [2]. After that the follow-up visits should be repeated every 6 months until the end of the 5th year and annual follow-up visits are recommended after that. Guidelines for the extent of follow-up have been based mainly on clinical experience with no empirical data to support the recommendations.

The benefits of a regular follow-up system of breast cancer patients have been discussed [3–5]. The main aim of follow-up is the detection and treatment of recurrences. The other reasons can include evaluating treatment, detection of new primary cancers and ensuring rehabilitation. In this

study we have evaluated whether an organized system of follow-up is feasible and whether recurrence of the cancer is detected more effectively through the routine follow-up visits organized by health services than through spontaneous ones initiated by the patient.

MATERIALS AND METHODS

The study was based on the follow-up of breast cancer patients residing in the area of Tampere University Central Hospital. The district is in central Finland with a population of about 500,000, i.e. 10% of the total Finnish population. All 551 new breast cancer patients diagnosed and reported from this area to the Finnish Cancer Registry in 1977–1980 were included. The Finnish Cancer Registry is nationwide and population based and the files of the registry are virtually complete [6].

All follow-up visits at the radiotherapy or surgical clinics of the university central hospital or at any other hospital with a surgical department within the central hospital area were included [7]. This consisted practically all visits and only four patients residing in the area but followed outside were excluded.

The patients were followed for 5 years in 1977–1985 or until the time of death whichever occurred first. Data were taken from hospital records. Information on primary treatment was found for all patients and 94% of the patients had at least one follow-up visit. Altogether 19 patients (4%) had no routine follow-up. In addition nine patients died before the expected first follow-up visit.

The observed follow-up visits were compared

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with recommendations and they were classified into routine follow-up visits and spontaneous visits. Routine visits were those initiated by the health services and they were divided into regular and interval visits. A regular visit was the expected visit according to the recommendation and an interval visit was the extra visit induced by the clinic due to blood tests, X-ray or other findings or treatment. Regular visits are therefore those conducted according to the recommended follow-up schedule whereas interval visits consisted of those initiated by the hospital responsible for the follow-up in between the scheduled times due to any reason. Spontaneous visits consist of only those visits the patient initiated on her own for any reason. The type of visit was related to the diagnosis of recurrence, which was defined as the first relapse either locoregionally or distantly. Attention was given to whether the diagnosis of recurrence of disease was originated from a regular or a spontaneous visit. The clinical diagnosis of recurrence was regarded as false if the recurrence was not confirmed within 1 year after the clinical indication. It was possible to ascertain on the basis of hospital records whether the original clinical diagnosis ultimately resulting in a confirmation of a recurrence originally stemmed from regular or spontaneous visits. It was not, however, possible to classify all the interval visits into those initiated by a regular or by spontaneous visits.

RESULTS

There were 1778 follow-up years during the first 5 years of follow-up for the 519 patients. According to the recommendation the number of regular visits was 4873 whereas the observed total number was 8248. There were twice as many observed follow-up visits as recommended visits in every follow-up year (Fig. 1). The mean number of visits per patient was 16 and the mean number of visits per follow-up year was 4.8.

Most of the follow-up visits were routine (84%). The mean number of routine visits was 14.4 per patient and 4.2 per follow-up year and the mean number of spontaneous visits was 1.5 per patient and 0.4 per follow-up year (Table 1).

Recurrence of breast cancer was confirmed in 252 of the 519 patients. Two point nine per cent of the regular visits ultimately resulted in a confirmed diagnosis of first recurrence whereas the prevalence was significantly higher (14.7%) for spontaneous visits (Table 2). The relative risk of diagnosis of a recurrence of the disease originated by a spontaneous visit was 5.1 compared to a regular visit.

The clinical diagnosis of recurrence turned out to be a false positive at diagnostic confirmation for 63 patients (12%) at least once during the first 4 years of follow-up. There were 41 false positives

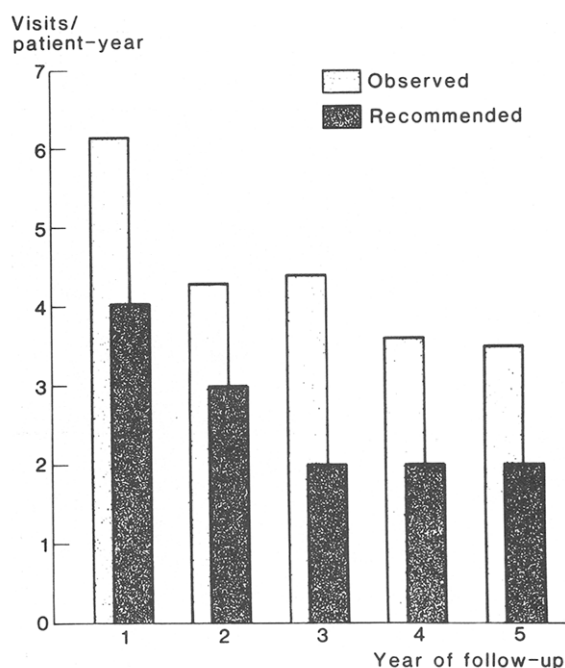


Fig. 1. Follow-up of breast cancer patients: observed and expected visits per patient year by year of follow-up.

originating from regular visits and 22 false positives due to spontaneous visits (Table 3).

DISCUSSION

The main aim of the follow-up practice for cancer patients is the detection of recurrence, either local or systemic. Routine follow-up is justified from this point of view only if there is evidence that it leads to detection of recurrence more effectively than the spontaneous system. The practice is based on the assumption that recurrences are detected better by the organized health services than by the patient.

In Finland there is a recommendation for frequent follow-up visits: four times during the 1st year, three times during the next and twice a year after that. The observed number of follow-up visits turned out to be almost twice that expected. Altogether 44% (112/252) of recurrent disease originated from a spontaneous visit between the routine visits organized by health services. This was more than five times as often as recurrences diagnosed due to a regular visit. In other studies the proportion was between 25 and 78% [4, 8–11]. The relative risk of detecting recurrence remains unknown in these studies because the total number of visits is not classified into spontaneous and regular visits. In some of the studies spontaneous visits with recurrence detected have included also those interval visits done at the interest of the clinic. All the 763 visits classified spontaneous in this study were due to the initiative of the patient herself. Also all recurrences were traced back to evaluate whether

Table 1. Follow-up of breast cancer patients: the number of recommended and observed follow-up visits during the first years related to the reason for visit

Reason for visit	Visit		
	Number	Per patient	Per follow-up year
Routine	7485	14.4	4.2
regular	4873	9.4	2.7
interval	2612	5.0	1.5
Spontaneous	763	1.5	0.4
Total	8248	15.9	4.6

the sequence of follow-up visits resulting in a confirmed diagnosis of recurrence started from a spontaneous visit or from a routine visit. This classification could not be done on basis of the hospital records on the other interval visits not directly related to the recurrence. Any sequence of interval visits can be initiated by a spontaneous or a regular one. No data are available to decide when such a sequence initiated by a spontaneous visit will change to a new sequence initiated by a regular visit. Therefore all the interval visits were excluded and the denominators include only regular visits and first spontaneous visits of a sequence. The exclusion of interval visits results in valid comparability in rates and an unbiased estimation of the relative risk of 5.1 of a woman detecting a recurrence by herself as compared to the organized follow-up system.

The recurrence itself is a cause of increase in the intensity of visits. Most of the interval visits were due to treatment of recurrent breast cancer, some of them were due to diagnostic confirmation, but

none was due to duplication, e.g. between surgical and radiological follow-up. This causal relationship is one more reason to exclude the interval visits when effectiveness is evaluated.

Most of the patients have symptoms when having recurrent disease. Only 9–23% have been observed to be asymptomatic when first recurrence was diagnosed [12–15]. It is likely that some of the patients who detected signs or symptoms of recurrences themselves waited for the time of regular follow-up visit. Such a recurrence was classified to be detected at regular visit resulting in a bias in the risk ratio. This bias led to a conservative estimate. Therefore the true relative risk was higher than the estimated 5.1.

On the other hand, there was a higher risk of false positive clinical diagnosis of recurrence at a spontaneous visit. The estimated relative risk was 3. The false positive diagnoses of recurrence (63) were much less common than correct positive (252) in absolute terms. The relative risk of true to false positives was 2.7 for the regular and 5.3 for the spontaneous visits. Even if the false positive causes fear and anxiety it is therefore not likely that it outweighs the value of higher effectiveness of diagnosing correct positive recurrence at spontaneous visits. In fact, the opposite may be true; because the spontaneous visit was initiated by the patient, she already suspected a recurrence with anxiety and fear attached to the discovery. The rather long lag of 1 year for the time of final confirmation may have removed some of the false positives. Such errors are not frequent enough to materially affect the ratio of recurrences to false positives.

If the aim of follow-up is the detection of recurrent disease we conclude that routine follow-up visits

Table 2. Follow-up of breast cancer patients: number and proportion (with 95% confidence intervals) of recurrent disease by reason for visit

Reason for visit	Recurrent disease			All visits
	Number	Percentage	C.I.	
Regular	140	2.9	(2.5–3.4)	4873
Spontaneous	112	14.7	(12.1–17.7)	763
Any reason	252	3.1	(2.7–3.5)	8248

Table 3. Follow-up of breast cancer patients. Number and proportion (with 95% confidence intervals) of false positive diagnoses for recurrence by reason for visit

Reason for visit	False positive			Total
	Number	Percentage	C.I.	
Regular	42	0.9	(0.6–1.2)	4873
Spontaneous	21	2.8	(1.7–4.2)	768
Any reason	63	0.8	(0.6–1.0)	8248

organized by health services are less effective than spontaneous ones. It is also unlikely that the routine system leads to earlier detection than spontaneous visits, but the reverse may be true, if patients detect signs or symptoms of recurrence by themselves but wait for the next regular follow-up visit. The main objective of follow-up, i.e. of detecting recurrent disease, can also be criticized. It may be that other aspects related to the quality of the patients' life are more important than affecting the survival. This is

especially true if the survival, i.e. length of patient's life, is rather independent of the follow-up practice. The routine system may prevent anxiety and fear of a patient and give better mental and social support to her. Therefore, the ultimate priority between the organized and spontaneous systems should not be based on effectiveness on detecting recurrence only but the preferences of the patient herself may be decisive in deciding the correct mode of follow-up.

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