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## Patients' Supportive Care Needs Beyond the End of Cancer Treatment: A Prospective, Longitudinal Survey

Jo Armes, Maggie Crowe, Lynne Colbourne, Helen Morgan, Trevor Murrells, Catherine Oakley, Nigel Palmer, Emma Ream, Annie Young, and Alison Richardson

#### A B S T R A C 1

## **Purpose**

To estimate prevalence and severity of patients' self-perceived supportive care needs in the immediate post-treatment phase and identify predictors of unmet need.

#### **Patients and Methods**

A multicenter, prospective, longitudinal survey was conducted. Sixty-six centers recruited patients for 12 weeks. Patients receiving treatment for the following cancers were recruited: breast, prostate, colorectal, and gynecologic cancer and non-Hodgkin's lymphoma. Measures of supportive care needs, anxiety and depression, fear of recurrence, and positive and negative affect were completed at the end of treatment (T0) and 6 months later (T1).

#### Results

Of 1,850 patients given questionnaire packs, 1,425 (79%) returned questionnaires at T0, and 1,152 (62%) returned questionnaires at T1. Mean age was 61 years; and most respondents were female (69%) and had breast cancer (57%). Most patients had no or few moderate or severe unmet supportive care needs. However, 30% reported more than five unmet needs at baseline, and for 60% of these patients, the situation did not improve. At both assessments, the most frequently endorsed unmet needs were psychological needs and fear of recurrence. Logistic regression revealed several statistically significant predictors of unmet need, including receipt of hormone treatment, negative affect, and experiencing an unrelated significant event between assessments.

## **Conclusion**

Most patients do not express unmet needs for supportive care after treatment. Thirty percent reported more than five moderate or severe unmet needs at both assessments. Unmet needs were predicted by hormone treatment, negative mood, and experiencing a significant event. Our results suggest that there is a proportion of survivors with unmet needs who might benefit from the targeted application of psychosocial resources.

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## INTRODUCTION

As more people survive cancer, there is growing recognition that they need support during the survival phase of their illness. <sup>1-3</sup> Although completion of treatment is eagerly anticipated, <sup>4,5</sup> few studies focus on the transition period between end of treatment and long-term survivorship (> 5 years). <sup>6</sup> Limited evidence suggests that patients are dissatisfied with care received at this time, as support from oncology professionals tails off with little concomitant increase in alternative support. <sup>7,8</sup>

Estimating quality of life (QoL) is the most common method for ascertaining sequelae in the post-treatment phase, with studies revealing the most frequently reported concerns to be psychological and social.<sup>2-3,9</sup> However, QoL measures were developed to assess patients newly diagnosed and/or

receiving treatment and so may not capture issues pertinent to survivors<sup>3</sup> such as fear of cancer recurrence, <sup>10,11</sup> early menopause, <sup>12</sup> fears about genetic inheritability of cancer, <sup>13</sup> and concerns about sexual function and fertility. <sup>14,15</sup> QoL measures can also be criticized because participants rate presence and/or severity of an item, rather than whether it is a problem for which they need help.

Needs assessment tools explicitly assess the gap between patients' experiences of services they receive and those they perceive they need. <sup>16</sup> Several cancer-specific supportive care needs assessment tools have recently been developed for use with survivors. <sup>17-21</sup> Studies using these report that approximately 30% to 50% of survivors have unmet needs, mainly for psychological support and coping with fear of recurrence. Predictors of unmet supportive care needs include younger age, advanced

disease, and negative mood disturbance. 20,22-26 However, all of the studies used cross-sectional methods, which do not permit prediction of future need. Other methodologic weaknesses include small samples, recruitment of participants at varied time points in the cancer trajectory, and limited inclusion of those in the immediate post-treatment phase. Moreover, few studies included robust measures of aspects such as psychological distress and fear of recurrence. This study investigated prevalence and severity of unmet supportive care needs of cancer patients completing radiotherapy and chemotherapy in England at the end of treatment and 6 months later and factors identified at the end of treatment that predict unmet supportive care needs 6 months later.

## **PATIENTS AND METHODS**

A multicenter, prospective, longitudinal survey design was adopted, with participants assessed on two occasions, at the end of treatment (T0) and 6 months later (T1). Sixty-six cancer facilities in England participated. Multicenter Research Ethics Committee approval was granted (05/MRE12/21), and research governance approval was gained from participating sites.

#### **Patients**

Consecutive eligible patients were recruited for 12 weeks between August and December 2005. We recruited patients with commonly occurring good-prognosis cancers. Patients were eligible to participate if they had a diagnosis of non-Hodgkin's lymphoma or breast, prostate, colorectal, or gynecologic cancer; were aware of their cancer diagnosis; were receiving treatment of curative intent; were metastasis free and had not experienced relapse during treatment; were receiving their last cycle of chemotherapy or episode of radiotherapy of their planned course of treatment; were more than 18 years old; and were able to read and understand English; and if the clinician caring for them agreed to participation. Patients were excluded if they had only received surgical treatment or their last planned treatment consisted of surgery.

#### Recruitment Procedures

Research nurses in the clinical setting screened and approached eligible patients in person, asking them to complete and return the questionnaire pack and signed consent form by mail. Before posting the second assessment, local oncology providers or general practitioners checked participants' health status by reviewing their medical records. Reminder letters were sent if questionnaires were not returned within 3 weeks.

## Sample Size Estimation

One thousand participants would give an error rate of  $\pm$  2% on any proportion, whereas 250 participants would give an error rate of  $\pm$  4% on any proportion. A response rate of 50% was estimated, taking into account non-response, refusal to participate, and attrition. Therefore, recruitment of 1,000 participants would result in a final sample size of 500 completing both assessments, and thus, the error rate would fall within acceptable bounds.

## Study Measures

The Supportive Care Needs Survey (SCNS), a valid and reliable 34-item measure, assesses cancer patients' unmet needs across the following five domains: psychological, health system and information, physical and daily activity, patient care and support, and sexuality.  $^{17,27}$  Need for help is rated on a 5-point scale as follows: 1= not applicable, 2= satisfied, 3= low need, 4= moderate need, and 5= severe need. The 22-item Health Concerns Questionnaire (HCQ) assesses fear of cancer recurrence and is reported to be valid and reliable.  $^{10,28-30}$  Higher scores indicate greater fear of recurrence. The Hospital Anxiety and Depression Scale (HADS) is a 14-item screening tool consisting of seven-item scales for anxiety (HADS-A) and depression (HADS-D).  $^{31}$  It has been used extensively with cancer patients and has excellent psychometric properties.  $^2$  The 20-item Positive Affect and Negative Affect Schedule (PANAS) is a widely used measure of the emotional style used to cope with life events  $^{32,33}$  and is composed of a 10-item scale each for positive affect

and negative affect. A high positive affect score indicates someone who is alert and enthusiastic, whereas a high negative score reflects high levels of distress. Participants provided information on personal, clinical, and treatment factors.

## Analysis

Descriptive measures were used to examine the point prevalence of unmet supportive care needs at both time points for individual items and by domain. Mean difference in scores was assessed using t tests.

The Markov Chain Monte Carlo method was used to replace missing data with imputed values using SAS V9 procedures MI and MIANALYZE available in SAS/STAT.<sup>34</sup> All 1,425 patients at T0 contributed to the imputation stage. Subscale means were calculated for each data set. The analysis data set was restricted to those patients who responded at T1.

Predictors of unmet need for each SCNS domain were identified using backward stepwise logistic regression. For each analysis, the dependent variable was dichotomized into no needs (score = 1 to 3) and those reporting at least one moderate/severe need (score = 4 to 5). All independent variables (Appendix Table A1, online only) were included in the initial model. A model was fitted to each imputed data set, and results were combined. The least significant variable was removed until only those statistically significant at the 5% level remained. Sensitivity of some models was low. Examination of residuals identified other factors that might better explain the variance in scores. Consequently, we included a new variable that represented participants who responded to an open-ended question that they had experienced a significant event between assessments. This we categorized as post-treatment complications, exacerbation of a pre-existing condition/major new illness, or nonhealth-related negative life event. We assessed for possible clustering effects as a result of treatment center by fitting a random intercept and, separately, a fixed effect factor for center to the model. The effect was negligible; therefore, center was excluded from all subsequent models.

## **RESULTS**

Figure 1 outlines flow of participants through the study. Of 1,850 eligible patients given a questionnaire pack, 79% returned the baseline questionnaires. Eighty-two percent of those completing T0 assessment returned follow-up questionnaires. The number that completed

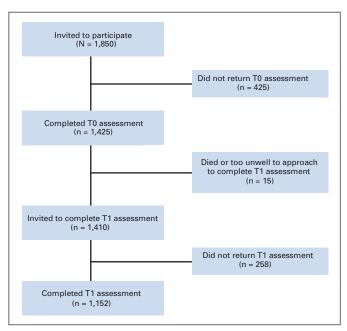


Fig 1. Flow of participants through the study. T0, baseline (at the end of treatment); T1, 6 months after baseline.

both assessments was 1,152, an overall response rate of 62%. Selection bias was not assessed because information was not available on patients who did not enter the study.

Personal and clinical baseline characteristics are listed in Table 1. The majority of patients were diagnosed with breast or prostate cancer, and mean age was 61 years. Comorbid disorders were present in more than 40% of patients, the most common being cardiovascular and musculoskeletal diseases.

At follow-up, almost half of the patients with breast cancer and a fifth with prostate cancer went on to receive hormone therapy. A minority (11%) reported experiencing a significant event in the period between assessments. The most common were post-treatment complications (43%) and major new illness/exacerbation of a pre-existing condition (30%).

At follow-up, 258 patients did not return the questionnaires. Baseline mean scores for all measures were compared for those who did and did not complete both assessments using unrelated t tests. Those who completed the first assessment only reported significantly

more needs across all SCNS domains, except the sexuality domain; greater fear of recurrence; and being more negative and less positive. Although they also reported significantly higher HADS anxiety and depression scores, these fell below the threshold for mild depression. Nevertheless, results suggest greater morbidity in those completing only the first assessment.

For individual SCNS items, the frequency of moderate/severe scores was ranked. Table 2 lists the top 10 unmet needs at both assessments. The most common concerns were psychological, and in particular, fear of cancer recurrence.

Mean scores on all questionnaires completed at both time points are listed in Table 3. HADS-A and HADS-D mean scores were low and reflected in the low proportion of patients ( $\leq$  9%) scoring  $\geq$  15. There was a statistically significant reduction in mean scores for all SCNS domains at follow-up, except sexuality needs. Similarly HCQ, HADS-D, and HADS-A scores reduced significantly between T0 and T1. With the exception of HCQ scores, the clinical significance of the differences in mean scores between the two time

						Diag	nosis							
	Breast		Prostate		Bowel		Gynecologic		NHL		Not Recorded		Total	
Characteristic	No. of Patients	%	No. of Patients	%	No. of Patients	%	No. of Patients	%	No. of Patients	%	No. of Patients	%	No. of Patients	%
Total patients	801	56	330	23	127	9	90	6	65	5	12	1	1,425	100
Age, years Mean Standard deviation	58.0 11.4		67.8 6.2		64.3 11.0		58.3 14.2		55.5 15.0		63.0 8.2		60.8 11.6	
Sex Male Female Not recorded	2 798 1	< 1 99 < 1	329 0 1	99 0 < 1	67 60 0	53 47 0	0 90 0	0 100 0	30 33 2	46 51 3	2 4 6	17 33 50	430 985 10	30 69 1
Race White Other	773 25	97 3	327 3	99 1	125 2	98 2	85 5	95 5	62 3	95 5	6 6	50 50	1,378 47	96 4
Educational level No formal qualifications GCSE/O level/A level Degree	283 332 173	35 42 22	147 104 74	45 32 22	57 39 26	45 24 20	34 32 20	38 38 22	22 36 7	34 26 10	1 3 2	8 25 17	544 548 302	37 39 22
Not recorded Treatment regimen RT only	13 7	1	5 192	1 58	5 4	3	2	2	0	0	6	50	207	15
CT only S + CT	3 16	< 1	0	0	8 78	6 62	6 24	7 27	34 4	52 6	0	0 25	51 125	2
S + RT S + CT + RT	133 109	17 14	32 0	10 0	0 23	0 18	34 12	38 13	3 12	5 19	0	0	202 157	14 11
S + CT + HT S + RT + HT S + CT + RT + HT	22 317 185	3 39 23	1 10 0	< 1 3 0	0 0 1	0 0 1	0 0 0	0 0 0	0 0 0	0 0 0	0 1 1	0 8 8	23 328 187	20 10
CT + RT CT + RT + HT	2	< 1 < 1	1	< 1 1	8	6	7	8	11	17 0	0	0	29	< 1
RT + HT Not recorded	3	< 1	89 2	27 < 1	0 5	0	0	0	0	0	0	0 50	92 18	-
Comorbid disease Yes	312	39	167	50	57	45	33	37	30	46	4	33	601	4:
No Not recorded	482 7	60 1	163 2	49 1	69 1	54 1	54 3	60 3	34 1	52 2	2 6	17 50	804 20	5

Abbreviations: NHL, non-Hodgkin's lymphoma; GCSE, General Certificate of Secondary Education; RT, radiotherapy; CT, chemotherapy; S, surgery; HT, hormone therapy.

			Patie	ents
Rank	SCNS Dimension	SCNS Need Item	No.	%
Baseline (N = 1,425)				
1	PsN	Fears about the cancer spreading	438	30
2	PsN	Concerns about the worries of those close to you	384	2
3	PsN	Uncertainty about the future	374	2
4	PsN	Worry that the results of treatment are beyond your control	320	2
5	PN	Lack energy/tiredness	305	2
6	HIN	Being informed about cancer that is under control or diminishing	290	2
7	HIN	Being informed about things you can do to help yourself get better	281	1
8	PsN	Anxiety	277	1
9	PN	Not being able to do things you used to do	272	1
10	HIN	Having one member of staff with whom you can talk about all aspects of your condition, treatment, and follow-up	269	1
Follow-up (n = 1,152)				
1	PsN	Fears about the cancer spreading	296	2
2	PsN	Uncertainty about the future	226	2
3	PN	Lack energy/tiredness	224	1
4	PsN	Concerns about the worries of those close to you	221	1
5	PsN	Worry that the results of treatment are beyond your control	196	1
6	HIN	Being informed about cancer that is under control or diminishing	191	1
7	PsN	Depressed	189	1
8	PsN	Anxiety	188	1
9	HIN	Being informed about things you can do to help yourself get better	187	1
10	SN	Changes in sexual feelings	181	1

sexuality needs.

points is questionable because they fall below the criterion of 0.5 standard deviation of baseline scores.<sup>35</sup>

Total supportive care needs were categorized according to whether participants reported no, few (one to four needs), or multiple (≥ five needs) moderate or severe unmet needs across all SCNS items for both time points. Table 4 lists the change in total needs between T0 and T1. Of the 34% of patients who reported having more than five supportive care needs at baseline, 20% continued to experience multiple problems 6 months later. In addition, a small proportion of

patients (11%) with no or few needs at baseline went on to report multiple unmet needs at T1.

## **Baseline Predictors of Unmet Need**

Statistically significant predictors of moderate and severe unmet needs for each SCNS domain were identified using backward stepwise logistic regression. Results are listed in Table 5. Odds ratios for continuous covariates, such as SCNS, HADS, PANAS, and HCQ, represent a 1-point increase in scores.

	No. of	Possible Score Range	T0 Score		T1 Score		t Test		
Questionnaire	Patients		Mean	SD	Mean	SD	Difference	95% CI	Р
SCNS									
Physical needs	1,130	5-25	10.0	4.5	9.0	4.5	-1.0	-1.3 to $-0.8$	< .000
Psychological needs	1,129	10-50	22.4	10.1	21.2	10.3	-1.2	-1.7 to $-0.8$	< .000
Patient care needs	1,134	5-25	9.4	3.7	8.7	4.1	-0.7	-0.9 to $-0.5$	< .000
Sexuality needs	1,124	3-15	5.3	3.1	5.3	3.3	0.1	-0.1 to 0.2	.366
Health system and information needs	1,130	11-55	23.8	8.9	21.0	9.9	-2.8	−3.3 to −2.3	< .000
HADS									
Anxiety	1,137	0-21	6.0	4.1	6.2	4.3	0.2	-0.0 to $0.4$	.020
Depression	1,128	0-21	3.5	3.2	3.4	3.2	-0.2	-0.3 to $0.0$	.015
PANAS									
Positive affect	1,109	10-50	32.9	8.3	33.1	8.7	0.3	-0.6 to $0.4$	.281
Negative affect	1,108	10-50	16.1	6.7	15.8	6.8	-0.3	-0.6 to $0.0$	.091
HCQ (fear of recurrence)	1,138	22-110	73.8	14.7	63.7	6.1	-11.0	−11.0 to −9.2	.000

Abbreviations: T0, baseline (at the end of treatment); T1, 6 months after baseline; SD, standard deviation; SCNS, Supportive Care Needs Survey; HADS, Hospital Anxiety and Depression Scale; PANAS, Positive Affect and Negative Affect Schedule; HCQ, Health Concerns Questionnaire.

Table 4. Change in Frequency of Unmet Moderate or Severe Total Needs

	T1									
	No Needs		1-4 Needs		≥ 5 Needs		Total			
ТО	No. of Patients	%								
No needs	353	30	68	6	41	4	462	40		
1-4 needs	132	11	91	8	80	7	303	26		
≥ 5 needs	64	6	89	8	234	20	387	34		
Total	549	47	248	22	355	31	1,152			

NOTE. Excludes T1 noncompleters ( $\chi^2=364$ , df = 4, P=<.000). Abbreviations: T0, baseline (at the end of treatment); T1, 6 months after baseline.

High SCNS physical and daily living unmet needs at baseline increased the likelihood of having moderate or severe unmet physical needs at follow-up. The chance of expressing unmet moderate or severe physical needs was more than 1.5 times greater for patients reporting a comorbid disorder, receiving hormone treatment, or who experienced a significant event. SCNS information needs, HADS-A, and HADS-D were also statistically significant predictors. Although the overall model was statistically significant, the variance explained by the model was low (Nagelkerke  $R^2 = 0.31$ ).

The four strongest predictors were baseline SCNS psychological needs and physical needs, PANAS negative affect, and HCQ fear of recurrence. Other statistically significant predictors included treatment with radiotherapy or hormone therapy and experiencing a significant event. The specificity and sensitivity of this model were reasonable at 69% and 83%, respectively.

The health system and information domain assesses need for information about diagnosis, treatment, and follow-up. Patients who had a comorbid disorder, were receiving hormone treatment, or experienced a significant event were more likely to experience moderate or severe unmet need at follow-up. Lower educational qualifications were associated with fewer unmet moderate or severe needs for help. Scoring highly at baseline on HCQ and other SCNS domains increased the likelihood of having unmet needs at follow-up.

Patient care and support needs relate to health care providers showing sensitivity to physical and emotional needs. The chance of having unmet moderate or severe needs was significantly greater for patients receiving hormone therapy, patients who had use of a car, or patients who were younger. High baseline unmet patient care needs, health system and information needs, physical needs, and HCQ scores were statistically significant predictors of unmet need on this domain.

Having a high level of unmet sexuality needs at baseline increased the likelihood of having moderate or severe unmet needs at follow-up. In addition, unmet sexuality need was positively related to being male, being married/cohabiting, being younger in age, receiving radiotherapy treatment, or experiencing a significant event. In addition, high baseline PANAS negative affect and unmet physical needs were statistically significant predictors.

#### DISCUSSION

This study aimed to assess prevalence of unmet supportive care needs in a cohort of patients with breast, prostate, colorectal, or gynecologic

cancer or non-Hodgkin's lymphoma at the end of treatment and 6 months later. Our results indicate that two thirds of patients had no or few unmet needs at the end of treatment and the number without unmet needs increased 6 months after treatment finished. This is consistent with findings from cross-sectional studies. <sup>19-22,26,36-38</sup> However, one third of participants at baseline reported five or more moderate to severe unmet needs, and for 60% of these patients, the situation did not improve over the 6-month period.

At both assessments, the most frequently endorsed unmet needs concerned psychological needs and possible cancer recurrence. We identified factors present at the end of treatment that consistently predicted unmet need across several SCNS domains 6 months later. These include fear of recurrence and receiving hormone therapy.

Fear of cancer recurrence was a significant predictor of unmet needs on all SCNS domains except physical and sexuality needs. This supports findings from other studies reporting an association between fear of recurrence and psychological distress<sup>39</sup> and reduced quality of life.<sup>40</sup> Therefore, the challenge for health professionals is to ensure patient awareness of signs of cancer recurrence without inducing anxious preoccupation and excessive distress. Cognitive behavioral interventions are being tested to help people cope with the negative impact posed by the threat of recurrence.<sup>41</sup>

Psychological factors have been reported as important determinants of supportive care needs in cancer. <sup>20-21,24,36</sup> In our study, however, baseline negative mood (PANAS or HADS) played a minor role in predicting unmet need because it was only associated with unmet physical and psychological needs. However, to our knowledge, ours is the only study to use a specific measure of fear of recurrence, which may account for this discrepancy.

In this study, hormone therapy emerged as a significant predictor of unmet needs. One explanation for this is that, unlike previous studies, we recruited a homogeneous sample whereby all participants had just completed chemotherapy and/or radiotherapy. A European study revealed that patients receiving hormone therapy often feel ill prepared concerning the potential severity and duration of adverse effects. <sup>42</sup> In the United Kingdom, the care of patients receiving hormone therapy is devolved to general practitioners, <sup>43</sup> but little is known about how this works in practice. Greater emphasis on how best to educate and support this group of patients might improve this situation.

Growing recognition of cancer patients' need for supportive care beyond the end of cancer treatment<sup>44</sup> means that health professionals need to consider how to improve care for these patients. 45 An important first step is systematic assessment of patients' needs at key moments in the cancer trajectory, 46 including completion of treatment. Development of individualized care plans should follow based on risk assessment and patient choice. This would ensure that those at risk of experiencing unresolved needs could be identified and support implemented.<sup>47</sup> Our study provides an initial indication of some predictors of unmet need, but further research is needed to confirm these. Evidence suggests that patients want information on rehabilitation issues such as self-management, follow-up care, and long-term adverse effects once treatment has finished. 48 Current models of follow-up often fail to respond adequately to patients' needs. 49 Further research is needed to better understand the needs of cancer survivors and test effective interventions to meet these needs.

The sample was one of convenience, and this could have implications for external validity of the results. Because we were not able to

Variable	β	t	Р	Odds Ratio	95% CI for Odds Rat
Physical needs*					
T0 SCNS physical needs	.158	8.20	< .001	1.17	1.13 to 1.22
T0 SCNS information needs	.036	3.86	< .001	1.04	1.02 to 1.06
T0 HADS Depression	.069	2.27	.023	1.07	1.01 to 1.14
TO HADS Anxiety	.045	2.02	.043	1.05	1.00 to 1.09
Hormone treatment	.499	3.42	< .001	1.65	1.24 to 2.19
Presence of comorbid disorder	.436	3.13	.002	1.55	1.18 to 2.03
Significant events†	.704	3.17	.002	2.02	1.31 to 3.12
Psychological needs‡					
T0 SCNS psychological needs	.073	4.71	< .001	1.08	1.04 to 1.11
TO SCNS physical needs	.093	3.86	< .001	1.10	1.05 to 1.15
TO SCNS information needs	.029	2.15	.031	1.03	1.00 to 1.06
TO PANAS negative affect	.096	4.61	< .001	1.10	1.06 to 1.15
TO HCQ fear of recurrence	.027	3.75	< .001	1.03	1.01 to 1.04
Hormone treatment	.408	2.42	.016	1.50	1.08 to 2.09
Radiotherapy	.715	3.21	.001	2.05	1.32 to 3.17
Significant event†	.728	2.75	.006	2.07	1.23 to 3.48
Information and health system needs§					
TO SCNS information needs	.075	5.97	< .001	1.08	1.05 to 1.10
TO SCNS physical needs	.056	3.14	.002	1.06	1.02 to 1.10
TO SCNS patient care needs	.091	2.99	.003	1.10	1.03 to 1.16
Hormone treatment	.488	3.28	.001	1.63	1.22 to 2.18
Presence of comorbid disorder	.280	1.98	.048	1.32	1.00 to 1.75
TO HCQ fear of recurrence	.028	4.95	< .001	1.03	1.02 to 1.04
Qualifications	.020	4.00	V.001	1.00	1.02 to 1.04
No formal qualifications	611	-3.28	.001	0.54	0.38 to 0.78
GCSE O/A levels	269	-1.15	.13	0.76	0.54 to 1.08
Degree† (reference)	.000	_	_	1.00	_
Significant event†	.537	2.39	.017	1.71	1.10 to 2.66
Patient care needs¶					
TO SCNS patient care needs	.095	3.43	< .001	1.10	1.04 to 1.16
TO SCNS physical needs	.063	3.57	< .001	1.07	1.03 to 1.10
TO SCNS information needs	.040	3.54	< .001	1.04	1.02 to 1.06
Hormone treatment	.414	2.72	.007	1.51	1.12 to 2.04
T0 HCQ fear of recurrence	.026	4.43	< .001	1.03	1.01 to 1.04
Car user	.808	2.93	.003	2.24	1.31 to 3.85
Age, years <sup>a</sup>					
19-59	.510	2.69	.007	1.67	1.15 to 2.41
60-67	.409	2.17	.030	1.51	1.04 to 2.18
> 68 (reference)	.000	_	_	1.00	_
Sexuality needs <sup>b</sup>					
To SCNS sexuality needs	.355	11.46	< .001	1.43	1.34 to 1.52
TO SCNS physical needs	.041	2.01	.045	1.04	1.00 to 1.08
TO PANAS negative affect	.033	2.21	.027	1.03	1.00 to 1.06
Domestic status	.728	3.21	.001	2.07	1.33 to 3.23
Radiotherapy	.708	2.84	.005	2.03	1.24 to 3.31
Sex	-1.126	-5.40	< .001	0.32	0.22 to 0.49
Age, years <sup>c</sup>	20	20		5.02	3.22 to 0.10
19-59	1.001	4.03	< .001	2.72	1.67 to 4.43
60-67	.788	3.52	< .001	2.20	1.42 to 3.41
> 68 (reference)		—	_	1.00	-
Significant event†	.564	2.20	.028	1.76	1.06 to 2.91

Abbreviations: SCNS, Supportive Care Needs Survey; T0, baseline (at the end of treatment); HADS, Hospital Anxiety and Depression Scale; PANAS, Positive Affect and Negative Affect Schedule; HCQ, Health Concerns Questionnaire; GCSE, General Certificate of Secondary Education.

\*Nagelkerke R² = 0.308; specificity = 79%; sensitivity = 59%.

<sup>†</sup>Experienced significant event between T0 and T1.

<sup>\*</sup>Nagelkerke  $R^2$  = 0.455; specificity = 69%; sensitivity = 83%. \*Nagelkerke  $R^2$  = 0.339; specificity = 78%; sensitivity = 62%. \*#F<sub>2.60,150</sub> = 5.60; P = .004.

Nagelkerke  $R^2 = 0.287$ ; specificity = 91%; sensitivity = 40%.  $^{4}$ F<sub>2,48,609</sub> = 3.93; P = .020.  $^{4}$ Nagelkerke  $R^2 = 0.450$ ; specificity = 92%; sensitivity = 54%.

 $<sup>^{\</sup>circ}F_{2,17,512} = 9.10; P = .001.$ 

assess for selection bias, it is possible that the sample may not be representative of the population, although this is tempered by the large sample size and good response rate. The emergence of hormone therapy as a significant predictor of unmet need on many SCNS domains suggests the needs of patients with breast and prostate cancer may differ from the needs of patients with other cancers, although diagnosis was not a confounding variable in the analysis. However, the dominance of women in the sample does suggest that caution may need to be exercised in generalizing findings to men. Although the level of attrition between the two assessments was relatively low (19%), there is evidence of a statistically significant difference between patients who completed both assessments as opposed to the initial assessment, suggesting greater morbidity in the latter group. Thus, our results may not be representative of patients with the most needs. If this is the case, it implies that our estimates are conservative. However, it is more likely that this is an artifact of the large sample size and not clinically significant because the mean difference is small and less than the recommended 0.5 standard deviation criterion.<sup>32</sup> A potential caveat concerns our reliance on patient-reported clinical characteristics because some patients might not have known or forgot details such as their treatment regimen. This was a pragmatic decision to ensure smooth running of the study, and based on evidence showing recording of clinical details in medical records, is at best variable and frequently unreliable.50

Finally, although the logistic regression models of predictor variables were statistically significant, variance explained was relatively low, limiting our ability to generalize from these findings. This may be explained by heterogeneity in our sample in terms of diagnosis and treatment received. However, it is also probable that factors not assessed in this study are influential in determining supportive care needs, such as specific coping style and perceived social support. To improve the precision of prediction models, future research should

consider ways to both increase the homogeneity of the sample and include other potentially explanatory variables.

Although most participants expressed no or few unmet moderate or severe supportive care needs at either the end of treatment or 6 months later, 30% repeatedly reported multiple unmet needs. Baseline fear of recurrence, treatment with hormone therapy, and subsequent experience of a significant event consistently predicted moderate to severe unmet needs 6 months later. Therefore, our results suggest that resources should be targeted to those who need them most. Differing models of care should be developed and tested to ensure their acceptability and effectiveness.

# AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

## **AUTHOR CONTRIBUTIONS**

**Conception and design:** Jo Armes, Maggie Crowe, Lynne Colbourne, Helen Morgan, Catherine Oakley, Nigel Palmer, Emma Ream, Annie Young, Alison Richardson

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Alison Richardson

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