The prevalence of unmet needs in 625 women living beyond a diagnosis of early breast cancer

Marta Capelan[1], Nicolò Matteo Luca Battisti[1], Anne McLoughlin[1], Vivienne Maidens[1], Nikki Snuggs[1], Patrycja Slyk[1], Clare Peckitt[2] and Alistair Ring*,[1]

[1]Breast Unit, The Royal Marsden Hospital, NHS Foundation Trust, Sutton, Surrey SM2 5PT, UK and [2]Research and Development, The Royal Marsden Hospital, NHS Foundation Trust, Sutton, Surrey SM2 5PT, UK

Background: There are over half a million women with a previous breast cancer diagnosis living in the UK. It is important to establish their level of unmet physical and psychosocial needs, as many are not routinely seen for follow-up under current models of care.

Methods: We conducted a retrospective analysis of early breast cancer survivors entering an Open Access Follow-Up (OAFU) programme in 2015. Unmet needs were assessed using the Holistic Needs Assessment (HNA) or extracted directly from the electronic patient record (EPR), when the HNA had not been completed.

Results: Six hundred and twenty-five patients were eligible. Sixty-one per cent of the survivors had at least one unmet need and 18% had $\geqslant 5$ needs. Consistently higher levels of unmet needs were identified using the formal HNA checklist as opposed to extraction from EPR ($P < 0.001$). Physical and emotional needs were the most frequently reported (55 and 24% respectively). Patients receiving endocrine therapy and those who had received chemotherapy were more likely to report unmet needs (both $P < 0.001$).

Conclusions: Unmet physical and emotional needs are common in breast cancer survivors. It is vital that the services are available for these patients as they transition from hospital-based follow-up to patient-led self-management models of care.

Breast cancer is the most commonly diagnosed cancer among women and the high survival rate for early stage disease means that breast cancer survivors represent the largest population of cancer survivors worldwide (Benson *et al*, 2009; DeSantis *et al*, 2014; Siegel *et al*, 2014). In 2010, there were estimated to be 570 000 female breast cancer survivors in the UK, and this is projected to reach nearly 1.7 million by 2040 (Maddams *et al*, 2012).

Many women may adjust well after completing initial treatment such as surgery, chemotherapy, radiotherapy and biological treatment for early breast cancer. However, this is not inevitably the case, and women can be at risk from a wide range of long-term physical and psychosocial effects following their diagnosis and

treatment (Kornblith *et al*, 2003; Hodgkinson *et al*, 2007; Ganz and Hahn, 2008; Armes *et al*, 2009; Harrington *et al*, 2010; Harrison *et al*, 2011; Valdivieso *et al*, 2012; Burg *et al*, 2015). In the UK current health policy advocates a shift away from routine follow-up of cancer survivors and a greater emphasis on individualised needs, promotion of recovery, health and well-being (Department of Health, 2011; Richards *et al*, 2011). Several randomised studies have shown that open access follow-up appointments are a feasible alternative to routine hospital-based follow-up among breast cancer survivors (Grunfeld, 2009; Kirshbaum *et al*, 2017). As a result many UK breast units have adopted follow-up services that are patient-led, enabling quick access to clinical teams as needed;

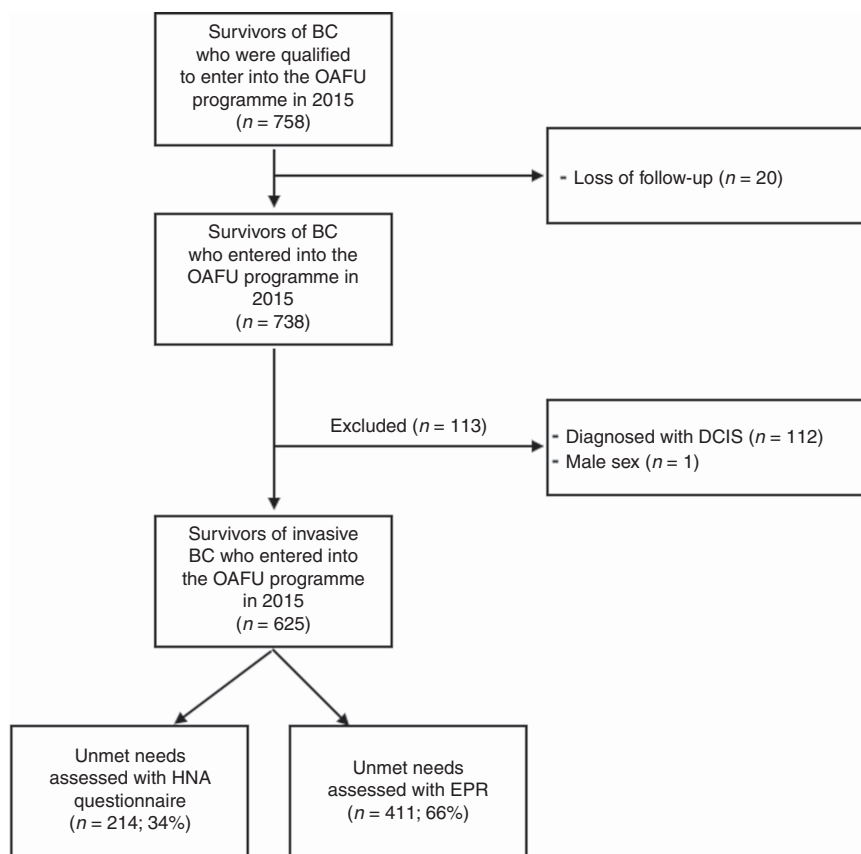*Correspondence: Dr A Ring; E-mail: Alistair.Ring@rmh.nhs.uk

Figure 1. Consort diagram of survivors of BC who entered into the OAFU programme in 2015.

instead of routine follow-up hospital appointments. These types of follow-up, such as the Open Access Follow-Up (OAFU) system used at our institution, are based on a principle of supported self-management.

Patients enter the OAFU programme after completion of the hospital-based treatment (surgery, radiotherapy and chemotherapy). They undergo a consultation with an advanced nurse practitioner regarding long-term treatment-related effects, duration of endocrine therapy, education about healthy life styles, breast cancer awareness and symptoms of recurrence. As part of this assessment patients are asked to complete a holistic needs assessment (HNA) using a formalised questionnaire/checklist to evaluate the whole person's needs including physical, emotional, family, practical, spiritual needs (Supplementary online Material). This form is sent to all patients by post 2 weeks before the OAFU consultation as part of it and it is required to be completed prior to the consultation. The HNA is an opportunity for the patients to reflect on his/her needs, and then discuss them at the time of the consultation. Holistic needs assessment is a process of gathering and discussing information with the patient in order to develop an understanding of what the person living with and beyond cancer knows, understands and needs. Moreover, holistic needs assessment helps to tailor an individualised care planning and therefore set up early interventions, with onward referral to relevant support services (such as psychological support, physiotherapy or dieticians). A discharge summary, which includes patient's unmet needs and her care planning, is created by the nurse practitioner at the end of the OAFU consultation and sent to the patient's general practitioner.

In order to optimise this service and to adapt it to the needs of our patient population we have conducted a service evaluation to describe the unmet needs of patients as they transition to supported self-management. The primary objective of this study

was therefore to estimate the prevalence of unmet needs in breast cancer survivors entering the OAFU programme. As secondary objectives we aimed to describe the nature of the unmet needs, and what factors might identify those patients at highest risk of having unmet needs at completion of hospital-based treatment.

MATERIALS AND METHODS

The population studied in this analysis were women with a previous diagnosis of early (stages I–III) breast cancer who had completed their initial treatment (surgery, chemotherapy, radiotherapy) and entered into the OAFU programme at the Royal Marsden Hospital (RMH) NHS Foundation Trust from 1 January to 31 December 2015. The catchment area of the RMH corresponds to central and South-West of London. Survivors of breast cancer who were followed up in clinical trials were not qualified to enter into the OAFU programme. Women with ductal carcinoma in situ, i.e., with no invasive cancer, men and women with invasive breast cancer who were lost before the OAFU appointment were excluded from this analysis (Figure 1).

Patient characteristics, tumour and treatment characteristic were collected from the electronic patient record (EPR). These included: age, menopausal status, race, marital status, working status, comorbidities according to Charlston scale, use of antidepressants, stage, hormone receptor status, human epidermal growth factor receptor 2-status, type of surgery, type of chemotherapy, endocrine therapy, radiotherapy and time from diagnosis to OAFU consultation.

Unmet needs were assessed using the formalised London HNA questionnaire (Holistic Needs Assessment, 2016; Supplementary online material), which was sent to all patients 2 weeks before the OAFU consultation. When the HNA had not been completed prior

Table 1. Patients' demographics, tumour and treatment characteristics				
Characteristics	Unmet needs using HNA form n (%)	Unmet needs using EPR n (%)	Total n (%)	P-value
Total breast cancer survivors	214 (34)	411 (66)	625 (100)	
Patient characteristics				
Age				
Median	62	58	59	
Range	30–97	27–92	27–97	
SD	12	13	13	P = 0.092
<40-year-old	6 (3)	24 (6)	30 (5)	
⩾40-year-old	208 (97)	387(94)	595 (95)	
Menopausal status				
Premenopausal	55 (26)	123 (30)	178 (28)	P = 0.267
Postmenopausal	159 (74)	288 (70)	447 (72)	
Race				
Caucasian	191 (89)	365 (89)	556 (89)	P = 0.674
Asian	16 (8)	27 (6)	43 (7)	
Black	7 (3)	19 (5)	26 (4)	
Marital status				
Single	16 (8)	45 (11)	61 (10)	P = 0.777
Married/ with partner	119 (55)	225 (55)	344 (55)	
Divorced	20 (9)	40 (10)	60 (9)	
Widow	21(10)	29 (7)	50 (8)	
Not reported	38 (18)	72 (17)	110 (18)	
Working status				
Working	87 (41)	178 (44)	265 (42)	P = 0.474
Not working	95 (44)	170 (41)	265 (42)	
Not reported	32(15)	63 (15)	95 (16)	
Living with				
Alone	56 (26)	98 (24)	154 (25)	P = 0.474
With someone	137 (64)	276 (67)	413 (66)	
Not reported	21 (10)	37 (9)	58 (9)	
Comorbidities				
Yes	29 (14)	56 (14)	85 (14)	P = 0.980
No	185 (86)	355 (86)	540 (86)	
Use of antidepressants				
Yes	13 (6)	33 (8)	46 (7)	P = 0.375
No	201 (94)	378 (92)	579 (93)	
Previous invasive cancer				
Yes	24 (11)	47 (11)	71 (11)	P = 0.934
No	190 (89)	364 (89)	554 (89)	
Time from diagnoses to OAFU				
< 12 months	162 (76)	266 (65)	428 (68)	P = 0.005
⩾ 12 months	52 (24)	145 (35)	197 (32)	
Median time from diagnosis to OAFU	8 months	9.5 months	8.9 months	P = 0.005
Tumour and treatment characteristics				
Stage				
I	80 (37)	136 (33)	216 (35)	
II	115 (54)	238 (58)	353 (56)	p = 0.615
III	19 (9)	37 (9)	56 (9)	
Hormone receptor status				
Positive	175 (82)	341 (83)	516 (83)	P = 0.709
Negative	39 (18)	70 (17)	109 (17)	
HER2- status				
Positive	27 (13)	64 (16)	91 (15)	P = 0.320
Negative	187 (87)	347 (84)	534 (85)	
Surgery				
Mastectomy	53 (25)	140 (34)	193 (31)	P = 0.017
Wide local excision	161 (75)	271 (66)	432 (69)	
Axillary clearance				
Yes	41 (19)	95 (24)	136 (22)	P = 0.230
No (SLNB)	172 (80)	310 (75)	482 (77)	
Not done	1 (1)	6 (1)	7(1)	
Chemotherapy				
Yes	91 (42)	170 (41)	261 (42)	P = 0.780
No	123 (58)	241 (59)	364 (58)	

Table 1. (Continued)

Characteristics	Unmet needs using HNA form n (%)	Unmet needs using EPR n (%)	Total n (%)	P-value
Taxanes				
Yes	60 (28)	132 (32)	192 (31)	$P = 0.294$
No	154 (72)	279 (68)	433 (69)	
Trastuzumab				
Yes	20 (9)	50 (12)	70 (11)	$P = 0.289$
No	194 (91)	361 (88)	555 (89)	
Endocrine treatment				
Yes	172 (80)	332 (81)	504 (81)	$P = 0.903$
No	42 (20)	79 (19)	121 (19)	
Type of endocrine treatment				
Tamoxifen	53 (25)	107 (26)	160 (26)	$P = 0.903$
Aromatase inh	113 (53)	212 (51)	325 (52)	
Goserelin + Tam	3 (1)	11 (3)	14 (2)	
Goserelin + AI	3 (1)	2 (1)	5 (1)	
No hormonal treatment	42 (20)	79 (19)	121 (19)	

Abbreviations: AI = aromatase inhibitors; EPR = Electronic Patient Record; HER2 = human epidermal growth factor receptor 2; HNA = Holistic Needs Assessment; OAFU = Open Access Follow-Up; SLNB = sentil lymph node biopsy; Tam = tamoxifen.

to the consultation, unmet needs were extracted directly from the EPR at the time of consultation.

Statistical analysis was performed using the Stata 14 program. Chi-squared tests were used to compare clinical and social factors between subjects whose unmet needs were captured from EPR or HNA. Univariate logistic regression analysis were performed to assess clinical and social factors associated with having or not unmet needs. Factors analysed included age, menopausal status, married status, working status, living status, comorbidities, use of antidepressant, underwent mastectomy, axillary clearance, chemotherapy, endocrine treatment were coded as a binary variable and time from diagnoses to OAFU as a continuous variable. Multivariate logistic regression analysis were performed to assess independence of any significant ($P < 0.05$) univariate factors.

This study was approved by the Royal Marsden Hospital Committee for Clinical Research as a Service Evaluation (utilising routinely collected data and not requiring written informed consent).

RESULTS

A total of 738 patients entered the OAFU programme in the 12 months studied, and 625 were eligible for this study (Figure 1). The median age of patients was 59 years old (range: 27–97). The median time from diagnosis to assessment at OAFU was 8.9 months with an interquartile range from 6.3 to 13.6 months (Table 1).

Unmet needs were identified in 214 (34%) breast cancer survivors from an HNA questionnaire and in 411 (66%) direct from EPR at the time of OAFU consultation (where the HNA had not been completed prior to the consultation). Demographics, tumour and treatment characteristics were not statistically different between the two groups apart from the type of surgery ($P = 0.02$) and the time from diagnosis to OAFU consultation ($P = 0.005$).

Unmet needs were categorised in three different groups: 0 needs, 1–4 needs, and ⩾5 needs. Over 60% (61%) of the survivors have at least one need and 18% have ⩾5 unmet needs. Consistently higher levels of unmet needs were identified using the HNA as opposed to extraction from EPR (Table 2). In the light of this observation we conducted a multivariate analysis (incorporating age, menopausal status, social situation, co-morbidities, treatments received and time from diagnosis to OAFU) to evaluate factors associated with completion of an HNA prior to return to

Table 2. Frequency of unmet needs evaluated using either HNA or EPR

	Unmet needs evaluated using HNA n (%)	Unmet needs evaluated using EPR n (%)	Total n (%)	P-value
Total patients	214	411	625	
No needs	34 (16)	208 (51)	242 (39)	$P < 0.001$
1–4 needs	72 (34)	199 (48)	271 (43)	
⩾5 needs	108 (50)	4 (1)	112 (18)	

Abbreviations: EPR = Electronic Patient Record; HNA = Holistic Needs Assessment.

OAFU. The two independent factors associated with completing HNA checklist were age 50 years or older and those who entered into the OAFU programme within 12 months of diagnosis ($P = 0.032$ and $P = 0.019$, respectively).

We classified the unmet needs in five different categories— practical, family, emotional, spiritual and physical needs – aligned to the HNA checklist questionnaire (Supplementary Online Material). Physical and emotional needs were the most frequently reported (55 and 24%, respectively). Practical, family and spiritual needs were reported in less than 10% (6, 5 and 4%, respectively) (Table 3). Unmet needs were more frequently identified using HNA assessment than extraction from EPR, for example: physical needs: 79 vs 43% ($P < 0.001$), emotional needs: 50 vs 10% ($P < 0.001$) (Table 3). The most frequently reported unmet needs are shown in Figure 2.

We conducted a multivariate analysis to examine which factors might be associated with patients with higher levels of unmet needs (Table 4). The model used included age, married status, working status, menopausal status, antidepressant use, comorbidities and treatment received. Receipt of endocrine therapy and chemotherapy were the only significant independent factors associated with having ⩾1 unmet needs vs no needs (Table 4).

General recommendations regarding healthy diet, exercise and alcohol consumption were given in 225 survivors (36%). Healthy diet and exercise recommendations were equally given to 30 and 29%, respectively. Alcohol consumption recommendation was only given in 10% of the survivors. In addition, referrals to acupuncture were made in 62 breast cancer survivors (10%), to treat different symptoms, such as hot flushes (9%), fatigue (3%) and pain (3%).

Table 3. Frequency of specific unmet needs

Categories of unmet needs	Unmet needs using HNA n (%)	Unmet needs using EPR n (%)	Total unmet needs n (%)	P-value
Total patients	214	411	625	
Physical	168 (79)	175 (43)	343 (55)	P<0.001
Hot flushes	88 (41)	55 (14)	143 (23)	P<0.001
Fatigue	91 (43)	38 (9)	129 (21)	P<0.001
Pain	62 (29)	58 (14)	120 (19)	P<0.001
Sleep problems	74 (35)	14 (3)	88 (14)	P<0.001
Dry, itchy or sore skin	52 (24)	16 (4)	68 (11)	P<0.001
Tingling in hands or feet	52 (24)	18 (4)	70 (11)	P<0.001
Changes in weight	47 (22)	14 (3)	61 (10)	P<0.001
Feeling swollen	31 (15)	16 (4)	47 (8)	P<0.001
Other medical condition	40 (19)	7 (2)	47 (8)	P<0.001
Moving around or walking	42 (20)	3 (1)	45 (7)	P<0.001
Constipation or diarrhoea	27 (13)	4 (1)	31 (5)	P<0.001
Cough	30 (14)	3 (1)	33 (5)	P<0.001
Breathless	31 (14)	3 (1)	34 (5)	P<0.001
Wound care	13 (6)	9 (2)	22 (4)	P<0.012
Indigestion	24 (11)	2 (1)	26 (4)	P<0.001
Changes in eating or appetite	22 (10)	1 (1)	23 (4)	P<0.001
Personal appearance	23 (11)	2 (1)	25 (4)	P<0.001
Sore or dry mouth	25 (12)	1 (1)	26 (4)	P<0.001
Nauseas or vomiting	13 (6)	3 (1)	16 (3)	P<0.001
Communication	10 (5)	0 (0)	10 (2)	P<0.001
Changes in taste	14 (7)	1 (1)	15 (2)	P<0.001
Passing urine	8 (4)	0 (0)	8 (1)	P<0.001
High temperature	5 (2)	0 (0)	5 (1)	P<0.002
Emotional	107 (50)	40 (10)	147 (24)	P<0.001
Worry, fear or anxiety	76 (36)	24 (6)	100 (16)	P<0.001
Sadness or depression	48 (22)	17 (4)	65 (10)	P<0.001
Memories or concentration problems	57 (27)	4 (1)	61 (10)	P<0.001
Anger, frustration or guilt	39 (18)	2 (1)	41 (7)	P<0.001
Sexual concerns	19 (9)	5 (1)	24 (4)	P<0.001
Loneliness or isolation	22 (10)	1 (1)	23 (4)	P=0.001
Hopeless	7 (3)	1 (1)	8 (1)	P<0.001
Practical	36 (17)	1 (1)	37 (6)	P<0.001
Work or education	21 (10)	0 (0)	21 (3)	P<0.001
Making plans	20 (9)	0 (0)	20 (3)	P<0.001
Housing or finances	16 (8)	0 (0)	16 (3)	P<0.001
Caring responsibilities	14 (7)	1 (1)	15 (2)	P<0.001
Laundry or housework	11 (5)	0 (0)	11 (2)	P<0.001
Grocery or shopping	7 (3)	0 (0)	7 (1)	P<0.001
Information needs	9 (4)	0 (0)	9 (1)	P<0.001
Transport and parking	6 (3)	0 (0)	6 (1)	P<0.001
Preparing food	6 (3)	0 (0)	6 (1)	P<0.001
Bathing and dressing	4 (2)	0 (0)	4 (1)	P<0.001
Family	26 (12)	5 (1)	31 (5)	P<0.001
Relation with children	14 (7)	2 (1)	16 (3)	P<0.001
Relation with partner	11 (5)	2 (1)	13 (2)	P<0.001
Relation with others	10 (5)	1 (1)	11 (2)	P<0.001
Spiritual	25 (12)	1 (1)	26 (4)	P<0.001
Loss of meaning or purpose on life	13 (6)	4 (1)	17 (3)	P<0.001
Regret about the past	15 (7)	0 (0)	15 (2)	P<0.001
Loss of faith or other spiritual concern	3 (1)	0 (0)	3 (1)	P<0.001

Abbreviations: EPR = Electronic Patient Record; HNA = Holistic Needs Assessment.

DISCUSSION

It is well-recognised that cancer survivors may experience long-term or late-effects related to the diagnosis and treatment of their cancer (Kornblith *et al*, 2003; Hodgkinson *et al*, 2007; Ganz and Hahn, 2008; Armes *et al*, 2009; Harrington *et al*, 2010; Harrison *et al*, 2011; Valdivieso *et al*, 2012; Burg *et al*, 2015). The main aim of this study was to determine the prevalence of unmet needs

women who had had previous treatment (with curative intent) for early stage breast cancer. The impetus to do this came from the changes in model of care in the UK, which mean that in many breast units these women are not being seen for regular follow-up.

Our results showed that over 60% of the survivors had at least one unmet need, and 18% of patients had at least five unmet needs. Needs were coded in three different categories: 0 needs, 1–4 needs and ⩾5 needs to be consistent with previous studies (Armes *et al*, 2009). Similar studies assessing unmet needs in survivors found
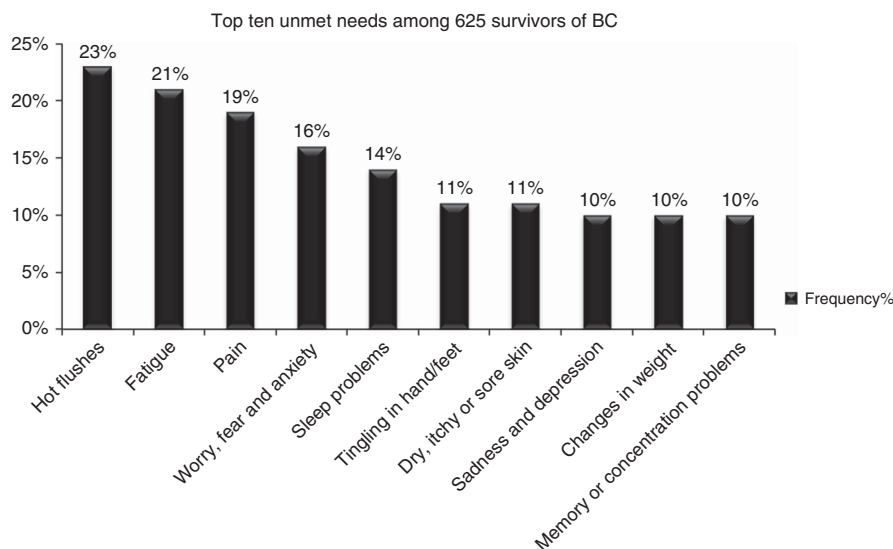
Figure 2. Top ten most frequent unmet needs among 625 survivors of BC (frequency $\geqslant$ 10%).

that 40–60% of survivors of all of type of cancer had a least one unmet need (Armes *et al*, 2009; Harrison *et al*, 2011; Burg *et al*, 2015; Hubbard *et al*, 2015). In a study conducted by Armes *et al*, in 1425 cancer survivors (including 801 with breast cancer) 34% experienced $\geqslant$5 unmet needs (Armes *et al*, 2009). It is not possible to compare between these studies, as the methods of ascertainment are different; nonetheless, it is clear that a significant proportion of breast cancer survivors have multiple unmet needs. Several studies have also shown that breast cancer survivors reported more unmet needs than other cancer survivors (Harrison *et al*, 2011; Burg *et al*, 2015). Women who had had previous chemotherapy or endocrine therapy were most likely to report unmet needs, most likely as a result of the attendant toxicities of these treatments.

Physical needs were the most commonly reported followed by emotional needs (55 and 24%, respectively), which is consistent with data published by the American Society of Clinical Oncology (ASCO) and other sources which report that 40% survivors experienced at least one physical need and 29% at least one emotional need (Burg *et al*, 2015). Hewitt *et al* (2007) reported that cancer survivors often reported that their medical needs are met, but psychological needs remain unaddressed. Likewise, in several studies conducted specifically among breast cancer survivors emotional needs such as fear of recurrence and anxiety were the most commonly frequently reported (Armes *et al*, 2009; Harrison *et al*, 2011).

The two most commonly reported unmet needs were: hot flushes (23%) and fatigue (21%). Hot flushes and other menopausal symptoms are a well-recognised problem in breast cancer survivors (Shapiro and Recht, 2001; Murthy and Chamberlain, 2012; Marino *et al*, 2014). However, it is also well-recognised that a variety of interventions, including behavioural, pharmacological and complementary may ameliorate these symptoms (Mao *et al*, 2015; Wiśniewska *et al*, 2016). Therefore it is important that proactive management of these symptoms be offered and be available to patients who are no longer being seen in secondary care. Fatigue is an unmet challenge in breast cancer survivors, and the results from this analysis are consistent with data published by Bower *et al* where 25–30% survivors of breast cancer reported cancer-related fatigue (Bower *et al*, 2014). As for menopausal symptoms, some interventions may help with cancer-related fatigue, and it is important that patients have access to support and advice (Capelan and Kingston, 2016). In our study, recommendations regarding exercise and acupuncture to manage cancer-related fatigue were

made in 43 (7%) and 16 (3%), respectively. In addition, general recommendations regarding healthy life styles including exercise, healthy diet and alcohol cessation were given in 225 (36%) of breast cancer survivors. Taking into account the impact that healthy life style changes have in cancer survivors, we are aware that more consistent advice and support should be given in the future (Runowicz *et al*, 2016).

Unmet needs were more likely to be detected when patients were assessed using the HNA as opposed extraction from EPR. This observation might be explained by the fact that having a formalised checklist that patients can complete at their leisure might lead to higher levels of reporting than in a face-to-face consultation and enable patients to self-reflect on their needs and concerns. In addition, the HNA questionnaire includes spiritual, family and practical needs, such as work and finances, that are not generally assessed by health professionals. This also might be partly explained by the fact that patients having an HNA assessment were more likely to undergo that assessment within 12 months of diagnosis (76 *vs* 65% for EPR extraction, $P = 0.005$). Nonetheless all patients undergoing assessment had of course completed their treatment at the time of this assessment, and in univariate analysis of needs *vs* no needs, there was no difference in the proportion of patients reporting needs between those who were assessed at less than 12 months or more than 12 months. The significance of the higher rate of ascertainment with HNA is unknown. However, evidence suggests that the HNA contributes to a better identification of a cancer survivors' needs which helps to tailor an individualised care planning and therefore set up early interventions (Richards *et al*, 2011). An electronic HNA (eHNA) has also been developed and piloted in four sites in UK. The benefits of this are an increase in the number of HNA completed compared to paper-based HNA, more rapid data processing, audit and analysis and the potential ability to share reproducible outcome data sets across cancer units and centres (Macmillan Cancer Support, 2013).

The main limitation of this study is its retrospective nature. There is a risk of bias with those patients completing HNA potentially being selected for those with more needs. Furthermore, some patients (either by HNA or EPR) may under or over-report symptoms. In addition, we were unable to assess the severity of unmet needs and whether they were present before the diagnosis of breast cancer. In the absence of longitudinal data, it is also not clear from this study, to what extent the needs reported may resolve over time.

Table 4. Variables associated with ⩾1 unmet needs (univariate and multivariate analyisis)

Variable	Total	Number ⩾1 need	%	Univariate			Multivariate		
				OR	OR 95% CI	*P*-value	OR	OR 95% CI	*P*-value
Age									
<50	114	67	59	1.14	0.75–1.72	0.543	NA	NA	NA
⩾50	551	316	62						
Married									
N	171	100	58	1.13	0.78–1.64	0.532	NA	NA	NA
Y	334	211	61						
Working									
N	265	151	57	1.33	0.94–1.88	0.110	NA	NA	NA
Y	265	169	64						
Living alone									
N	413	245	59	1.20	0.82–1.76	0.350	NA	NA	NA
Y	154	98	64						
Comorbidities									
N	540	330	61	0.95	0.59–1.52	0.827	NA	NA	NA
Y	85	53	62						
Antidepressants									
N	579	350	60	0.60	0.31–1.17	0.134	NA	NA	NA
Y	46	33	72						
Menopause status									
Pre	178	115	65	0.82	0.57–1.18	0.282	NA	NA	NA
Post	447	268	60						
Mastectomy									
N	432	257	59	1.28	0.90–1.82	0.170	NA	NA	NA
Y	193	126	65						
Axillary clearance									
N	482	293	61	1.18	0.80–1.76	0.407	NA	NA	NA
Y	136	88	65						
Chemotherapy									
N	364	205	56	0.60	0.43–0.84	0.003	0.50	0.35–0.71	*P*<0.001
Y	261	178	68						
Endocrine treatment alone									
N	121	60	50	0.55	0.37–0.82	0.004	0.44	0.29–0.67	*P*<0.001
Y	504	323	64						
Radiotherapy									
N	105	61	58	0.85	0.56–1.31	0.463	NA	NA	NA
Y	520	322	62						
Time from diagnosis to OAFU									
<12 months	428	264	62	0.95	0.67–1.34	0.761	NA	NA	NA
⩾12 months	197	119	60						
Abbreviations: CI = confidence interval; OAFU = Open Access Follow-Up; OR = odds ratio.									

Irrespective it is clear that a significant proportion of women with a previous diagnosis of early breast cancer have a number of unmet needs as they move from hospital follow-up to patient-self self-management in an Open Access Follow-up programme. Those women at particular risk are those who have had chemotherapy or are receiving endocrine therapy, as reported in other studies (Armes *et al*, 2009). It is vitally important, that women coming to the end of their hospital-based routine follow-up have their needs assessed, ideally with a structured tool such as the HNA or eHNA. It is equally important that where unmet needs are found, women are empowered to access help and expertise and resources should be available to help them.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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