

*Original Article*

# Quality of Life and Experience of Care in Women With Metastatic Breast Cancer: A Cross-Sectional Survey

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## Abstract

**Context.** Despite developments in the medical management of metastatic breast cancer, little is known about the quality of life (QoL) and experience of care in women with it.

**Objectives.** To explore QoL, experience of care, and support needs of women living with metastatic breast cancer in the U.K.

**Methods.** Questionnaire-based, cross-sectional study, undertaken in two U.K. cancer centers and online via the Breast Cancer Care Web site, assessing QoL and experience of care in 235 women with metastatic breast cancer.

**Results.** QoL was assessed using the Functional Assessment of Cancer Therapy—Breast QoL measure. Overall, QoL was low (mean 89.0, standard deviation 21.8) for total score. Low scores were seen uniformly in physical, social, emotional, and functional well-being domains. Symptom burden was a significant problem, with over one-third of women (34%) reporting high levels of pain and other uncontrolled symptoms. In multiple regression analysis, social well-being was significantly better for older women ( $P < 0.001$ ) but was lower in those with bone metastases only ( $P = 0.002$ ). Functional well-being was significantly higher in women without children ( $P = 0.004$ ). Satisfaction with experience of care was low and appeared to be predominantly in the hospital setting, with little evidence of involvement of general practitioners and palliative care services.

**Conclusion.** Despite improvements in treatment and survival of women with metastatic breast cancer, this group reports high symptom burden and dissatisfaction with elements of their care, indicating that alternative models of service delivery should be explored. *J Pain Symptom Manage* 2011;■:■—■.

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## Key Words

*Metastatic breast cancer, quality of life, experience of care, symptom burden*

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## Introduction

Despite the implementation of screening and advances in the management of breast cancer, a significant number of women will go on to develop metastatic disease, although the actual number is unknown, as these data are not collected. In the U.K., a significant proportion of the 550,000 women estimated to be alive with a diagnosis of breast cancer will be living with metastatic disease.<sup>1</sup> The needs of those with metastatic breast cancer are increasingly receiving both national<sup>2</sup> and international attention.<sup>3</sup> Evidence suggests that the provision of care for women with metastatic breast cancer is inadequate<sup>4</sup> and the focus of clinical teams and breast care nurse specialists has predominantly been on supporting those with primary disease.<sup>5</sup>

The prognosis of metastatic breast cancer is improving as a result of the development of more effective and better tolerated therapies that can be applied to a wider range of patients sequentially over time,<sup>6,7</sup> and for many, it may become a long-term illness. Women presenting with visceral metastases may have a relatively short-life expectancy, whereas those presenting with skeletal metastases and no other site of metastases have an average life expectancy of approximately 24–36 months. Those with more indolent disease may live for many years (10–15 years in some cases).<sup>8</sup> Considering the potential long-term nature of metastatic disease, those living with it are now considered to be cancer survivors rather than necessarily at the end of life.<sup>9,10</sup>

Because the focus of specialist palliative care teams is on end-of-life care, many women with metastatic breast cancer are not deemed to be in the end-of-life phase of illness, and they often do not receive palliative care input until the last weeks of life. This may be some years after advanced disease is first recognized.

Quality of life (QoL) in women with breast cancer has been extensively studied but there is a paucity of research exploring the QoL and well-being of women with metastatic disease, outside of clinical trials of new treatments. To date, there has been little information available to suggest whether women with metastatic breast cancer have unmet needs. The prevalence of problems and needs and the experience of care received by these women have not

previously been described in the current context of the increased treatment options and prolonged life expectancy.

Although extensive data on the incidence and mortality of breast cancer have been routinely collected for a number of years, there are gaps. In particular, data relating to diagnosis of metastatic breast cancer has not been collected. We are not aware of any country worldwide that collects national data on the incidence of metastatic breast cancer. This means that the natural history of metastatic breast cancer, for example, duration of survival after metastatic disease is recognized, number and types of treatments received, service use or QoL and how this changes over time following the development of metastatic disease, is unknown.

The prevalence of metastatic breast cancer and the longer illness trajectory for many women have potential implications for health service provision and the cost of treatment and care. It is, therefore, imperative that the needs for support and the impact of ongoing treatment for metastatic breast cancer on women with the disease are understood.

The objective of this study was to assess the QoL, experience of care, and need for support services for women with metastatic breast cancer and to identify whether there were particular groups of women with greater need for support. For example, it was hypothesized that women with visceral disease would have a poorer QoL and higher symptom burden than women with bone metastases and no visceral disease because the former is deemed to be more aggressive and advanced. A secondary objective was to identify whether there were other subgroups of women who may have greater need for support.

This article reports the first detailed data focusing on the QoL and experience of care for women with metastatic breast cancer in the U.K., outside of clinical trials.

## Methods

To ensure participation in the study of a large number of women with metastatic breast cancer, a cross-sectional survey using quantitative methods, and open and closed free-text questions, was used. Women were identified in local

cancer centers, and by recruitment through a national online recruitment campaign.

Women with metastatic breast cancer attending for treatment or follow-up in two cancer centers in the southeast of England were recruited over a 24-month period. Concurrently, women responding to a media campaign about the study were invited to complete the survey using the Web site of a U.K.-wide breast cancer charity.

The inclusion criteria were a confirmed diagnosis of metastatic breast cancer for women recruited in the cancer centers, and Web site participants were asked to describe the extent of their metastatic disease.

Ethical approval was granted by the Southampton and South West Hampshire Local Research Ethics Committee.

### *Sample Size*

It was estimated that around 300 women in total might be available to be approached from the cancer centers. Assuming a contact, consent, and response rate to the survey of 60%, we aimed to yield a sample of 180 women from the cancer centers. The number of likely cases from the Web site was unknown, but the target sample size was set at 100. The sample size was determined by availability of women rather than by statistical power. However, a total sample of at least 220 women split approximately one-third to two-thirds for bone metastases vs. visceral metastases would provide 80% power to detect standardized differences of 0.4 between the two groups in terms of the Functional Assessment of Cancer Therapy—Breast (FACT-B) and experience with care subscale scores.

### *Participants*

All women attending breast cancer treatment and follow-up clinics in the two cancer centers were screened by searching their medical notes. All those with a confirmed diagnosis of metastatic breast cancer were identified and approached by the principal investigator in one cancer center and a research nurse in the second to participate in the study. Some women were identified but not approached at the time because of a number of reasons, such as the fact that they were receiving information about disease progression and were distressed by their situation at that time or

were felt to be in the midst of making decisions about their treatment. In these cases, they were approached at a later, more appropriate time. All women approached were given the study information sheet and at least 24 hours to consider study participation. Subject to consent, they were asked to complete a questionnaire either face-to-face or to return it in a prepaid envelope.

Concurrently, the same survey was placed on the Web site of a U.K.-wide breast cancer charity Web site. The principal investigator undertook media promotion about the study on national radio, news Web sites, and local radio stations to call for women with metastatic breast cancer to take part in the online survey. Subject to consent, women were asked to complete questionnaires about their QoL, personal experience of care, and support needs and how they sought support to address these.

To avoid duplication, postcodes were checked to ensure none had taken part in both the cancer center and Web site survey or submitted more than one response to the Web site survey.

The survey was piloted face-to-face and online and appeared to yield broadly consistent responses from each method of recruitment.

### *Outcome Measures*

The FACT-B, a self-administered questionnaire, was used to assess QoL and symptom burden. This multidimensional instrument was chosen because it consists of domains that the study aimed to investigate, measuring physical well-being, social/family well-being, emotional well-being, functional well-being, and breast cancer-specific concerns.

The total FACT-B score is calculated by adding the results for each domain. The questionnaire has a total of 37 items asking women to rate how true each one is for the period of the last seven days. Response scales range from 0 (not at all) to 4 (very much). The FACT-B questionnaire has been shown to have high internal consistency/reliability and has been well validated as a patient-reported outcome measure.<sup>11,12</sup>

The experience with care measure incorporated 34 items in three domains (information and advice, personal experience of care, and satisfaction with care), with each individual item rated on a five-point Likert scale, and an overall rating of support received.<sup>13</sup> The information and advice domain comprised 11 items that

considered the level of information and advice given and whether the women knew where to seek further assistance. The personal experience of care domain consisted of 10 items and considered the quality of communication with health care professionals, and whether the participant felt valued and heard. The satisfaction with care domain comprised 13 items relating to the thoroughness of care and whether the women's needs and concerns were addressed. Ratings of level of support received were accessed on a visual analogue scale from 0 to 10.

For women from the cancer centers, clinical data relating to breast cancer diagnosis and treatment were collected from their medical notes. Socioeconomic status was measured using the Townsend deprivation index,<sup>14</sup> derived from postcodes.

Open-text questions explored the experience of living with metastatic breast cancer, specifically the women's physical, emotional, and social problems and needs, and where they sought support for these. Access to support services was determined using specific questions about which health care professional the women would choose to see regularly and why.

### *Statistical Methods*

FACT-B subscale scores were calculated using standard methods and summarized according to subgroups of survey participants, using means and standard deviations (SDs). For the experience of care data, a positive response was defined for each item in the questionnaire by grouping the higher two categories (agree/strongly agree or very/completely satisfied) out of five options. Then, for each woman, the number of positive responses was summed within each of the three domains separately (information and advice, personal experience with care, and satisfaction with care). The number of positive responses within each of the three experiences of care domains was then converted to a percentage out of the number of questions within each domain to facilitate comparisons between the domains because the domains were based on a different number of questions. These percentages represented the proportion of items within an experience of care domain for which an individual participant gave a positive response. Mean (SD) percentages of positive responses for each domain of the satisfaction with care questionnaire were used to summarize across groups of women.

Although the distributions of the satisfaction with care subscales were skewed, it was not possible to find a suitable transformation to normalize the data; results were checked using nonparametric methods, which made very little difference so have not been presented.

Where there were missing items, FACT-B subscales were calculated on a prorated basis according to the number of items in a scale that were completed, provided that at least 50% of the items were available, as recommended in the FACT-B scoring manual (there was no item with less than 50% data available). Because no similar guidelines exist for the satisfaction with care module, no adjustment for missing data was done for these subscales.

Analyses were carried out to assess how self-reported QoL and experience of care varied according to the number of prespecified demographic and clinical characteristics including age, marital status, whether or not the woman had children, socioeconomic status, time since diagnosis of metastatic disease, and site of spread. To account for multiple testing, a more conservative cut-off of  $P = 0.01$  was taken to indicate statistical significance.

We compared mean scores of the FACT-B and experience with care subscales between groups using *t*-tests and one-way analyses of variance for the univariate analyses. To take into account associations between clinical and demographic characteristics, all factors were entered into multiple linear regression analyses to determine independent associations with the FACT-B and experience with care subscales. The Chi-squared test was used to test associations between categorical variables, such as patient characteristics with place of recruitment and some elements of the experience with care questionnaire. Trend tests were used where appropriate.

FACT-B and experience of care data were analyzed using SPSS (SPSS, Inc., Chicago, IL). Open-text responses about support needs were transcribed verbatim and analyzed by the principal investigator using the qualitative research software NVivo (QSR International [U.K.] Limited, Southport, U.K.). Categorical indexing was generated from the original themes of the open questions, and subcategories generated within these, identifying the key themes.<sup>15</sup> Themes generated from the analysis were verified by a second researcher.

## Results

### Participants

In total, 235 women with metastatic breast cancer completed the study questionnaires. One hundred and thirty-six women consented to take part from the two cancer centers (72.3% of the 188 women identified with metastatic disease) and 110 completed the questionnaires (a response rate of 80.8%). Recruitment of two women was considered inappropriate by their oncologist. One woman had poor cognitive ability and one was close to the end of life. A total of 221 women looked at the online survey, 135 completed it, and 125 correctly described themselves as having metastatic breast cancer. Nineteen Web site responses (17.2%) were repeated submissions of questionnaires so were excluded and a further 10 (9.9%) women who described regional recurrence were excluded.

The age range of cancer center participants was 25–84 years, with a mean age of 58 years. Web site participants' ages were collected in ranges; therefore, the overall mean age score cannot be calculated. Web site participants were significantly younger ( $P < 0.001$ ). Forty-two percent of Web site participants were aged between 45 and 55 years compared with 27% from the cancer centers, whereas 35% of those recruited from cancer centers were older than 65 years compared with 2% from the Web site. Participants from both cancer centers were recruited from urban and rural areas. There were similar distributions between the cancer center and Web site participants for all demographic variables other than age. The sociodemographic profile of the each cancer center was similar. Ninety-five percent of participants were of white ethnic origin. The median time since diagnosis of metastatic disease was two years (range one week to 15 years) (Table 1).

Within the whole study population ( $n = 235$ ), 75 women (31.9%) had metastatic disease confined to bone, and the remainder had visceral disease with or without bony metastases (159/67.7%) (one unknown) (Table 1).

### Clinical Characteristics of Cancer Center

#### Participants

It was not possible to collect accurate clinical characteristics from the online participants. Of the cancer center participants

( $n = 110$ ), six (5.5%) had initially presented with metastatic breast cancer but the majority (93 [84.5%]) were treated for early stage disease (for the remaining 10%, these data were unknown). For those women developing metastatic disease after primary breast cancer treatment, the median time interval between primary diagnosis and development of metastatic disease was four years (range nine months to 23 years) (Table 2). Of the cancer center participants, 37 (33.6%) had bone metastases only, seven (6.3%) had nodal disease only, 18 (16.3%) had a single visceral metastatic site, 47 (42.7%) had multiple metastatic sites (two or more), and 1 (0.9%) had an unknown site (Table 2).

At the time of recruitment to the study, the majority of women were receiving hormonal therapy or chemotherapy, in some cases in combination with trastuzumab, and in over one-half with bisphosphonates (Table 2).

### Quality of Life

The mean scores for overall QoL and for each of the domains were low (reflecting worse QoL) when compared with normative data derived from the 295 patient validation sample for the FACT-B questionnaire, where only 20% of women had distant metastases<sup>12</sup> (Table 3).

Pain and other symptom scores for the women indicated concerns with symptom control, with 81 (34.5%) scoring "quite a bit/very much" (the highest two scoring categories) for the statement "I have certain parts of my body where I experience significant pain." Those with bone metastases only were more likely to report significant pain (33 of 75, 44.0%) compared with other metastatic sites (48 of 158, 30.4%). In addition, lack of energy was reported as "quite a bit/very much" by 89 (37.9%), nausea by 62 (26.4%), and shortness of breath by 63 (26.8%). Interestingly, there was no relationship between time since diagnosis of metastatic breast cancer and symptom burden, indicating that uncontrolled symptoms may be a problem throughout the illness trajectory and not necessarily worsening with disease progression. There was a small association between time since diagnosis and pain (worsening as the disease progresses) but this was not statistically significant.

Table 1  
Demographic and Clinical Characteristics of Survey Respondents According to Place of Recruitment

Characteristic	Cancer Centers	Web site	Total	$\chi^2$ Test for Comparison of Place of Recruitment
	(n = 110)	(n = 125)	(n = 235)	
	n (%)	n (%)	n (%)	Pvalue
Age (years)				<0.001 <sup>a</sup>
25–44	12 (10.9)	43 (34.4)	55 (23.4)	
45–54	30 (27.3)	52 (41.6)	82 (34.9)	
55–64	29 (26.4)	26 (20.8)	55 (23.4)	
≥65	39 (35.5)	3 (2.4)	42 (17.9)	
Unknown	0	1 (0.8)	1 (0.4)	
Marital status				0.21
In relationship	75 (68.2)	97 (77.6)	172 (73.2)	
Not in relationship	31 (28.2)	26 (20.8)	57 (24.3)	
Unknown	4 (3.6)	2 (1.6)	6 (2.6)	
Children				0.96
None	20 (18.2)	25 (20.0)	45 (19.1)	
≥1	80 (72.7)	93 (74.4)	173 (73.6)	
Unknown	10 (9.1)	7 (5.6)	17 (7.2)	
Townsend deprivation index quintile <sup>b</sup>				0.54 <sup>a</sup>
1 = Most deprived	27 (24.5)	12 (9.6)	39 (16.6)	
2	19 (17.3)	19 (15.2)	38 (16.2)	
3	16 (14.5)	24 (19.2)	40 (17.0)	
4	19 (17.3)	21 (16.8)	40 (17.0)	
5 = Least deprived	24 (21.8)	14 (11.2)	38 (16.2)	
Unknown	5 (4.5)	35 (28.0)	40 (17.0)	
Time since diagnosis of metastases				0.45 <sup>a</sup>
<6 months	31 (28.2)	32 (25.8)	63 (26.9)	
6–12 months	17 (15.5)	28 (22.6)	45 (19.2)	
1–2 years	30 (27.3)	33 (26.6)	63 (26.9)	
2–5 years	24 (21.8)	29 (23.2)	53 (22.6)	
>5 years	8 (7.3)	2 (1.6)	10 (4.3)	
Unknown	0	1 (0.8)	1 (0.4)	
Site of spread				0.73
Bone only	37 (33.6)	38 (30.4)	75 (31.9)	
Other	73 (66.4)	86 (68.8)	159 (67.7)	
Unknown	0	1 (0.8)	1 (0.4)	

<sup>a</sup>Trend test.

<sup>b</sup>Townsend deprivation index unknown for 40 participants.

Univariate analysis of associations between demographic/clinical characteristics and the FACT-B QoL subscales are shown in Table 4. Having children was associated with lower functional well-being. There was some evidence to suggest that physical well-being diminished with increasing age and that social well-being improved with increasing age, although this was not statistically significant. There was also some suggestion that emotional well-being improved as time increased since the diagnosis of metastatic disease but, again, this showed only borderline significance. There was no significant association between deprivation scores and QoL (Table 4).

In multiple regression analysis, social well-being was significantly better for older women ( $P < 0.001$ ) and in those with bone metastases

only ( $P = 0.002$ ). Functional well-being was significantly higher in women without children ( $P = 0.004$ ). There were no statistically significant associations with the breast cancer or total FACT-B scores, and no significant associations for marital status and deprivation with any of the subscales. Unsurprisingly, those receiving chemotherapy had lower functional well-being than those receiving hormone therapy ( $P = 0.007$ ).

#### Experience With Care

Just over one-half of the women highlighted dissatisfaction with the items related to information and advice (Table 5). Satisfaction with their personal experience of care was higher (mean positive responses 71%), whereas for satisfaction with care, the mean percentage of

*Table 2*  
**Clinical Characteristics of Cancer Center Survey  
 Participants at the Time of Recruitment**

Clinical Characteristic	Total ( <i>n</i> = 110)	
	<i>n</i>	(%)
Time from primary diagnosis to metastatic disease (years)		
<1	13	(11.8)
1–2	20	(18.2)
2–5	37	(33.6)
5–10	21	(19.0)
>10	18	(16.3)
Unknown	1	(0.9)
Site of metastatic spread at the time of survey completion		
Bone only	37	(33.6)
Nodal disease only	7	(6.3)
Single site visceral disease	18	(16.3)
Multisite disease (two or more sites)	47	(42.7)
Unknown	1	(0.9)
Treatment at the time of study recruitment		
Hormone therapy	58	(52.7)
Of those receiving hormone therapy		
First treatment	29	(50.0)
Second treatment	18	(31.0)
≥Third treatment	11	(19.0)
Chemotherapy	48	(43.6)
Of those receiving chemotherapy		
First treatment	30	(62.5)
Second treatment	11	(22.9)
≥Third treatment	7	(14.6)
Trastuzumab	25	(22.7)
Bisphosphonates	60	(54.5)

positive responses was less than 50%. The mean overall rating of support received was only 6.0 (SD 2.4), measured on a visual analogue scale from 0 to 10 (Table 5).

In a univariate analysis, women aged older than 65 years, those with site of spread other than bone, and those recruited from a cancer center were more satisfied with the information

*Table 3*  
**FACT-B QoL Results for All 235 Survey  
 Respondents**

FACT-B QoL Subscales	Total ( <i>n</i> = 235); Mean (SD) <sup>a</sup>	
	Study Score	Normative Score <sup>b</sup>
Physical well-being	16.8 (7.4)	22.1 (5.3)
Social well-being	20.1 (5.6)	22.7 (5.2)
Emotional well-being	12.9 (5.3)	16.3 (3.5)
Functional well-being	17.3 (6.2)	20.6 (6.4)
Breast cancer score	21.9 (7.5)	24.1 (6.5)
Total score	89.0 (21.8)	112.8 (20.9)

FACT-B = Functional Assessment of Cancer Therapy–Breast; QoL = quality of life. Missing data for social well-being (2), emotional well-being (1), functional well-being (1), breast cancer score (1), and total FACT-B score (3).

<sup>a</sup>Higher score reflects greater well-being.

<sup>b</sup>See reference 11.

and advice they had been given. Older women and those recruited from a cancer center were more satisfied with their personal experience of care and were also more likely to feel well supported (Table 6). There was some indication that those with bone metastases only were less satisfied with their care, felt less supported and rated the support they received as lower, although these findings were only approaching statistical significance. These findings highlight that younger woman and those with bone metastases only may have poorer experiences of care.

Multiple regression analysis supports these findings, with younger women being less satisfied with the information and advice they received ( $P = 0.003$ ) and their personal experience of care ( $P < 0.001$ ), and were more likely to rate the overall support they received as lower than older women ( $P < 0.001$ ). Women with children were less satisfied with their personal experience of care ( $P = 0.007$ ) and less satisfied with the care they received ( $P = 0.002$ ).

Again, multiple regression analysis suggests that those with had bone metastases only may be less satisfied with the information and advice they received ( $P = 0.05$ ), with their experience of care ( $P = 0.03$ ) and less likely to feel well supported ( $P = 0.03$ ) when compared with those with metastatic disease in sites other than bone, although these findings are only approaching statistical significance.

There were no statistically significant associations for marital status and deprivation with any of the experience with care domains.

Open-text responses aimed to elicit reasons for dissatisfaction with the experience of care. Women revealed that the experience of being diagnosed with metastatic breast cancer compared unfavorably with the experience of the primary diagnosis. They highlighted dissatisfaction with the provision of information and support from health care professionals when compared with their experience of being diagnosed with early stage disease, when the participants described feeling well supported and in receipt of adequate information.

### *Relationships With Health Care Professionals*

The women appeared to have limited contact with their general practitioners (GPs), and with specialist palliative care services,

Table 4  
Results of Univariate Analyses of Associations Between Demographic/Clinical Characteristics and FACT-B QoL Subscales for All 235 Survey Respondents

Characteristic	Physical Well-Being	Social Well-Being	Emotional Well-Being	Functional Well-Being	Breast Cancer Score	Total Score
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Age (years)	<i>P</i> = 0.04	<i>P</i> = 0.002	<i>P</i> = 0.15	<i>P</i> = 0.25	<i>P</i> = 0.38	<i>P</i> = 0.64
25–44	18.2 (6.8)	19.3 (4.8)	12.3 (4.8)	17.3 (5.8)	22.5 (6.6)	89.6 (18.8)
45–54	16.7 (6.8)	19.4 (6.1)	12.3 (5.6)	16.4 (6.7)	22.0 (8.1)	86.8 (23.7)
55–64	16.8 (8.0)	20.0 (5.5)	13.8 (5.0)	17.6 (6.2)	21.6 (7.5)	90.0 (21.0)
≥65	14.9 (8.1)	23.1 (4.8)	13.3 (5.7)	18.4 (5.9)	21.2 (7.6)	90.6 (22.9)
Marital status	<i>P</i> = 0.60	<i>P</i> = 0.46	<i>P</i> = 0.84	<i>P</i> = 0.85	<i>P</i> = 0.71	<i>P</i> = 0.93
In relationship	17.1 (7.1)	19.9 (5.0)	12.8 (5.2)	17.0 (6.2)	21.8 (7.4)	88.8 (21.5)
Not in relationship	16.5 (7.5)	20.6 (7.1)	12.9 (5.4)	17.2 (6.1)	22.3 (8.0)	89.1 (23.1)
Children	<i>P</i> = 0.89	<i>P</i> = 0.06	<i>P</i> = 0.08	<i>P</i> = 0.001	<i>P</i> = 0.47	<i>P</i> = 0.03
None	16.8 (8.2)	21.6 (4.6)	14.1 (5.5)	20.1 (4.4)	22.6 (9.1)	95.7 (23.1)
≥1	17.0 (7.2)	19.9 (5.7)	12.6 (5.2)	16.7 (6.4)	21.7 (7.2)	87.7 (21.4)
Townsend deprivation index quintile	<i>P</i> = 0.82	<i>P</i> = 0.31	<i>P</i> = 0.44	<i>P</i> = 0.65	<i>P</i> = 0.45	<i>P</i> = 0.51
1 = Most deprived	16.1 (7.1)	19.6 (5.8)	12.2 (5.2)	17.3 (6.2)	22.0 (7.4)	86.9 (19.9)
2	17.2 (7.8)	21.6 (4.2)	13.3 (5.4)	18.8 (5.5)	21.0 (8.0)	91.8 (19.3)
3	16.9 (7.9)	19.9 (5.7)	12.6 (5.2)	17.0 (6.9)	21.6 (7.2)	88.0 (23.7)
4	16.6 (7.1)	19.8 (5.4)	12.2 (5.8)	16.5 (6.7)	22.9 (7.3)	88.0 (21.2)
5 = Least deprived	16.8 (7.8)	21.8 (5.2)	13.7 (4.6)	17.7 (5.8)	22.5 (8.7)	92.5 (23.2)
Time since diagnosis of metastases	<i>P</i> = 0.38	<i>P</i> = 0.39	<i>P</i> = 0.02	<i>P</i> = 0.18	<i>P</i> = 0.59	<i>P</i> = 0.07
<6 months	16.4 (7.5)	19.7 (6.5)	12.5 (5.6)	16.8 (6.3)	22.3 (7.9)	87.6 (22.1)
6–12 months	17.2 (7.2)	20.2 (5.2)	11.3 (5.6)	16.5 (6.8)	21.1 (6.9)	85.8 (22.2)
1–2 years	15.4 (7.7)	20.1 (5.6)	12.7 (5.1)	17.3 (6.0)	20.4 (7.6)	86.0 (21.1)
>2 years	18.1 (6.8)	20.6 (4.9)	14.5 (4.7)	18.2 (6.0)	23.4 (7.3)	95.2 (21.1)
Site of spread	<i>P</i> = 0.90	<i>P</i> = 0.09	<i>P</i> = 0.70	<i>P</i> = 0.91	<i>P</i> = 0.39	<i>P</i> = 0.46
Bone only	16.9 (7.3)	19.2 (5.4)	12.6 (5.1)	17.3 (6.2)	21.2 (7.4)	87.3 (20.5)
Other	16.7 (7.4)	20.6 (5.6)	12.9 (5.4)	17.2 (6.3)	22.2 (7.6)	89.6 (22.4)
Place of recruitment	<i>P</i> < 0.001	<i>P</i> < 0.001	<i>P</i> < 0.001	<i>P</i> = 0.74	<i>P</i> < 0.001	<i>P</i> < 0.001
Center 1	16.0 (7.4)	21.9 (4.3)	13.7 (5.2)	17.8 (5.8)	20.8 (8.0)	89.8 (21.8)
Center 2	8.9 (6.4)	21.9 (5.7)	9.3 (4.2)	17.0 (7.4)	16.5 (4.9)	73.8 (11.4)
Web site	19.6 (5.6)	18.6 (5.8)	13.4 (5.3)	17.1 (6.1)	24.2 (6.9)	93.0 (22.4)

FACT-B = Functional Assessment of Cancer Therapy–Breast; QoL = quality of life.

*P*-values shown correspond to *F*-test from analysis of variance (trend test for age, Townsend index, and time since diagnosis).

with only 20 (8.5%) choosing their GP and 17 (7.3%) choosing a palliative care nurse as the health care professional they would want to see regularly. When asked which health care professional they would choose to see on a regular basis, the majority indicated this was their hospital consultant (146 [62.1%]). The reasons given were being confident in their knowledge and expertise, the specialist's familiarity with the individual's cancer and treatment, and ease of access. The choice of health care professional also was determined by their perceived qualities such as trust, mutual respect, approachability, empathy, ease of access, and the ability to act effectively on the individual's behalf.

Responses to the open-text questions indicated that the nature and quality of interactions

with health care professionals had an impact on how women coped with their situations. When the women established a good relationship with the health care professionals involved in their care, they felt respected and treated as an individual.

Thematic analysis of free-text questions relating to the experience of metastatic breast cancer revealed insights into some issues that are important to women living with progressive disease. The majority (162 [68.9%]) felt that their main source of psychological support was from family and friends, whereas a small number (33 [14%]) felt unable to burden those close to them, so spoke to no one. Those who received formal support services felt these were beneficial but a significant number did not know how to seek formal support.

Table 5  
Responses to Experience of Care Subscales for All Survey Respondents According to Place of Recruitment

Experience of Care	Cancer Centers (n = 110)	Web site (n = 125)	Total (n = 235)	†Test for Comparison of Place of Recruitment
				P-value
Mean (SD)				
Information and advice, % of positive responses out of 11 questions (range 0–100)	62.1 (22.4)	49.6 (24.8)	55.5 (24.5)	<0.001
Personal experience of care, % of positive responses out of 10 questions (range 0–100)	78.4 (28.1)	64.2 (31.7)	70.8 (30.9)	<0.001
Satisfaction with care, % positive responses out of 13 questions (range 0–100)	52.4 (37.9)	44.5 (39.1)	48.2 (38.7)	0.119
Overall rating of support received (range 1–10)	7.5 (1.9)	5.0 (2.4)	6.0 (2.4)	<0.001

Missing data for satisfaction with care (3), overall rating of support (43).

## Discussion

The women in this cross-sectional survey reflect the heterogeneity of women with metastatic breast cancer. One-half of the women had been living with metastatic disease for at least two years at the time they completed the survey and nearly one-third had metastatic disease to bone only, a clinical subgroup with disease that is known to behave more indolently and thus have a better prognosis. Therefore, although the women in this study had significant disease burden from a life-limiting illness, few were necessarily at the end-of-life stage of illness.

Our findings unsurprisingly show that the overall QoL of women with metastatic breast cancer is poor. Low scores were seen uniformly across all domains of the FACT-B instrument, reflecting the impact of disease and treatment on all aspects of daily life. Scores appeared to be influenced by women's age and whether or not they had children. Younger age was associated with poorer social well-being and having children was associated with worse functional well-being. Although we were unable to determine the association between these two variables, it could be considered that younger women are more likely to have aggressive disease and sequential treatments, and may struggle to maintain their social roles, particularly in caring for children. This may be a subgroup of women with breast cancer who need particular attention.

Just over one-third of women indicated that they were experiencing significant pain, and among women with bone metastases, nearly one-half reported significant levels of pain, suggesting that symptom control was inadequate. Given that these women were in regular contact

with the cancer centers where there was also ready access to specialist palliative care services, it would appear that women are not currently accessing the support they need.

We hypothesized that those with visceral disease would be more likely to have chemotherapy, have a greater disease burden, and be more likely to have uncontrolled pain and other symptoms. Therefore, the finding that those with bone metastases and no visceral disease were more likely to have uncontrolled pain is interesting and significant. There was some indication that those with bone metastases only had poorer experiences of care but these findings only bordered on significance; further research comparing site of metastatic spread and experience of care is needed. A possible explanation for these findings is that in contrast to those with visceral disease, who may be more likely to have chemotherapy and regular follow-up, those presenting with bone metastases alone are managed conservatively, commonly with hormonal therapy and bisphosphonates, and thus may be seen less regularly by the clinical team than those receiving chemotherapy; this would result in fewer opportunities to seek information, support, or symptom control. Again, this may be a subgroup with specific unmet needs that are not addressed within the current service provision.

The experience of care of women who participated in this study compared unfavorably with that reported by patients receiving treatment for advanced lung cancer,<sup>16</sup> albeit in the context of a randomized controlled trial comparing nurse-led follow-up with conventional clinic follow-up.

It appears from this survey that, for women with metastatic breast cancer, their main

Table 6  
Results of Univariate Analyses of Associations Between Demographic/Clinical Characteristics and Experience With Care Subscales for All 235 Survey Respondents

Characteristic	Information and Advice	Personal Experience of Care	Satisfaction with Care	Overall Rating of Support Received	Do You Feel Well Supported at the Moment?
	Mean (SD), % Positive Responses Out of 11 Questions	Mean (SD), % Positive Responses Out of 10 Questions	Mean (SD), % Positive Responses Out of 13 Questions	Mean (SD)	n (%) Responding "Yes"
Age (years)	<i>P</i> = 0.01	<i>P</i> = 0.001	<i>P</i> = 0.25	<i>P</i> < 0.001	<i>P</i> = 0.003
25–44	53.7 (24.6)	65.2 (30.3)	47.8 (39.0)	5.3 (2.4)	36 (65.5)
45–54	52.4 (25.1)	65.2 (34.4)	45.4 (38.6)	5.6 (2.7)	56 (70.0)
55–64	53.7 (22.8)	75.8 (27.1)	46.0 (37.7)	6.2 (2.3)	40 (80.0)
≥65	66.9 (22.3)	83.1 (24.8)	57.9 (39.3)	7.5 (1.9)	37 (90.2)
Marital status	<i>P</i> = 0.73	<i>P</i> = 0.76	<i>P</i> = 0.64	<i>P</i> = 0.84	<i>P</i> = 0.82
In relationship	55.8 (23.9)	71.3 (30.2)	47.8 (37.5)	5.9 (2.4)	123 (74.1)
Not in relationship	54.5 (26.5)	69.9 (33.1)	50.6 (41.8)	5.9 (2.9)	43 (76.8)
Children	<i>P</i> = 0.26	<i>P</i> = 0.04	<i>P</i> = 0.01	<i>P</i> = 0.24	<i>P</i> = 0.08
None	59.4 (22.6)	80.1 (24.1)	61.6 (38.6)	6.3 (2.7)	38 (86.4)
≥1	54.9 (24.6)	69.5 (31.9)	45.7 (38.1)	5.8 (2.4)	121 (72.0)
Townsend deprivation index quintile	<i>P</i> = 0.68	<i>P</i> = 0.08	<i>P</i> = 0.26	<i>P</i> = 0.51	<i>P</i> = 0.72
1 = Most deprived	55.4 (25.9)	61.3 (35.4)	44.2 (41.7)	6.0 (3.0)	28 (73.7)
2	60.0 (23.7)	79.7 (25.7)	55.1 (39.2)	5.9 (2.7)	30 (85.7)
3	52.3 (21.2)	70.0 (32.5)	45.5 (35.3)	6.1 (2.2)	27 (69.2)
4	52.3 (26.5)	64.5 (31.8)	43.0 (38.8)	5.9 (2.4)	29 (74.4)
5 = Least deprived	62.0 (21.5)	82.6 (22.6)	61.9 (36.2)	6.6 (2.4)	27 (75.0)
Time since diagnosis of metastases	<i>P</i> = 0.10	<i>P</i> = 0.20	<i>P</i> = 0.04	<i>P</i> = 0.19	<i>P</i> = 0.50
<6 months	53.0 (23.1)	69.9 (31.6)	43.6 (35.5)	5.8 (2.3)	46 (75.4)
6–12 months	51.7 (27.2)	63.8 (33.9)	42.1 (39.0)	5.5 (2.5)	31 (73.8)
1–2 years	57.9 (24.0)	72.8 (29.8)	49.1 (41.2)	5.8 (2.6)	41 (66.1)
>2 years	58.8 (23.7)	75.0 (28.8)	56.9 (37.9)	6.5 (2.5)	51 (83.6)
Site of spread	<i>P</i> = 0.01	<i>P</i> = 0.13	<i>P</i> = 0.03	<i>P</i> = 0.04	<i>P</i> = 0.07
Bone only	49.8 (27.7)	66.4 (33.7)	40.1 (39.8)	5.4 (2.7)	50 (66.7)
Other	58.4 (22.2)	73.0 (29.4)	52.3 (37.5)	6.2 (2.4)	119 (78.8)
Place of recruitment	<i>P</i> < 0.001	<i>P</i> < 0.001	<i>P</i> = 0.17	<i>P</i> < 0.001	<i>P</i> < 0.001
Center 1	60.2 (21.5)	78.5 (28.0)	49.6 (36.7)	7.2 (2.0)	62 (89.9)
Center 2	65.7 (23.9)	78.3 (28.9)	57.8 (40.1)	7.7 (1.9)	31 (88.6)
Web site	49.6 (24.8)	64.2 (31.7)	44.5 (39.1)	5.0 (2.4)	76 (61.8)

*P*-values for information and advice, personal experience of care, satisfaction with care, and overall rating of support correspond to *F*-test from analysis of variance (trend test for age, Townsend index, and time since diagnosis).

interaction with the health system is with their specialist oncologist. Few participants cited palliative care services or their GPs as the health care professional they would choose to see regularly. These findings are consistent with a previous study describing the care received by women with breast cancer during the last six months of life, which found little evidence of GP or palliative care service involvement with these women, even when the patient was nearing death. The authors surmised that a low rate of deaths at home and a high rate of emergency admissions and subsequent deaths in acute care beds occurred as a result of care being delivered predominantly by hospital-based specialists in outpatient clinics.<sup>17</sup>

A possible explanation for the apparent lack of symptom management in our study may be that women with metastatic breast cancer are being actively treated throughout their illness trajectory. Therefore, they are either not referred to palliative care services or are themselves reluctant to access palliative care services, associating these with end-of-life care.

## Conclusion

The findings from this study highlight that the multidimensional problems and needs of those living with progressive breast cancer are largely unmet. Living with metastatic breast

cancer challenges the personal resources of the individual and poses interesting questions about how health care professionals provide information, effective symptom control, and emotional and practical support to women with a significant disease burden—where the illness trajectory is becoming increasingly unpredictable and complex because of life-prolonging treatment and who may not be receiving support from palliative care services. We surmise that although much has been done to improve survival, insufficient attention has been paid to the well-being of those living with metastatic breast cancer. These findings suggest that the quality of care for women with metastatic breast cancer has not kept pace with the development of life-prolonging treatments although further research specifically exploring this is needed. Improvements in symptom control, psychosocial support, and information provision for women with metastatic breast cancer may improve their health and well-being and their experience of care.

In the U.K., breast cancer clinical nurse specialists provide care for women from the point of diagnosis through their treatment and survivorship. However, provision of breast care nursing for women with metastatic breast cancer is currently inadequate.<sup>18</sup> Core competencies and standards of care have been identified to assist in the development of support services for women with metastatic breast cancer.<sup>19</sup> Although there is national guidance in the palliative and supportive care of those with advanced cancer,<sup>20</sup> clearly these services are not currently meeting the needs of this population, and palliative care services need to consider novel means of identifying those with metastatic breast cancer and ways in which they can work more closely with oncology services to address unmet needs.

Longitudinal data exploring QoL and experience of care over time is needed to build a more detailed picture of the challenges of living with metastatic breast cancer. Further research is required to explore whether alternative models of service delivery can result in improvements in QoL and experience of care. Further research also is needed exploring the relationship of site of metastatic disease with QoL and experience of care.

### *Limitations*

The study is limited to insights gained from women at a single time point in the course of their metastatic disease and, therefore, cannot reflect the variability in QoL and experience of care that individuals may go through during the course of their illness. Although neither the cancer center nor the online participants can be said to be representative of all those with metastatic breast cancer, recruitment of women via the Web site enabled us to collect information from a group who were being treated in a variety of different settings, including women who may not have been attending hospital follow-up. However, we acknowledge that it was reliant on self-reported disease and treatment information and may have been subject to ascertainment bias and the volunteer effect. Data were equivalent for the two sources of women, although a younger and less socially deprived group of women responded to the online version of the survey. As the use of online surveys become increasingly popular, future research is needed to explore whether face-to-face and online surveys yield equivalent findings.

It is not currently possible to derive population numbers through cancer registries, which would have allowed us to access a diverse population of women with metastatic breast cancer in the U.K.

Despite these caveats, we feel that this study reflects the experience of many women receiving treatment for metastatic breast cancer in the U.K.

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