Follow-up of long-term survivors of breast cancer in primary care versus specialist attention

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Received 16 February 2013; Revised 23 May 2013; Accepted 28 May 2013.

Background. Hospitals have traditionally been the place where the follow-up of breast cancer patients occurs in Spain.

Objective. To describe the evolution of long-term survivors of breast cancer according to type of follow-up received (in primary or specialist/hospital care), measuring impact of care type on health, cost, health-related quality of life (HRQL) and satisfaction results.

Method. Retrospective study of cohorts with disease-free patients followed up for at least 5 years in Oncology. Using personal questionnaires, the type and cost of the follow-up, events, HRQL and satisfaction were analysed.

Results. Ninety-eight women were surveyed, 60 in primary and 38 in specialist care. There were no differences between groups in diagnosis of metastasis or new primary tumours. The number of annual visits per patient was 0.98 (0.48) in primary and 1.11 (0.38) in specialist care (P = 0.19). In primary, 44.6% were programmed and 55.4% on demand; in specialist, 94.6% were programmed and 5.4% on demand (P = 0.0001). The costs of follow-up in primary care were lower—€112.86 (77.54) versus €184.61 (85.87) per patient and year (P = 0.0001). No differences were reported in HRQL. Preference for specialist care was expressed by 80%, versus 10% for primary, with 10% indifferent. Patients showed greater satisfaction with specialist care in all questionnaire dimensions.

Conclusions. Compliance with follow-up protocol was high in both groups. In specialist care nearly all the visits were programmed and in primary almost half were on demand. In our locality, primary is more cost-effective than specialist care, but patients express greater satisfaction with specialist follow-up and hence prefer it.

Keywords. Breast cancer, follow-up care, health care models, long-term survivors.

Introduction

In Spain, there are more than 1500000 of survivors of cancer, of whom 27% were diagnosed with breast cancer. Breast cancer is the most frequent malignancy in women and research on post-therapy follow-up is important, since 85% of them will survive more than 5 years from time of diagnosis.

Unlike in other health care systems, and apart from a few exceptions of non-proven efficiency, for many years now, long-term survivors of breast cancer have been receiving follow-up care in Spain’s public health system, mostly in hospitals. Frequently, this follow-up is duplicated or triplicated since patients are seen not only by their specialist oncologist but also by the oncology radiotherapist, surgeon or gynaecologist. In addition, survivors of breast cancer consume health care services at the primary care level, like any other user.

The recommendations for less intensive follow-up with periodic history taking, physical exploration and mammography continue being applicable for breast cancer survivors. Even though studies demonstrate that follow-up outside the hospital context is an alternative that is safe, efficient and satisfactory, these patients continue to be referred for follow-up at the specialist care level in the Spanish public health system. In health care systems like that in which this study has been conducted, with an adequately developed level of primary care, it seems logical for the primary care doctor to be responsible for the routine follow-up of women who have been treated
for breast cancer but always with the option of renewing specialist care when and if necessary. In other health care systems, primary care doctors have demonstrated their readiness to share the responsibility for the follow-up of these women.11

An assessment of the appropriate policy for the follow-up of survivors of breast cancer should consider the principal health outcomes, principally survival, health-related quality of life (HRQL) and patient satisfaction, and of the costs generated by such care. There is no clear evidence that survival, or the pattern of relapses or subsequent primary tumours, presents differences in function of type of follow-up received.5,9 Survivors of a breast cancer, like those of other cancers, enjoy, in general and in the long term, a good quality of life. However, in some cases, the secondary effects of treatments received, and comorbidities, result in a worsening of their HRQL that can persist for a long time or become a chronic health condition.12 There is evidence that primary or specialist follow-up can be adopted without worsening the HRQL of these women,5,9 and a higher degree of satisfaction with the follow-up provided by primary care doctors, compared with that by specialists, has been reported.8 There are differences between primary care and hospital doctors in respect of the number and type of diagnostic tests requested and in respect of the duration and frequency of patient visits.8,9 Lastly, the estimated financial cost is less when the follow-up care is provided by primary care doctors.10

Our centre serves approximately 220 000 inhabitants of the cities of Cadiz and San Fernando. In 2003, the current breast cancer procedure began to be implemented.13 For this, a joint protocol was developed with primary care centres; coordination with this care level was established; and channels of rapid communication were set up for dealing with patients. A plan was agreed for the follow-up of long-term survivors that provided for the primary care service to take responsibility commencing 5 years after treatment for the cancer. A survey of long-term survivors of breast cancer has been conducted to analyse the follow-up according to the type of attention received (follow-up care in primary or specialist service), measuring its impact on health outcomes, HRQL, patient satisfaction, consumption of resources and cost.

Method

Study design and population of patients
A retrospective cohort study was conducted to compare two cohorts, one followed up in a hospital service and the other in primary care. The patients included were those with histopathological diagnosis of carcinoma of the breast in stages 0, I, II and III,14 who had survived after being treated and who had been followed up for at least 5 years, in specialist consultations of Medical Oncology.

One of the two cohorts was constituted by the women assigned to primary care follow-up after 5 years and the other by women who continued their follow-up in the Oncology Service beyond 5 years. The criterion for inclusion in the corresponding cohort was that the women had to be free of disease at the time of their transfer to primary care for follow-up. The follow-up protocol considered standard, from 5 years after primary treatment, consisted of annual history-taking, physical exploration and mammography. Other complementary explorations were performed only if thought necessary after the history-taking or physical exploration.

Cases suitable for inclusion in the study were identified from the database of Medical Oncology. Patients were contacted by telephone to propose their participation, and those agreeing were given an appointment to obtain their informed consent and then to complete the questionnaires of the study. Those patients who did not respond were contacted again twice, after 2 and 4 weeks had elapsed. The study was approved by the local Ethical Research Committee.

Questionnaire for the patients
Between January 2010 and March 2012, by means of a clinical interview with the patients, data were collected on the actual follow-up received (number of visits per patient and year, visits programmed and made ‘on demand’ and referrals to the specialist service), and the clinical events that occurred over the same period (metastasis, new primary tumour, menopausal status, bone health, obesity, chronic toxicity, other diseases and pregnancy).

The SF-36 HRQL survey questionnaire, in Spanish,15 was also administered to the patients to obtain HRQL data. This instrument includes eight multi-item measurement scales: on physical functioning, role limitations due to physical problems, pain, social functioning, mental health, role limitations due to emotional problems, vitality and general health. The response options take the form of Likert-type scales that evaluate intensity or frequency. For each of the eight dimensions, the items are coded, aggregated and transformed to a scale that ranges from 0 (the worst state of health for that dimension) to 100 (the best state of health). The questionnaire has not been designed to generate a global index. However, by the combination of the scores for each dimension, two summary scores can be calculated, one physical and the other mental.

An assessment was also made of the degree of satisfaction of the patients under the following headings: health care attention received; recommendation of the service; information received; attention paid by the doctors and by the nurses; and respect and friendliness...
shown. The Likert-type responses ranged between one (very much worse than expected) and four (very much better than expected). Thus, a score of 1 denotes dissatisfaction; a score of 2 indicates that the patient’s expectations have been met but not exceeded, while a score of 3 or 4 indicates moderate or high degree of satisfaction, respectively. Tests of reliability and internal consistency were carried out on the total sample using Cronbach’s Alpha, and the criterion for considering the coefficient acceptable was set at a value of between 0.70 and 0.85.

Measurement and analysis of costs
An estimate of the direct costs was made; these were defined as the value (in Euros) of all the health care services (visits and complementary tests) provided during the follow-up. The source consulted for this is the Order of 14 October 2005 of the Consejería de Salud, Junta de Andalucía, setting the public prices of the health care services provided by Centres belonging to the Public Health system of Andalusia (BOJA Nº. 210).

Statistical analysis
The program SPSS v.15 was used for statistical analysis of the data. $P < 0.05$ was taken to indicate statistical significance. A descriptive analysis was made of all the data, calculating absolute and relative frequencies for the qualitative variables, and means and standard deviation (SD) for the quantitative variables. The chi-square test with Fisher’s correction was applied where necessary, to compare differences between the qualitative variables; the Student $t$-test of two tails was applied for quantitative variables between groups.

Because many of the questionnaire items possess asymmetric distribution, non-parametric Wilcoxon or Mann–Whitney tests were applied. The percentage of patients who presented the item at the levels of ‘fairly’ and ‘very much’ was obtained, and the comparison between groups was made comparing binomial proportions or by the chi-square test.

An adjustment has been made for the variables of ‘age’ and ‘chemotherapy’ for the comparison of the physical dimension of the HRQL questionnaire between groups. A univariate-generalized linear model has been employed, introducing the variables of patient age, whether or not the patient has received chemotherapy.

Results

Patient characteristics
Figure 1 is the flow diagram of the study for recruitment of participants. Of 323 women selected as eligible, 98 were finally included: 60 in primary care and 38 in specialist attention. The median period of follow-up of all patients from the date of initial treatment was 128 months, the range being from 69 to 368 months. The characteristics of the 98 women are described in Table 1. The patients in the specialist attention group were younger than those in primary care, and most of them had received chemotherapy. No differences were observed in respect of the rest of the variables analysed.
Health results in primary care and specialist attention

There were no differences between the two groups in the clinical incidents occurring during the follow-up (Table 2). Although overall there were no differences in chronic toxicity between one group and the other, the prevalence of lymphedema was greater in the primary care group (11.6%) than in those in specialist attention (2.6%).

Use of health care resources and costs of follow-up in primary care and specialist attention

Regarding the number of visits made per patient per year, 0.98 visits (SD 0.48) were made in primary care, against 1.11 (0.38) in specialist attention (P = 0.19). In primary care, 44.6% of the visits were programmed and 55.4% on demand; in specialist attention, 94.6% were programmed and 5.4% on demand (P = 0.0001). There were 7 patients (11.7%) transferred back to specialist attention from primary care and 6 (15.8%) from specialist (P = 0.55). There were no differences between the groups in respect of the complementary tests performed.

The costs of the follow-up in primary care were less than in specialist attention, at €112.86 (77.54) versus €184.61 (85.87) per patient and year (P = 0.0001); the differences were due principally to the costs per visit. Specified in Table 3 are the costs per unit of the medical
visits and the complementary explorations performed, the number of these explorations per patient and year, and the total cost generated per patient and year.

Quality of life and satisfaction in primary care and specialist attention

Table 4 gives the scores on the various dimensions of the HRQL survey (SF-36 questionnaire) in the two groups studied. The only differences found are in physical functioning, in favour of specialist attention ($P = 0.044$). However, when adjusted for the variables of age and type of chemotherapy, the differences in physical functioning between the groups disappear ($P = 0.64$ and 0.15, respectively).

The results of the questionnaire on satisfaction were reliable (Cronbach’s Alpha = 0.88). Preference for specialist attention was expressed by 80%, versus 10% for primary, while 10% were indifferent. The women showed greater satisfaction with specialist attention in all the questionnaire dimensions (Table 5).

Discussion

There is growing interest in reassessing the system for following up women survivors of breast cancer, by considering alternatives to the hospital outpatients’ clinic. The results of the questionnaire survey presented to the women followed up in primary care and in the hospital do not show any significant differences except in costs and in the satisfaction expressed with the attention received. The follow-up was less costly in primary care, and although the patients expressed high levels of satisfaction with each type of follow-up, their preference was for specialist care at the hospital.

The population of women followed up in specialist attention was younger and had received adjuvant chemotherapy treatment more frequently. The conditioning factors we propose as the cause of this imbalance are the decision taken by the patient and their oncologist of reference and participation in clinical trials. Thus, some patients decided against transferring to primary
care, and the patients recruited for clinical trials at the hospital also had to continue beyond the first 5 years.

No differences were observed in the number of cases of metastasis and second primary tumours diagnosed in each group. In this patient population, the detection of second primary tumours can be an event as frequent as the detection of metastasis. As in our study, the cancers most commonly identified in the European and American records are those of the endometrium and the breast, although a wide variety of these types can be detected.17 Logically, the fact of receiving follow-up attention in one or other care system should not have any impact on survival nor on risk of relapse or of suffering a new primary tumour, unless the screening and other preventive measures are applied suboptimally. It has been shown that doctors of both primary care and specialist attention provide long-term survivors with cancer prevention measures similar to those received by the general population,18,19 although long-term survivors of breast cancer are less frequently submitted to mammographies in primary care.18 Our study did not analyse delays in the diagnosis of relapses and second tumours. This is a factor that could be a parameter that differentiates between primary care and hospital attention, but the only published study in which these delays were analysed in survivors of breast cancer did not find differences.10

Our survey was also designed to analyse the incidence of other clinical conditions of high prevalence in this population. Rather than reporting the absence of differences between groups, it is relevant that more than 80% of all patients studied were menopausal, either by their age or due to the secondary effects of their treatments, that 33% of them had been diagnosed with osteoporosis and that 14% were obese. The impact of these medical conditions on long-term survivors of breast cancer is well known.20 Our study found only one case of pregnancy; only a very small percentage of women who are fertile after breast cancer treatment will become pregnant, and the literature on this double condition is very limited.21

The survey also investigated the persistence of clinical conditions that could be interpreted as possible secondary effects of the treatments received. In this case again, when toxicity was analysed globally, there were no differences found between the women attended in

<table>
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1 = bad; 2 = neither good nor bad; 3 = good; 4 = very good.
each type of care. Lymphedema secondary to the axillary lymphadenectomy is the principal complication following surgery and occurs with a frequency that varies between 10% and 40% of cases. In our study, this was also the most prevalent secondary effect, affecting 7% of participants. We cannot find a plausible explanation for the differences found between primary care and hospital attention, except the absence of a random distribution.

Globally, rather more than half of the women suffered some type of comorbidity, but no differences between the two groups were detected. Survivors of cancer have worse health than the general population, with osteoarticular and cardiovascular diseases being the most frequently reported.

One published study has evaluated the use of health care resources for follow-up in the hospital and in primary care; in that study, differences were demonstrated in the frequency of visits and in the type and number of tests requested. In our study, there was reasonably good compliance with the frequency of visits protocol in the two types of care, and no differences were seen between the two. However, the majority of visits under specialist attention were programmed, while in primary care these accounted for approximately half. In respect of the complementary explorations requested in this study, there were no differences, in contrast to the study of Grunfeld et al., in which the primary care doctors requested more complementary radiology tests. Our study, therefore, does not ratify the explanation given for this, which was that primary care doctors would request more complementary tests than specialists due to lack of confidence in their clinical abilities when dealing with patients of this type.

The costs generated by the follow-up of these patients were less in primary care, as also reported by Grunfeld et al. The difference was due to the higher cost of the medical visit and not because of the variability in the complementary tests seen in the randomized clinical trial. Other modalities of follow-up with direct participation of nurses have also demonstrated their efficiency in the follow-up of these patients, as an alternative to hospital follow-up. The economic impact of the growing population of long-term cancer survivors is a strong incentive for researchers to define the most cost-effective option for follow-up.

The long-term consequences of breast cancer therapy can contribute to a deterioration in the HRQL of the survivors, particularly in the sexual, psychosocial and physical symptoms dimensions, although studies generally report a good or adequate overall HRQL. Scores obtained in the HRQL questionnaire show little difference from those of other published studies. Most long-term survivors of breast cancer are shown to be satisfied with the care provided by their primary care doctor, particularly in general health care, psychosocial support and promotion of good health. They do, however, report a lower degree of satisfaction with the attention related to the actual breast cancer, in primary care. The questionnaire administered was a general inquiry in which these specific questions were not analysed. Although participants expressed greater satisfaction with hospital attention on all dimensions of the questionnaire, the degree of satisfaction with primary care was also high: very few patients expressed dissatisfaction. Other studies also suggest that visits in primary care or with nursing attendance are forms of follow-up that are acceptable, although these patients prefer visits in the Oncology service. It is difficult to respond to the important question raised by this study—what should be done when patients prefer the more costly option, which does not give them any additional health benefit? The economics of health care must clearly be taken into account, particularly in times of crisis like the present. However, there are possible complementary measures that might be taken in this context. Firstly, in their contacts with the patients, both the oncologist and the primary care doctor should take the opportunity to provide education that may lessen any reservations they may have about receiving primary care follow-up; they can discuss fully the options open to the women, explain the ways in which the quality of care is equivalent in both primary and specialist and agree consensual plans with them for the more appropriate place and method of follow-up for practical reasons to the patient’s advantage. Secondly, the health professionals in primary and specialist fields should attempt to understand in greater depth the reasons for the preference expressed by the women. The final point to make is that the opinions of the patients should always be respected, and the primary care and specialist doctors should continue to share the duties of follow-up and accept that some women will feel the need to continue to be followed up by their ‘own’ oncologist.

Conclusions

Our study describes the experience of a single hospital centre coordinated with its various ‘satellite’ local health centres. A high degree of compliance of the follow-up protocol was confirmed in both types of care, but some differences were found between specialist and primary care follow-up. First, primary care is more cost efficient. Second, in specialist attention nearly all visits were programmed, whereas in primary care almost half were on demand. And, third, the women express greater satisfaction with and preference for follow-up in specialist attention. No similar experiences in Spain have been reported. For this reason, although the study has limitations, it does have the notable value of being a first approach to comparing the follow-up of long-term survivors of breast cancer in hospital and primary care in our country.
Declarations

Funding: Spanish Society of Medical Oncology; Spanish Federation for Breast Cancer, 2009 call for bids (SEOM-FECMA 2009).

Ethical approval: local Ethical Research Committee.

Conflict of interest: none.

References


