

ORIGINAL ARTICLE

## Fear of cancer recurrence and unmet needs among breast cancer survivors in the first five years. A cross-sectional study

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### ABSTRACT

**Background:** It is unclear to which degree the services available after end of treatment are sufficient to meet the needs of women treated for breast cancer. The aim of the present study was to identify patient-reported supportive care needs and the prevalence of fear of cancer recurrence (FCR) following end of treatment in women treated for breast cancer.

**Material and methods:** Using a cross-sectional design, women treated for breast cancer ( $n = 155$ ; mean age 63) completed questionnaires concerning supportive care needs and FCR. Inclusion criteria were:  $\geq 18$  years of age and treated for primary breast cancer at Aarhus University Hospital, Aarhus, Denmark and between three months and five years after diagnosis. Associations between demographic characteristics, clinical factors, side effects, late effects and the two dependent variables, unmet needs (examined with linear regression model), and FCR (examined with logistic regression model) were analyzed.

**Results:** The response rate was 79.9%. Almost all (82.6%) women reported at least one unmet need (mean number 9.3; range 0–34). More than half (59.3%) of the unmet needs were rated as strong unmet needs. The most frequent unmet needs were concerned with doctors collaborate to coordinate care; the need for having ongoing dialog with healthcare providers to receive available local health care services, understandable and up-to-date information, to manage side effects and feeling reassured that the best medical care are given.

Having unmet needs were associated with young age, short time since primary surgery, and having clinical FCR. FCR was reported by 54.8% of the women and was associated with short time since primary surgery, having chemotherapy, having unmet needs, and moderate to severe muscle and joint pain and fatigue.

**Conclusions:** Breast cancer survivors experience substantial unmet needs years after end of treatment, particularly among younger women and women having clinical FCR. Furthermore, FCR is frequent among women, particularly when closer in time to primary surgery.

### ARTICLE HISTORY

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There are currently approximately 62,000 survivors treated for breast cancer in Denmark [1] and identifying their needs is essential for planning appropriate follow-up services in breast cancer care [2]. A personalized approach, distinguishing between physical, psychological, and social needs, has been recommended [3]. Unmet needs have been defined as the healthcare services received compared to the needs required [4]. There is considerable evidence that unmet needs can affect cancer patients' everyday life negatively [5].

It has been suggested that addressing survivors' needs by evidence-based assessment tools may help identify and manage survivor's unmet needs [6], hence improving health care services for these survivors.

Needs of patients with various cancer diagnoses are often assessed with a variety of questionnaires constructed for people with cancer [7]. Most instruments include a wide range of items covering various need domains, with respondents

being asked to rate their level of need for each item. In addition, some studies [8,9] have developed individual ad hoc questions.

A review among cancer patients with various cancer diagnoses concludes that up to nearly 100% report some degree of unmet needs throughout the disease trajectory [4]. Furthermore, the most commonly explored area of unmet need of cancer patients is within the information need area. Reviews have shown unmet information needs about diagnosis, prognosis and treatment, information about family and partner issues, and information on practical and coping issues [8,9].

In three cross-sectional Danish studies of patients with various cancer diagnoses ( $N = 1490$ ,  $N = 3439$  and  $N = 4108$ ), the prevalence of unmet needs ranged between approximately 10–50% [10–12]. The unmet needs reported were concerning lacking help managing physical and psychological

symptoms and late effects, returning to normal everyday life and dealing with financial and work-related consequences.

A recent systematic review of studies of needs and predictors of needs of women with breast cancer at different disease stages showed that information about cancer recurrence symptoms, side effects of treatments, and up-to-date and understandable information are needs reported by more than 30% of patients. Furthermore, needs in the psychological area, such as help with how to deal with fear of cancer recurrence (FCR), how to manage everyday life, and concerns about the future ranked high [13]. Predictors of greater care needs were primarily shorter time since primary diagnosis, having mastectomy, chemotherapy and radiotherapy, having symptoms of depression and anxiety, and younger age [13].

FCR is common, with a recent systematic review showing that up to 97% of survivors report some degree of FCR [14]. Similar results have been found in large sample of Danish and Australian survivors (7–9 years after diagnosis) treated for breast cancer ( $N=1885$ ) which further indicating that FCR generally remains stable over the survivorship trajectory [15]. The systematic review showing predictors of having FCR as age, time since primary surgery, surgery type, treatment type, having symptoms of pain, depression, fatigue, and unmet needs [14].

Although several studies have assessed the types of problems experienced by breast cancer survivors, it still remains unclear to what degree help is required to manage these problems and whether patients actually receive the help required. Furthermore, different culture may play a role in the scoring of needs. In the existing Danish studies, needs have been determined by questions specifically developed for each specific study, and to our knowledge, so far no studies have examined care needs of Danish breast cancer patients using validated questionnaires such as the Cancer Survivor's Unmet Needs (CaSUN) questionnaire.

The aim of the present cross-sectional study was therefore to determine the frequency of needs and FCR among women treated for primary breast cancer, followed at an outpatient clinic up to five years after completing primary treatment. Second, we also explored the associations between unmet needs and FCR and factors such as demographic characteristics, clinical characteristics, side effects, and late effects.

## Material and methods

### Patients and procedure

The study was designed as a cross-sectional questionnaire study of 194 women scheduled for an outpatient visit at the Department of Oncology, Aarhus University Hospital, Denmark, between November 2014 and January 2015. Inclusion criteria were women 18 years of age or older, diagnosed and treated for primary breast cancer, and between three months and five years after diagnosis. Patients diagnosed less than three months previously, having recurrent disease, secondary cancer or previous malignant disease, and language or cognitive difficulties were excluded. Eligible women were informed about the study and enrolled by

seven clinical oncologists from the breast cancer team at the scheduled outpatient visit.

The questionnaires were either a paper-and-pencil version returned by mail in a pre-paid envelope or an electronic version (SurveyXact, version 8.0) completed within one week after the scheduled follow-up visit. A single reminder, together with a new copy of the questionnaire, was mailed out after two weeks. The questionnaire package included the questionnaires CaSUN [16] and Concerns About Recurrence of Cancer (CARQ-4) [15], together with questions concerning breast cancer-related side effects, late effects, and psychosocial problems.

### Measures

CaSUN [16] consists of 35 unmet needs items, with 28 of the unmet needs items covering five domains: Existential Survivorship needs, Comprehensive Cancer Care needs, Information needs, Quality of Life needs and Relationship needs. Domains are scored by summing all items in that domain and the average number of needs in a domain is reported. Items on the CaSUN can be scored in terms of met, unmet, and total need. Total scores consist of the sum of all need items. Higher scores indicate greater needs (range 0–35). The strength of the endorsed unmet needs is scored as 'weak', 'moderate' or 'strong'. In accordance with guidelines, the women were asked to evaluate their needs within the last month.

The CaSUN has among cancer survivors shown high degree of internal consistency (Cronbach alpha 0.96) [16]. Maximum likelihood factor analysis of the five need domains has shown a range between 0.78 and 0.93 [16] and the test-retest reliabilities of three of the five domains have shown to be 0.19, indicating a low agreement [16].

The questionnaire was translated from English into Danish by three independent translators, and a final version was negotiated. Back-translation was performed by a translator with the English language as the mother tongue. Prior to administering the CaSUN, the cognitive equivalence and comprehensibility were evaluated in 15 women, treated with breast cancer and seen in the outpatient clinic.

The four-item CARQ-4 has previously been adapted into Danish and assesses three different aspects of FCR and the perceived risk of recurrence [15]. Item 1–3 are rated on an 11-point Likert scale ('not at all' to 'a great deal'). In Item 4, the perceived risk of recurrence is scored as a number (up to 100%). A cutoff score  $\geq 12$  has been shown to indicate clinical FCR [15]. In a sample of Australian and Danish breast cancer patients the CARQ-4 has shown to be reliable and valid [15]. Furthermore, a Rasch analysis identified item bias relative to age [15].

The ad hoc questions concerned side effects, late effects, and psychosocial problems and were developed based on a literature search concerning breast cancer patients and an experienced research nurse following 23 outpatient visits of breast cancer over a period of two weeks. The questionnaire items were self-rated on a four-point Likert scale ('not at all', 'mild', 'moderate' or 'severe').

Prior to the present study, the questionnaire had been tested with respect to wording, relevance, and face- and content validity of the items. A total of 27 patients treated for breast cancer were asked to complete the questionnaire and were then interviewed about their perceptions of the questionnaire. In addition, three experienced healthcare professionals working with patients treated for breast cancer at the Department of Oncology (one outpatient clinic nurse, one clinical oncologist and one radiation therapist) were asked to comment on content, wording, and volume of the questionnaire. The procedures lead to a few number of adjustments.

Breast cancer-related disease characteristics were obtained from the Danish Breast Cancer Cooperative Group (DBCG) registry and included: date and type of primary surgery, malignancy grade, and type of treatment.

### Statistical analyses

Response frequencies were calculated for the type of needs and the mean numbers were calculated for the type and domains of needs. For the CaSUN, all 35 items were included in the calculations. The internal consistencies of the subscales and the total scale were examined by calculating Cronbach's alpha. The stability of the CaSUN was evaluated with the four-week test-retest correlation in a subsample of 45 women. Finally, the fit of the factor structure of the Danish version of CaSUN was evaluated with confirmatory factor analysis (CFA) [17].

The mean value of the CARQ-4 total score and the frequency of women had a CARQ-4 score  $\geq 12$ , indicating clinically significant FCR was calculated. Scores on the CARQ-4 item 4 were transformed to a scale consistent with the scoring scale of Item 1–3, in line with the scoring manual [15].

The unadjusted associations between the dependent variables (unmet needs and clinical FCR) and of the possible predictors were analyzed with linear regression (unmet needs), and logistic regression (clinical FCR). In addition to the unadjusted analyses for each independent variable, a multiple, hierarchical logistic regression was conducted with clinical FCR as dependent variable. Likewise, unadjusted analyses and a multiple, hierarchical linear regression was conducted with unmet needs as dependent variable. These analyses involved the following independent variables: age, time since primary surgery, type of surgery, type of treatment, tumor grade, chemotherapy, radiotherapy muscle and joint pain, depression, and fatigue [13] which were statistically significant at the level 10% level. The 10% significance level was used to balance the risk of over- and underfitting the data.

A *p* Value below 0.05 was considered statistically significant and all analyses were performed in STATA, version 13.0 (Stata Corp, College Station, TX, USA).

### Ethics

The study was approved by the Danish Data Protection Agency (case no 2014-41-3476) and the Danish Regional Ethics Committee System (case no 1-16-02-477-14).

## Results

### Participants, responders, and non-responders

Of the eligible 194 patients (all women treated for primary breast cancer registered in the hospital-based electronic chart system during a three-month period), 177 (91%) agreed to participate and fill in the questionnaires either in a paper-and-pencil version ( $n = 86$ ) or an electronic version ( $n = 91$ ). Of the 177 patients, 22 failed to return the questionnaire. The 17 (9%) patients who declined to participate gave the following reasons for not participating: lack of time, energy or motivation ( $n = 12$ ), and workload ( $n = 5$ ). Compared with participants, non-participants and non-responders had a higher number of positive lymph nodes. No other differences were found. All 155 patients (mean age 63) who completed and returned the questionnaire were included in the analyses.

Cronbach alpha for the total CaSUN was 0.95, indicating good internal consistency. Alphas for the subscales ranged between 0.87 (Comprehensive Cancer Care) and 0.93 (Information). Test-retest reliability between time 1 and 2 was 0.36. The results of the CFA revealed the following values:  $\chi^2$  (832.1;  $p < 0.0001$ ); comparative fit index (CFI) = 0.852 (CFI  $> 0.9$  indicating a good fit); root mean square error of approximation (RMSEA) = 0.097 (90% CI 0.088–0.105) (RMSEA  $< 0.08$  indicating an acceptable fit) and standardized root mean residual (SRMR) = 0.069 (SRMR  $< 0.08$  indicating good fit).

### Needs

The most frequently reported 'unmet' needs were in the domain 'existential survivorship' (mean 3.0, range 0–14) followed by the domain 'comprehensive cancer care' (mean 2.8, range 0–6) (Table 1). Likewise, the most frequently reported 'met' needs were in 'existential survivorship' domain (mean 1.8, range 0–12), followed by the 'comprehensive cancer care' (mean 1.3, range 0–5) (Table 1).

Only eight women (5.2%) reported no need at any item, and the majority of women ( $n = 147$ ; 94.8%) reported at least one need (met or unmet). The women reporting at least one need had a mean number of 14.4 met or unmet needs (range 0–34) (Table 2). Most women ( $n = 128$ ; 82.6%) reported at least one 'unmet' need, (mean number 9.3, range 0–34) (Table 2). More than two-thirds of these women ( $n = 92$ ; 71.9%) rated an 'unmet' need as strong with a mean number of strong (mean number 4.2, range 0–29).

**Table 1.** CaSUN domains ranked by the mean number of needs ( $N = 155$ ).

Rank	CaSUN <sup>a</sup> domain	Unmet needs		Met needs	
		Mean (SD)	Range	Mean (SD)	Range
1	Existential survivorship	3.0 (3.8)	0–14	1.8 (2.7)	0–12
2	Comprehensive cancer care	2.8 (2.3)	0–6	1.3 (1.7)	0–5
3	Information	1.1 (1.3)	0–3	0.9 (1.2)	0–3
4	Quality of life	0.8 (0.9)	0–2	0.3 (0.6)	0–2
5	Relationships	0.5 (0.9)	0–3	0.3 (0.7)	0–3

<sup>a</sup>Cancer Survivor's Unmet needs measure.  
SD: standard deviation.

## Unmet needs

The most frequent 'unmet' needs (Table 3) were concerned with the domains of comprehensive cancer care (doctors collaborate to coordinate care; to feel like I am managing my health together with the medical team, and available local health care services); information (understandable and up-to-date information); quality of life (manage side effects), and existential survivorship (concerns about the cancer coming back).

The unadjusted and adjusted associations with unmet needs during the last month are shown in Table 4. Of the independent variables, age, time since primary surgery and FCR remained statistically significant, explaining 15.9% of the variance in unmet needs. So, more unmet needs were associated with younger age, shorter time since primary surgery, and having clinical FCR.

## Met needs

In total, 52.9% of the women, ( $n=82$ ) reported at least one 'met' need, with a mean number of met needs of 5.3 (range 0–26) 'met' needs. The most frequently reported 'met' needs by women treated for breast cancer are shown in Table 3 and were related to the domains of information (up-to-date and understandable information); comprehensive cancer care

(doctors collaborate to coordinate care; to feel like I am managing my health together with the medical team, and local health care services); and existential survivorship (concerns about the cancer coming back and help to move on with life).

## Fears of cancer recurrence

The mean CARQ-4 total score was 15.2 [standard deviation (SD) 9.9, range 0–40]. A total of 85 women (54.8%) had a CARQ-4 total score  $\geq 12$ , indicating clinically significant FCR. The unadjusted and adjusted associations with having clinical FCR are shown in Table 5. Of the independent variables, time since primary surgery, having chemotherapy, unmet needs and moderate or severe: muscle and joint pain and fatigue remained statistically significant, explaining 24.54% of the variance in FCR. So, shorter time since primary treatment, having chemotherapy, unmet needs, moderate or severe muscle and joint pain and fatigue were associated with having a clinical score of clinical FCR.

## Discussion

To our knowledge, this cross-sectional study is the first to investigate met and unmet needs among Danish survivors treated for breast cancer using the validated CaSUN questionnaire after end of primary treatment. Almost all women reported at least one need ('met' or 'unmet') and more than three-quarters of the women reported that one or more of their needs were unmet. Of these 'unmet' needs, over two-thirds reported their 'unmet' needs as strong. More than half of the women treated for breast cancer reported a CARQ-4 total score  $\geq 12$ , the cutoff score for clinical FCR.

Understanding survivorship issues and needs of breast cancer patients is important as follow-up outpatient visits move from frequent visits under treatment to less frequent visits during follow-up, leaving patients with less healthcare

**Table 2.** CaSUN items reported in different need types ( $N=155$ ).

CaSUN (35 items)	Patient number (%)	Mean number <sup>e</sup>	SD	Range
No needs reported	8 (5.2)	20.3	9.3	0–35
Need (met or unmet)	147 (94.8) <sup>a</sup>	14.4	7.4	0–34
Met need	82 (52.9) <sup>b</sup>	5.3	5.5	0–26
Unmet need (in total)	128 (82.6) <sup>c</sup>	9.3	8.5	0–34
Strong unmet needs	92 (71.9) <sup>d</sup>	4.2	5.6	0–29
Moderate unmet needs	97 (75.8) <sup>d</sup>	2.4	3.1	0–15
Weak unmet needs	106 (82.8) <sup>d</sup>	2.8	3.1	0–13

<sup>a</sup>At least one need (met or unmet); <sup>b</sup>At least one met need; <sup>c</sup>At least one unmet need (in total); <sup>d</sup>At least one unmet need subdivided as weak, moderate and strong; <sup>e</sup>Mean number of sum score of each patient.

**Table 3.** CaSUN. Most frequent needs reported by women with breast cancer three months to five years after diagnosis ( $N=155$ ).

Rank <sup>a</sup>	Item	Need		Met % <sup>c</sup>	Unmet		Domain
		<i>N</i>	% <sup>b</sup>		<i>n</i>	%	
1	I need to know that all my doctors talk to each other to coordinate my care	107	69.0	38.3	66	42.6	Comprehensive cancer care
2	I need the very best medical care	106	68.4	44.3	59	38.1	Comprehensive cancer care
3	I need to feel like I am managing my health together with the medical team	105	67.7	48.6	54	34.8	Comprehensive cancer care
4	I need information provided in a way that I can understand	91	58.7	51.6	44	28.4	Information
5	I need any complaints regarding my care to be properly addressed	78	50.3	17.9	64	41.3	Comprehensive cancer care
5	I need up-to-date information	78	50.3	67.9	25	16.1	Information
6	I need local health care services that are available when I require them	70	45.2	57.1	30	19.3	Comprehensive cancer care
7	I need help to manage ongoing side effects and/or complications of treatment	59	38.1	47.4	31	20.0	Quality of life
8	I need help to manage my concerns about the cancer coming back	53	34.2	52.8	25	16.1	Existential survivorship
9	I need an ongoing case manager to whom I can go to find out about services whenever they are needed	41	45.4	41.5	24	15.5	No domain
10	I need emotional support to be provided for me	40	27.7	47.5	21	13.5	Existential survivorship

<sup>a</sup>Rank based on women reporting the most frequent needs (met or unmet); <sup>b</sup>Percentage based on the women included ( $N=155$ ); <sup>c</sup>Percentage based on the women reporting the item need.

resources, less communication and support from professionals. Follow-up programs are recommended to focus on meeting the so far unmet needs of breast cancer patients using a more holistic approach [18–20].

Some of the most ranked unmet needs in this present study were in the domain of information which included items such as the need for receiving understandable and up-to-date information. This is comparable with a study of women diagnosed with breast cancer 2–10 years after diagnosis which shows, that when rating unmet needs using the CaSUN survey, 26% needed information communicated in a way that was understandable [21]. Furthermore, in a review of the informational needs of breast cancer survivors; lack of information about follow-up and lack of understandable information from the healthcare providers were found [22].

The women's most frequent needs in the present study were similar to those identified in a systematic review of studies examining supportive care needs of women diagnosed with breast cancer using different supportive care needs scales [13]. The previously identified most frequent needs, rated as moderate or high, were: being informed about side effects of treatment (63%), being informed about things to do to get well (59%), having one specific staff member to talk to (51%), being informed about how to manage illness at home (49%), and having access to professional counseling (43%) [13]. As information appears to be a central topic for breast cancer survivors, the timing and sources preferred for receiving information have been investigated in a systematic review [23], which concluded that information is required throughout the entire treatment trajectory and not only at the time of diagnosis.

The frequency of unmet needs reported in the present study (82.6%) are higher than found in a systematic review of studies of survivors with breast cancer and their supportive care needs throughout the disease trajectory [13]. The discrepancy could be due to the differences in the assessment time points since diagnosis with the 23 studies included showing a large variation in time since diagnosis, ranging from recent diagnosis to 15 years into remission. In the present study, breast cancer patients were included up to five years after primary diagnosis. Differences in the questionnaires used could be another explanation for the difference in frequencies of unmet needs. The studies examined in the systematic review [13] used 12 different supportive care needs scales. Other differences between the present and previous studies include variations in disease stage, with some studies focusing on patients with recurrent diseases and others including only stage I and II cancers [13]. Furthermore, the studies reviewed had investigated patients from a range of different cultures such as Chinese, English, French, German, Japanese, Korean, Taiwanese, and Turkish.

FCR was prevalent (54.8%) in the women investigated in the present study, and similar prevalences have been found in a systematic review of studies of cancer survivors [14]. Furthermore, FCR has been found to persist in breast cancer survivors for up to five years after completed treatment [21]. The predictors of needs and FCR in the present study were found to be younger age, shorter time since primary surgery, having received chemotherapy, and experiencing muscle and joint pain and fatigue. The predictors of FCR are similar to those previously reported [13,14]. Younger women may have a need to obtain as much knowledge as possible about the

**Table 4.** Predictors of unmet needs: multiple hierarchical linear regression analysis ( $N = 155$ ).

Predictor	Unadjusted			Adjusted		
	Beta ( $\beta$ )	95% CI	$p$ Value	Beta ( $\beta$ )	95% CI	$p$ Value
Disease and patient characteristics (Step 1)						
Age						
<45 years	7.09 <sup>a</sup>	2.54–13.25	0.004	6.51 <sup>1</sup>	1.25–11.78	0.016
≥45 years	ref			ref		
Years since primary surgery						
<1 year	5.57 <sup>a</sup>	2.53–8.61	0.001	4.97 <sup>a</sup>	1.93–8.00	0.001
≥1 year	ref			ref		
FCR and depression (Step 2)						
*Adjusting for age and years since primary surgery						
FCR						
Clinical	5.28 <sup>a</sup>	2.69–7.86	0.001	3.84	1.18–6.49	0.005
No clinical	ref			ref		
Depression						
Yes	4.80 <sup>a</sup>	1.14–8.46	0.010	3.93	0.41–7.45	0.029
No	ref			ref		
Final model**						
Entering age, years since primary surgery, FCR and depression						
Age						
<45 years				5.48	0.32–10.65	0.038
≥45 years				ref		
Years since primary surgery						
<1 year				3.52	0.45–6.59	0.025
≥1 year				ref		
FCR						
clinical				3.41	0.73–6.08	0.013
No clinical				ref		
$R^2 = 0.159^3$						

<sup>a</sup>Statistically significant ( $p < 0.10$ ). \*Adjusting for Disease and patient characteristic variables, which were statistically significant at  $p < 0.10$  in Step 1; \*\*Entering all variables from Step 2, including variables from Step 1 adjusted for, that reached statistical significance ( $p < 0.10$ ). Only the results for variables from Step 1 and 2 which reached statistical significance ( $p < 0.05$ ) in the final model are shown.  $R^2$ : coefficient of determination.

**Table 5.** Predictors of clinical FCR: multiple hierarchical logistic regression analysis (N = 155).

Predictor	Unadjusted			Adjusted		
	OR	95% CI	p Value	OR	95% CI	p Value
Disease and patient characteristics (Step 1)						
Age						
<45 years	8.17 <sup>a</sup>	1.01–66.16	0.049	6.43 <sup>a</sup>	0.76–54.52	0.088
≥45 years	ref			ref		
Years since primary surgery						
<1 year	4.91 <sup>a</sup>	1.99–12.06	0.001	4.53 <sup>a</sup>	1.83–11.27	0.001
≥1 year	ref			ref		
Chemotherapy						
Yes	0.53	0.28–1.01	0.055	0.41 <sup>a</sup>	0.21–0.83	0.013
No	ref			ref		
Unmet needs, muscle and joint pain, depression and fatigue (Step 2)						
Unmet needs	1.09 <sup>a</sup>	1.04–1.14	0.001	1.07 <sup>a</sup>	1.02–1.12	0.005
*Adjusting for age, years since primary surgery and having chemotherapy						
Muscle and joint pain						
Yes	4.19 <sup>a</sup>	1.60–10.97	0.003	4.38 <sup>a</sup>	1.54–12.48	0.006
No	ref					
Depression						
Yes	3.74 <sup>a</sup>	1.32–10.62	0.013	3.78 <sup>a</sup>	1.23–11.61	0.020
No	ref					
Fatigue						
Yes	3.22 <sup>a</sup>	1.54–6.75	0.002	3.79 <sup>a</sup>	1.69–8.47	0.001
No	ref					
Final model** Entering age, years since primary surgery, chemotherapy, unmet needs, muscle and joint pain, depression, and fatigue						
Years since primary surgery						
<1 year				3.82 <sup>a</sup>	1.31–11.10	0.014
≥1 year				ref		
Chemotherapy						
Yes				0.31 <sup>a</sup>	0.14–0.69	0.004
No				ref		
Unmet needs						
				1.07 <sup>a</sup>	1.01–1.13	0.018
Muscle and joint pain						
Yes				3.61	1.20–10.87	0.022
No				ref		
Fatigue						
Yes				3.79 <sup>a</sup>	1.60–9.01	0.002
No				ref		
R <sup>2</sup> =0.2454						

<sup>a</sup>Statistically significant ( $p < 0.10$ ). \*Adjusting for disease and patient characteristic variables, which were statistically significant at  $p < 0.10$  in Step 1; \*\*Entering all variables from Step 2, including variables from Step 1 adjusted for, that reached statistical significance ( $p < 0.10$ ). Only the results for variables from Step 1 and 2 which reached statistical significance ( $p < 0.05$ ) in the final model are shown. OR: odds ratio.

disease and its treatment. They are thus more prepared for cooperation with the healthcare providers in the follow-up period, using their knowledge and understanding of the discussed issues [23]. Furthermore, a study evaluating the perceptions and needs of breast cancer survivors in relation to health care, revealed that survivors often had the perception that healthcare providers could not meet their needs [24], which may invoke FCR [25].

Among the strengths of the present study are that all women treated for breast cancer registered in the hospital-based electronic chart system during a three-month period were asked to participate. Other strengths are the use of validated questionnaires measuring unmet needs and FCR and the inclusion of registry data on demographic, disease, and treatment characteristics. In addition, we obtained a relatively high response rate of approximately 80%, which may be due to eligible women being informed about the study and enrolled by clinical oncologists from the breast cancer team at the scheduled outpatient visit.

Some limitations should also be noted. One aspect is the cross-sectional design, limiting our understanding of how needs and FCR interacts over time. Although the women

were recruited from only one oncology department, the results from the present study are likely to be generalizable to other Danish hospitals as breast cancer is diagnosed and treated according to national guidelines. However, external validity may be limited by the relatively small sample size (N = 155). There may also be cultural differences with regard to expression of symptoms/needs and healthcare utilization that could limit generalizability.

As this is the first study using a Danish adaptation of the CaSUN questionnaire, we explored its psychometric properties. The Cronbach alphas indicated high internal consistency. Disregarding the  $\chi^2$ , which generally will be statistically significant in sufficiently large samples, two of the three remaining goodness-of-fit indices showed a fit somewhat below 'good fit', suggesting the need to explore the fit of alternative models. However, due to the moderate sample size (N = 155) in the present study, which could possibly explain the results, further testing of the CaSUN goodness-of-fit indices in a larger Danish sample size could be relevant. Finally, the test-retest correlation was relatively low. This could be explained by the small test-retest sample size (N = 45). Another possible explanation could be that unmet needs are

highly sensitive to change over time. Further understanding of the dynamics of unmet needs over time is needed.

## Conclusion

The results of present study indicate that a substantial number of survivors treated for breast cancer recruited from a Danish outpatients oncology clinic experience unmet needs. The results also confirm previous findings that FCR is a frequently reported problem, especially among younger women. Identifying unmet needs and FCR at an individualized and holistic approach after the end of treatment is important to facilitate optimal delivery of health care at follow-up visits and to intervene appropriately to those needs.

## Disclosure statement

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