

Comparison of breast cancer patient satisfaction with follow-up in primary care versus specialist care: results from a randomized controlled trial

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SUMMARY

Background. Routine follow-up of breast cancer patients in specialist clinics is standard practice in most countries. Follow-up involves regularly scheduled breast cancer check-ups during the disease-free period. The aims of follow-up are to detect breast cancer recurrence and to provide psychosocial support to the patient; however, little is known about patients' views on breast cancer follow-up.

Aim. To assess the effect on patient satisfaction of transferring primary responsibility for follow-up of women with breast cancer in remission from hospital outpatient clinics to general practice.

Method. Randomized controlled trial with 18 months' follow-up in which women received routine follow-up either in hospital outpatient clinics or from their own general practitioner. Two hundred and ninety-six women with breast cancer in remission receiving regular follow-up care at two district general hospitals in England were included in the study. Patient satisfaction was measured by means of a self-administered questionnaire supplied three times during the 18-month study period.

Results. The general practice group selected responses indicating greater satisfaction than did the hospital group on virtually every question. Furthermore, in the general practice group there was a significant increase in satisfaction over baseline; a similar significant increase in satisfaction over

baseline was not found in the hospital group.

Conclusion. Patients with breast cancer were more satisfied with follow-up in general practice than in hospital outpatient departments. When discussing follow-up with breast cancer patients, they should be provided with complete and accurate information about the goals, expectations, and limitations of the follow-up programme so that they can make an informed choice.

Keywords: breast cancer; patient satisfaction; RCT; follow-up; primary care.

Introduction

Routine follow-up of breast cancer patients in specialist clinics is standard practice in most countries with specialist cancer care systems.^{1,2} Routine follow-up involves regularly scheduled breast cancer check-ups during the disease-free period. Its principal goal is to detect breast cancer recurrence and new contralateral breast primaries. Another main goal is to provide psychosocial support to the patient.

A growing body of research has evaluated the effectiveness and efficiency of specialist-based routine follow-up for detecting breast cancer recurrence.^{3,4} The research has shown that most recurrences are not detected at routine follow-up visits but by patients themselves during the interval between follow-up visits.^{1,5} Frequently these patients present to their general practitioner — not to their specialist — with signs or symptoms of recurrence.⁵⁻⁷ This indicates that primary care physicians play an important informal role in breast cancer follow-up.

A survey of family physicians (FPs) in Ontario found that 73% have been involved in the follow-up of a patient with breast cancer; 77% believed it is appropriate for FPs to assume responsibility for follow-up and 90% would accept responsibility for follow-up if asked to do so.⁸ Similarly, general practitioners (GPs) in the United Kingdom (UK)⁹ and Italy¹⁰ prefer a more active role in follow-up of breast cancer patients. This suggests that the role of primary care physicians in follow-up can become something more than an informal responsibility.

While controversy exists over the extent to which the practice of follow-up in specialist clinics is beneficial, what is not in doubt is that the practice has a significant impact on the lives of women with breast cancer.^{11,12} Nevertheless, little is known about patients' views on breast cancer follow-up. Studies have shown that patients prefer regularly scheduled follow-up visits and diagnostic tests.^{4,10,13-15} A majority of both GPs and specialists agree that breast cancer patients expect follow-up to take place in a specialist clinic.¹⁶ At the same time, however, a majority of GPs prefer a system of routine follow-up based in general practice.¹⁷

As demands on specialist resources rise with the increase in the prevalence of diagnosed breast cancer, an evaluation of specialist-based follow-up versus a primary care model was warranted. To this end, we conducted a randomized controlled trial (RCT) of specialist versus primary care follow-up of breast cancer patients.¹⁸ Full descriptions of study participants, study methods, and results of the primary outcomes of time to diagnosis of

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recurrence and health related quality of life (HRQOL) are reported elsewhere.¹⁸ The results show that general practice follow-up is not associated with increase in time to diagnosis of recurrence, increase in anxiety, or a deterioration in HRQOL.¹⁸ When two methods of health service delivery show no important difference in the primary clinical outcomes, patient satisfaction becomes more important as an outcome upon which to evaluate the two services.^{19,20} For this reason, we report here the results of the comparison of breast cancer patient satisfaction with follow-up in primary care versus specialist care — a secondary outcome of the RCT.

Method

Participants of the study were 296 women with breast cancer in remission and receiving regular follow-up care at two district general hospitals in England. These women were taking part in a RCT to evaluate a primary care-based system of routine breast cancer follow-up whereby they were randomized to one of two groups: continued routine follow-up in outpatient clinics according to usual practice (hospital group), or routine follow-up from their own GP (general practice group). Ethical approval to conduct the study was obtained from the local research ethics committees.

Measurement and analysis of patient satisfaction

The instrument used in this study to measure patient satisfaction had to be adaptable to both hospital and general practice outpatient settings, and applicable to the UK. No published instrument was available that satisfied all these criteria. The most widely used patient satisfaction questionnaires, for example, had been developed and tested in the United States.^{21,22} Others, such as the one developed for use in the National Health Service (NHS), were specific to the hospital setting.^{23,24} One instrument developed for use in general practice was still considered to be under development.²⁵ We therefore decided to use an instrument developed in the UK by the College of Health.

The instrument consisted of fifteen statements, each with four response categories: 'Yes, I agree', 'I agree sometimes', 'No I disagree', and 'I can't say'. The instrument was adapted for use in this study. Specifically, the questions were introduced with the statement, 'When you go for your breast cancer check up...' so that patients would relate their response to their breast cancer follow-up visits. In presenting the data, questions have been grouped into three categories:

1. Questions related to service delivery,
2. Questions related to the consultation, and
3. Questions related to continuity of care.

Item responses were considered to reflect satisfaction if 'agree' or 'agree sometimes' were selected for a positively-worded statement, or 'disagree' was selected for a negatively-worded statement.

Patient satisfaction was assessed at three points in time during the three-month study period: baseline, mid-trial, and at the end of the trial. As a preliminary assessment of the reliability of the questionnaire, the internal consistency of items in the questionnaire was examined at each of the three times of measurement by calculating Cronbach's alpha.²⁶ The results for this aspect of reliability were satisfactory: 0.70, 0.67, and 0.70, respectively.

The patient satisfaction instrument formed part of the questionnaire package containing the instruments measuring HRQOL, described previously.¹⁸ Questionnaire packages were posted to study participants and one reminder letter was sent if the questionnaire had not been returned within two weeks.

Participants completed the mid-trial questionnaire within 10 days of a follow-up visit. For this reason, the mid-trial assessment was selected as the comparator to baseline to evaluate change in responses over time. (Baseline responses in both groups relate to follow-up appointments in specialist clinics.) As there were no important differences in the results obtained at the mid-trial from those obtained at the end of the trial, only mid-trial results are reported here.

The chi-squared test to assess the significance of between-group differences in proportions, and the Cronbach's alpha statistic were calculated with the software package SPSS (version 6.1.2). The Stuart–Maxwell test to assess the significance of differences between paired observations with more than two categories²⁷ was calculated with the software package SAS (version 6.11). Confidence intervals were calculated using the statistical programme CIA (Garner SB, Winter PD, Gardner MJ, 1991; version 1.1). All analyses were on an intention-to-treat basis.

Results

Response rates

After the denominator was adjusted for patients who had died or moved, the response rates in general practice and hospital groups respectively were 99.3% (147/148) and 95.3% (141/148) at baseline, 97.2% (140/144) and 88.7% (126/142) at mid-trial, and 97.2% (137/141) and 88.1% (119/135) at the end of the trial. There were no significant differences between the two study groups on responses to the baseline patient satisfaction questionnaire. As the adjusted response rate in the hospital group had fallen to just above 88% while remaining above 97% in the general practice group, non-responders in the hospital group were compared on baseline characteristics and selected domains of the HRQOL instruments. There were no differences between non-responders and responders on any of these variables.

Patient satisfaction

The general practice group selected responses indicating greater satisfaction than did the hospital group on virtually all questions (Table 1). Furthermore, in the general practice group there was a significant increase in the proportion of patients selecting responses indicating greater satisfaction at mid-trial over baseline (Table 2); a similar significant increase in satisfaction over baseline was not found in the hospital group (Table 3).

Satisfaction with service delivery. Almost all patients in both the general practice and hospital group were seen within 20 minutes of their appointment time (Table 1), reflecting a significant increase over baseline for both groups (Tables 2 and 3). However, more patients in the general practice group than in the hospital group could see the doctor on the same day for urgent problems and had enough time to discuss problems with their doctor (Table 1). On these items, the general practice group showed significantly more satisfaction over baseline (Table 2) while the hospital group showed no change over baseline (Table 3).

Satisfaction with the consultation. Most patients in both groups agreed that the doctor examined them thoroughly and explained clearly what was wrong (Table 1). Of note were that the responses reflecting dissatisfaction among a large proportion of patients in both groups relate to aspects of patient–physician communication — more than one-quarter of patients agreed it was difficult to discuss concerns with the doctor, that the doctor should listen more to what they said, and that the doctor should tell them more about their problem and treatment. However, significantly more

Table 1. Patient satisfaction at mid-trial by trial group.

Question	Group n		Agree ^a n (%)		Difference between groups (95% CI)	P-value ^b
	GP	Hospital	GP	Hospital		
Service delivery						
If it's urgent you can see a doctor on the same day	138	120	116 (84.1)	61 (50.8)	33.2 (22.4 to 44.1)	<0.001
You are usually seen by the doctor within 20 mins of appointment time	138	122	134 (97.1)	111 (91.0)	6.1 (0.3 to 11.9)	0.009
There is not enough time to discuss your problems with the doctor	136	119	38 (27.9)	56 (47.1)	-19.1 (-30.8 to -7.4)	0.005
The consultation						
You get good advice about how to keep yourself healthy	138	121	112 (81.2)	77 (63.6)	17.5 (6.8 to 28.3)	0.001
It is sometimes difficult to discuss your concerns with the doctor	136	121	39 (28.7)	48 (39.7)	-11.0 (-22.6 to 0.57)	0.175
The doctor explains clearly what is wrong	138	120	126 (91.3)	103 (85.8)	5.5 (-2.3 to 13.3)	0.321
The doctor examines you thoroughly when necessary	138	121	136 (98.6)	119 (98.3)	0.2 (-2.8 to 3.2)	0.507
Sometimes you feel the doctor should listen more to what you say	136	119	36 (26.5)	52 (43.7)	-17.2 (-28.8 to -5.6)	0.004
The doctor should tell you more about your problem and treatment	135	119	63 (46.7)	76 (63.9)	-17.2 (-29.3 to -5.1)	0.001
The doctor encourages you to talk about your problem and treatment	137	120	126 (92.0)	91 (75.8)	16.1 (7.2 to 25.0)	0.009
Continuity of care						
You see a doctor that knows you well	138	121	124 (89.9)	65 (53.7)	36.1 (25.9 to 46.3)	<0.001
If you need to see a doctor you have to wait too long for an appointment with the doctor you want	136	118	54 (39.7)	31 (26.3)	13.4 (2.0 to 24.9)	<0.001

^aResponse categories 'agree' and 'agree sometimes' collapsed for clarity of presentation; ^bP-value for difference between groups: χ^2 with 2 df based on three response categories: agree/agree sometimes, can't say, disagree.

patients in the general practice group than in the hospital group were satisfied with these aspects of the consultation (Table 1), and significantly more were satisfied than they were at baseline (Table 2 and 3).

Satisfaction with continuity of care. Almost 90% of patients in the general practice group saw a doctor who knew them well at their follow-up visit, as compared with approximately 50% of patients in the hospital group. While more than one-quarter of patients agreed that they had to wait too long to see the doctor they wanted for urgent problems, significantly more patients in the general practice group than in the hospital group disagreed with this statement (Table 1). In the hospital group there was no change over baseline in the proportion of patients who were satisfied with continuity of care (Table 3). In the general practice group there was a significant increase over baseline in the proportion of patients who were satisfied with continuity of care (Table 2).

Discussion

As an outcome measure, patient satisfaction is considered a multi-dimensional construct that includes satisfaction with interpersonal factors, technical quality, accessibility/convenience, availability, and financial aspects of care.^{20,25,28,29} Two further dimensions that cancer patients identified as important are communication skills and continuity of care.³⁰ The instrument used in this study

included questions pertaining to all but one of these dimensions. 'Financial aspects of care' was not included, as all the women in the study were NHS patients who made no direct payment for their medical care.²⁵

This study's finding of generally high levels of satisfaction in both groups is consistent with other research on patient satisfaction.²⁰ Results of patient satisfaction surveys are usually highly skewed, with most patients giving high satisfaction ratings.^{19,28,31,32} The thinking is that patients deny dissatisfaction — despite assurances of confidentiality — for fear that the standard of care they receive might be jeopardized.³⁰ This is difficult to prove or refute because there is no 'gold standard' criterion against which patient satisfaction instruments can be validated.^{19,20,22} This ceiling effect,³⁰ however, often makes it difficult to differentiate nuances of satisfaction among the generally positive responses. Nonetheless, despite this well recognized problem with patient satisfaction instruments, virtually every question in this study showed that patients in the general practice group were more satisfied at follow-up than at baseline, and that they were more satisfied than patients in the hospital group at both mid-trial and trial end assessments.

There is always a problem in finding validated measures of satisfaction with appropriate content when making comparisons of patients' experiences across disparate settings and services. That the instrument chosen in this trial to examine patient satisfaction has not been extensively validated is a potential limit-

Table 2. Change in patient satisfaction from baseline at mid-trial: GP group (n = 140).

Question	Time	Number	Agree ^a n (%)	Disagree n (%)	Can't say n (%)	P-value ^b
Service delivery						
If it's urgent you can see a doctor on the same day	Baseline	133	85 (63.9)	8 (6.0)	40 (30.1)	0.001
	Mid-trial		111 (83.5)	4 (3.0)	18 (13.5)	
You are usually seen by the doctor within 20 mins of appointment time	Baseline	135	109 (80.7)	23 (17.0)	3 (2.2)	<0.001
	Mid-trial		132 (97.8)	1 (0.7)	2 (1.5)	
There is not enough time to discuss your problems with the doctor	Baseline	130	62 (47.7)	63 (48.5)	5 (3.8)	0.004
	Mid-trial		38 (29.2)	87 (66.9)	5 (3.8)	
The consultation						
You get good advice about how to keep yourself healthy	Baseline	130	83 (63.8)	24 (18.5)	23 (17.7)	<0.001
	Mid-trial		108 (83.1)	7 (5.4)	15 (11.5)	
It is sometimes difficult to discuss your concerns with the doctor	Baseline	132	63 (47.7)	62 (47.0)	7 (5.3)	<0.001
	Mid-trial		38 (28.8)	89 (67.4)	5 (3.8)	
The doctor explains clearly what is wrong	Baseline	132	117 (88.6)	8 (6.1)	7 (5.3)	0.64
	Mid-trial		121 (91.7)	6 (4.5)	5 (3.8)	
The doctor examines you thoroughly when necessary	Baseline	134	128 (95.5)	2 (1.5)	4 (3.0)	0.34
	Mid-trial		132 (98.5)	1 (0.7)	1 (0.7)	
Sometimes you feel the doctor should listen more to what you say	Baseline	130	59 (45.4)	58 (44.6)	13 (10.0)	<0.001
	Mid-trial		33 (25.4)	92 (70.8)	5 (3.8)	
The doctor should tell you more about your problem and treatment	Baseline	130	79 (60.8)	4 (31.5)	10 (7.7)	0.03
	Mid-trial		61 (46.9)	57 (43.8)	12 (9.2)	
The doctor encourages you to talk about your problem and treatment	Baseline	133	105 (78.9)	17 (12.8)	11 (8.3)	0.007
	Mid-trial		122 (91.7)	6 (4.5)	5 (3.8)	
Continuity of care						
You see a doctor that knows you well	Baseline	133	82 (61.7)	44 (33.1)	7 (5.3)	<0.001
	Mid-trial		119 (89.5)	10 (7.5)	4 (3.0)	
If you need to see the doctor you have to wait too long for an appointment with the doctor you want	Baseline	129	49 (38.0)	49 (38.0)	31 (24.0)	0.005
	Mid-trial		53 (41.1)	65 (50.4)	11 (8.5)	

^aResponse categories 'agree' and 'agree sometimes' collapsed to give three response categories for test statistic. Baseline responses relate to patients responding at mid-trial; ^bP-value for difference between times, Stuart–Maxwell test; test statistic compared with the chi-squared distribution

ation of the study. However, the trial itself provided an opportunity to assess some of the measurement properties of the College of Health questionnaire. Evidence for reliability in terms of internal consistency of items was encouraging. Also, the results of the trial provide one of the few pieces of evidence to examine responsiveness (sensitivity to change) of a patient satisfaction questionnaire, and a number of items of the instrument showed significant sensitivity to change.

General practice patients' responses reflected greater satisfaction with service delivery, the quality of the consultation, and continuity of care. These are factors that are important both to cancer patients³⁴ and general practice patients.³⁵ However, these factors are not necessarily the dominant criteria by which patients measure their level of satisfaction. For example, 100% of cancer patients rank technical competence as important to satisfaction.³⁰ As there is evidence that patients' criteria for satisfaction may be specific to the disease problem and medical setting,³⁶ technical skills may be of greater importance in the specialist setting while other dimensions of satisfaction may have greater importance in the general practice setting. A hierarchy of concerns may influence levels of satisfaction, with patients regarding continuity of care, interpersonal factors, and factors related to service delivery important only *after* they are confident in the technical skills of the practitioner. Patients would therefore generally want to be assured that their clinical care is equivalent in either general practice or a specialist setting before other criteria, such as continuity of care, become relevant to their appraisal

of satisfaction.

In this study, over 95% of patients in both groups agreed that the doctor examined them thoroughly. This was one of the few questions for which no significant differences were found between either group or over time. In contra-distinction, a focus group study reported that cancer patients repeatedly expressed concern about the cursory examinations they received at NHS specialist outpatient follow-up visits.³⁴ In both studies, however, the results were similar with respect to the rushed nature of the follow-up visit — the complaint that there was insufficient time to obtain information at follow-up visits documented in the focus group study³⁴ is supported by the finding of this study that half the patients in the hospital group felt that there was not enough time to discuss problems with the doctor.

Conclusion

An important concern regarding the results of this research is that purchasers of health services will interpret the results as indicating that specialist follow-up is unnecessary for *all* patients, and a wholesale devolution of follow-up to primary care will occur. The matter of patient preferences must be considered. In the UK, the National Cancer Alliance undertook a study of patients' experiences and views on their cancer care.³⁴ The question of a primary care-centred alternative to specialist follow-up was specifically discussed in these focus groups. Patients who had a negative experience with their GP at the time of initial diagnosis

Table 3. Change in patient satisfaction from baseline at mid-trial: Hospital group (n = 126).

Question	Time	Number	Agree ^a n (%)	Disagree n (%)	Can't say n (%)	P-value ^b
Service delivery						
If it's urgent you can see a doctor on the same day	Baseline	113	62 (54.9)	3 (2.7)	48 (42.5)	0.61
	Mid-trial		56 (49.6)	4 (3.5)	53 (46.9)	
You are usually seen by the doctor within 20 mins of appointment time	Baseline	115	93 (80.9)	21 (18.3)	1 (0.9)	0.009
	Mid-trial		104 (90.4)	11 (9.6)	0 (0)	
There is not enough time to discuss your problems with the doctor	Baseline	112	59 (52.7)	48 (42.9)	5 (4.5)	0.33
	Mid-trial		52 (46.4)	55 (49.1)	5 (4.5)	
The consultation						
You get good advice about how to keep yourself healthy	Baseline	113	76 (67.3)	24 (21.2)	13 (11.5)	0.48
	Mid-trial		71 (62.8)	24 (21.2)	18 (15.9)	
It is sometimes difficult to discuss your concerns with the doctor	Baseline	115	51 (44.3)	58 (50.4)	6 (5.2)	0.65
	Mid-trial		46 (40.0)	64 (55.7)	5 (4.3)	
The doctor explains clearly what is wrong	Baseline	114	102 (89.5)	6 (5.3)	6 (5.3)	0.64
	Mid-trial		97 (85.1)	8 (7.0)	9 (7.9)	
The doctor examines you thoroughly when necessary	Baseline	115	107 (93.0)	4 (3.5)	4 (3.5)	0.08
	Mid-trial		113 (98.3)	2 (1.7)	0 (0)	
Sometimes you feel the doctor should listen more to what you say	Baseline	113	56 (49.6)	51 (45.1)	6 (5.3)	0.40
	Mid-trial		49 (43.4)	56 (49.6)	8 (7.1)	
The doctor should tell you more about your problem and treatment	Baseline	111	74 (66.7)	32 (28.8)	5 (4.5)	0.09
	Mid-trial		72 (64.9)	26 (23.4)	13 (11.7)	
The doctor encourages you to talk about your problem and treatment	Baseline	113	86 (76.1)	20 (17.7)	7 (6.2)	1.00
	Mid-trial		86 (76.1)	20 (17.7)	7 (6.2)	
Continuity of care						
You see a doctor that knows you well	Baseline	115	65 (56.5)	42 (36.5)	8 (7.0)	0.50
	Mid-trial		62 (53.9)	48 (41.7)	5 (4.3)	
If you need to see the doctor you have to wait too long for an appointment with the doctor you want	Baseline	112	30 (26.8)	39 (34.8)	43 (38.4)	0.43
	Mid-trial		28 (25.0)	31 (27.7)	53 (47.3)	

^aResponse categories 'agree' and 'agree sometimes' collapsed to give three response categories for test statistic. Baseline response relates to patients responding at mid-trial. ^bP-value for difference between times, Stuart-Maxwell test; test statistic compared with the chi-squared distribution

were clearly unwilling to have the GP take responsibility for follow-up. When patients had confidence in their GP, however, the involvement of the GP during follow-up was regarded as vital.³⁴

It is important to provide patients with the information they need to make informed choices. It is also important to implement a flexible system that can respond to the needs of individual patients. Patients should be offered a choice of method of follow-up with complete and accurate information about the goals, expectations, and limitations of the follow-up programme. Giving patients accurate information and offering them a choice is consistent with findings that patients want more information, would like to be involved in the decision-making process, and experience better psychosocial adjustment if good communication is a part of their cancer care.^{37,38}

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