ORIGINAL RESEARCH ARTICLE

Distress, problems and unmet rehabilitation needs after treatment for gynecological cancer

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Abstract

Introduction: The prevalence of distress, problems and need for rehabilitation among women treated for gynecological cancer is largely unknown. The aims of this study were to examine the prevalence of distress, problems and unmet rehabilitation needs in the first years after treatment for gynecological cancer.

Material and methods: Women treated for gynecological cancer within the last 2 years were invited. Participants responded to the National Comprehensive Cancer Network Distress Thermometer and Problem List measuring distress and problems. They also answered a questionnaire regarding physical endurance, muscle strength, and need for rehabilitation services.

Results: Of 114 eligible women, 92 (81%) agreed to participate. Mean time since last treatment was 7.6 months (range 0–24.5 months). A total of 57% of the participants reported distress. The four most common problems reported were fatigue (58%), tingling in hands/feet (54%), worry (53%), and problems with memory/concentration (50%). Problems associated with distress were: dealing with partner, all emotional problems (i.e. depression, fears, nervousness, sadness, worry, and loss of interest in usual activities), appearance, memory/concentration, pain, sex, sleep, and problems with physical endurance and muscle strength. Fifty-two per cent reported unmet needs for rehabilitation services. Women with distress reported more unmet rehabilitation needs than those in the non-distressed group.

Conclusions: The prevalence of distress in this population of women treated for gynecological cancer was high. Having a high number of problems and having unmet needs for rehabilitation services were both associated with distress. Hence, measurement of distress seems to be helpful when assessing the need for rehabilitation services.

KEYWORDS
distress, gynecological cancer, problems, survivor, unmet rehabilitation needs

1 | INTRODUCTION

Improved diagnostics and treatment have led to increased overall survival and a higher number of gynecological cancer survivors.[1–3] Dependent on type of gynecological cancer and stage of disease, patients may be treated with surgery, chemotherapy, and radiotherapy either given as a stand-alone treatment or in combination. Cancer treatment put these women at risk for adverse effects such as fatigue, nausea, peripheral neuropathy, bowel problems, and sexual dysfunction.[2,4,5] Acute adverse effects occur during and shortly after treatment, whereas late effects are adverse effects lasting for more than a year or occurring more than 1 year after the end of treatment.[2,6] Living with these late effects may lead to a reduction in quality of life and work ability and thereby have considerable implications for their lives.[2,7] To identify patients in need of rehabilitation (i.e. health care aiming to improve their daily function), and to develop programs aiming to prevent the risk for and/or mitigate acute adverse effects and late effects, is therefore important in survivorship care.

Assessment of distress among survivors has been suggested to identify individuals with unmet needs for rehabilitation. Distress is defined as "a multifactorial unpleasant experience of a psychological, social, spiritual, and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment".[8] Most cancer patients experience some level of distress as a consequence of the disease and its treatment.[8] The National Comprehensive Cancer Network (NCCN) recommends the Distress Thermometer to measure distress among cancer patients and survivors, the Problem List (PL) as a supplement to understand the underlying factors for distress, and to use this information to evaluate whether or not a patient needs further evaluation and/or referrals.[8] A cut-off of four on the Distress Thermometer has been associated with symptoms of anxiety and depression,[9] and is therefore often recommended as a cut-off to identify responders with potential distress and need for treatment/rehabilitation.[8,9]

Five studies have examined distress and problems among women diagnosed with gynecological cancer. Before surgery, 66% reported distress, and nervousness, worry, fears and fatigue were the most reported problems.[10] Before surgical staging, 61% reported distress,[11] 49% reported distress after surgical treatment,[12] and 57% reported distress undergoing chemotherapy.[13] None of these studies reported perceived problems. In a recent American cohort study in women with gynecological cancer, 30% reported distress, and fatigue, worry, and tingling were the most prevalent problems.[14] To our knowledge, studies examining distress, underlying problems, and the need for rehabilitation in the first years after treatment for gynecological cancer are missing. Moreover, little is known regarding referral patterns and the association between distress and unmet rehabilitation needs.

The present study therefore aimed to (1) examine the prevalence and degree of distress and the prevalence of problems within the first 2 years after treatment for gynecological cancer, (2) identify demographic- and cancer-related factors and problems associated with having distress, and (3) assess the prevalence of unmet rehabilitation needs and their association with distress.

> **Key message**
>
> More than half of women treated for gynecological cancer reported distress. Having a high number of problems was associated with distress. Patients with distress reported more unmet rehabilitation needs than non-distressed patients.

2 | MATERIAL AND METHODS

This cross-sectional study was conducted at the outpatient clinic at the Department of Gynecologic Oncology, Oslo University Hospital (OUH) from October 2017 to March 2018. OUH is a large tertiary referral hospital serving the South-Eastern Norway Regional Health Authority with a catchment area of 3.0 million. Women who had received primary treatment, or treatment for relapsed or progressive disease, for Stage I–IV ovarian/tube/peritoneal, cervical, corpus, or vulvar cancer within the last 2 years were eligible. Patients undergoing cancer treatment, with a borderline tumor, with severe psychiatric diseases, or who were unable to complete the questionnaire because of language difficulties were excluded.

Four weeks before a scheduled routine follow-up visit at the outpatient clinic, eligible women received written information about the study by mail, together with an informed consent form, the NCCN Distress Thermometer and Problem List (DTPL) and a questionnaire. The week before the follow-up visit the study coordinator phoned the women to answer potential questions about the study. Women who wanted to participate met the study coordinator at the outpatient clinic for collection of signed informed consent. At the meeting, they also went through the responses to the NCCN DTPL and discussed the potential need for referrals to available rehabilitation services.

2.1 | Outcome assessments

Distress and problems were assessed by the NCCN DTPL.[15] NCCN DTPL (Version 2. 2017) was translated into Norwegian according to the forward and backward translation procedure by professional translators. An authorized bilingual translator born and raised in Norway translated the American version into Norwegian. The Norwegian version was discussed with cancer survivors and health professionals working at OUH and the University of Oslo and adjusted thereafter. Then, an authorized bilingual translator born and raised in the USA translated the adjusted Norwegian version back to American English. The back-translated American English version was verified by NCCN. (Reproduced with

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The NCCN Distress Thermometer is an 11-point rating scale from 0 to 10, where 0 is no distress and 10 is extreme distress. Patients are instructed to circle the number that best describes how much distress they have experienced in the past week. We used a cut-off of four or more to categorize patients with distress.[8] The NCCN PL includes 39 problems categorized into five topics: practical problems ($n = 6$), family problems ($n = 4$), emotional problems ($n = 6$), spiritual/religious concerns ($n = 1$), and physical problems ($n = 22$). Patients are instructed to indicate their problems from the past week by responding "yes" or "no" for each problem. The PL also includes a field named "other problems" where the patient can specify problems not included among the 39 items.

Additionally, we included two 11-point rating scales, each from 0 to 10, where 0 is no problem and 10 is an extreme problem, to measure physical endurance and muscle strength. As for distress, a cut-off of four or more was used to categorize patients with these problems.

For the five problem categories on the PL, and for problems with physical endurance and muscle strength, the patients were asked if they were or had been in need of any healthcare or rehabilitation services (hereby termed rehabilitation) for some of the listed problems (yes/no). If they were or had been in need, they were asked if they had been referred to (yes/no) and had received (yes/no) any kind of rehabilitation for any of their perceived problems. The rehabilitation needs were categorized as; (a) "no need" if patients reported that they were not or had not been in need of any rehabilitation service for any of the listed problems within each category and had not received a relevant service; (b) "met needs" if patients reported that they were or had been in need of any rehabilitation service for some of the listed problems within each category and were referred to and had received a relevant service; and (c) "unmet needs" if patients reported that they were or had been in need of any rehabilitation service for some of the listed problems within each category, but were not referred to or had not received a relevant service. Patients with unmet needs were given information about available options for support and if desired they were referred to the relevant rehabilitation services such as physiotherapy, a psychologist, or inpatient rehabilitation facilities.

2.2 | Explanatory variables

Demographics were self-reported and included relationship, childcare, education and employment status. Cancer-related data were obtained from the electronic medical records and included the primary diagnosis of gynecological cancer categorized into four groups: (a) ovarian, tube or peritoneal cancer; (b) cervical cancer; (c) corpus cancer; and (d) vulvar cancer; and type of treatment

categorized into four groups: (a) surgery only; (b) radiotherapy only or in combination with surgery or chemotherapy or both; (c) surgery and chemotherapy; and (d) chemotherapy only, relapse (yes/no); and date of last treatment. Time since last treatment was calculated as the number of months from last treatment to study inclusion.

2.3 | Statistical analysis

Descriptive statistics included number and percentages for the categorical variables and mean, standard deviation, median, and range for the continuous variables. Independent sample t tests were used to identify continuous variables associated with distress, and chi-squared test and Fisher's exact test were used to identify categorical variables and problems associated with distress. Values of P less than 0.05 were considered statistically significant and all tests were two-sided. All analyses were performed using SPSS version 25 for Windows (IBM Corp).

2.4 | Ethical approval

The study was a quality improvement study at OUH (ePhortenumber 2017/3064), and is considered outside the mandate of the South-East Regional Committee for Medical and Health Research Ethics. According to the Personal Data Act, the legal basis for processing personal and health information in the project was the General Data Protection Regulation article 6 number 1a and article 9 number 2j. The Privacy and Data Protection Officer at OUH evaluated the study and recommended the personal data and health information processing. Written informed consent was obtained from all participants.

3 | RESULTS

Of 114 eligible women, 92 (81%) agreed to participate. Demographic and cancer-related characteristics are shown in Table 1. More than half of the participants (57%) reported distress (Table 1). The mean level of distress was 4.0 (standard deviation 2.7) (Table 1). The most commonly reported problems on the PL were fatigue, tingling in hands/feet, worry, and problems with memory/concentration (Figure 1).

Eleven of 92 (12%) specified other problems not included in the PL, for example lymphedema and itching, whereas 50 (54%) reported problems with physical endurance and 39 (42%) reported problems with muscle strength (data not shown).

3.1 | Factors associated with distress

None of the demographic or cancer-related variables was associated with distress (Table 1). The number of problems was significantly

	All N = 92	Distress ≥4	Distress <4	*p* value between groups[b]
Prevalence of distress, *n* (%)				
≥4	52 (57)			
<4	40 (44)			
Level of distress				
Mean (SD)	4.0 (2.7)	6.0 (1.5)	1.4 (1.1)	<0.001
Median (range)	4.0 (0–9)	6.0 (4–9)	1.0 (0–3)	
Demographic characteristic				
Age at survey, years				
Mean (SD)	58.6 (17.0)	57.3 (17.2)	60.3 (16.8)	0.405
Median (range)	61.0 (23–90)	61.0 (25–90)	65.5 (23–84)	
Living with a partner, *n* (%)				
Yes	51 (55)	28 (54)	23 (58)	0.890
No	41 (45)	24 (46)	17 (43)	
Children <18 years living at home, *n* (%)				
Yes	18 (20)	11 (21)	7 (18)	0.863
No	74 (80)	41 (79)	33 (83)	
Education, *n* (%)				
>13 years	47 (51)	29 (56)	18 (45)	0.416
≤13 years	45 (49)	23 (44)	22 (55)	
Employment status, *n* (%)				
Working	27 (29)	16 (31)	11 (28)	0.912
Not working	65 (71)	36 (69)	29 (73)	
Cancer-related characteristics				
Months since last treatment				
Mean (SD)	7.6 (6.8)	7.3 (6.5)	8.0 (7.3)	0.610
Median (range)	5.0 (0–24.5)	4.1 (0–21.7)	5.3 (0.3–24.5)	
Gynecological cancer diagnoses, *n* (%)				
Ovarian/tube/peritoneal	42 (46)	22 (42)	20 (50)	0.481
Cervical	27 (29)	15 (29)	12 (30)	
Corpus	16 (17)	9 (17)	7 (18)	
Vulvar	7 (8)	6 (12)	1 (3)	
Treatment, *n* (%)				
Surgery only	26 (28)	14 (27)	12 (30)	0.988
Radiotherapy only or combined with surgery, chemotherapy, or both[a]	26 (28)	15 (29)	11 (28)	
Surgery and chemotherapy	34 (37)	19 (37)	15 (38)	
Chemotherapy only	6 (7)	4 (8)	2 (5)	
Relapse, *n* (%)				
Yes	25 (27)	15 (29)	10 (25)	0.861
No	67 (73)	37 (71)	30 (75)	

Note: Percentages may not add up to 100 because of rounding.

[a]Radiotherapy only (*n* = 2), radiotherapy combined with surgery (*n* = 3), radiotherapy combined with chemotherapy (*n* = 13), and radiotherapy combined with surgery and chemotherapy (*n* = 8).

[b]Independent-samples *t* test and chi-squared test/Fisher's exact test.
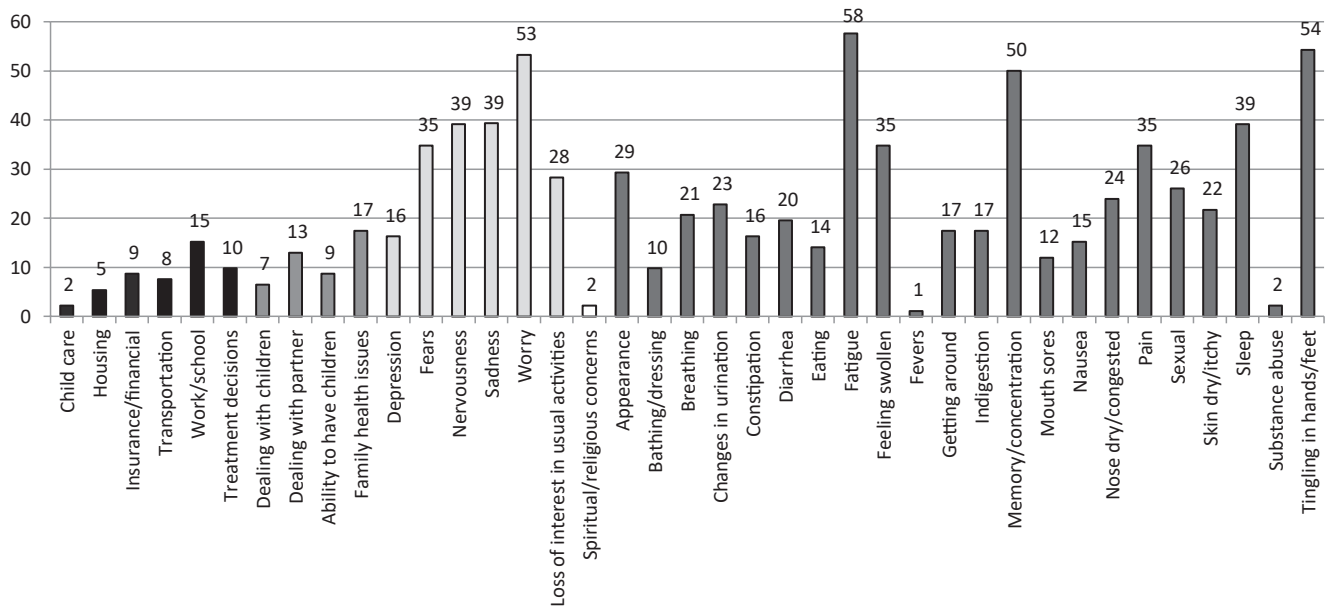
FIGURE 1 Percentage of participants reporting problems for the 39 items on the National Comprehensive Network Problem List

higher among women with distress than among those without distress (Table 2). Problems on the PL associated with distress were: dealing with partner, depression, fears, nervousness, sadness, worry, loss of interest in usual activities, appearance, memory/concentration, pain, sexual function, and sleep (Table 2).

Among those with distress, 75% had a problem with physical endurance, whereas 28% had a problem with physical endurance in the non-distressed group ($p < 0.001$). Likewise, 62% of distressed women reported having a problem with muscle strength compared with 18% in the non-distressed group ($p < 0.001$) (data not shown).

3.2 | Rehabilitation needs

Among all participants, 48 (52%) reported unmet needs for any rehabilitation service for one or more problems (Figure 2 and Table 3). Among those with distress, 33 (64%) reported unmet needs for any rehabilitation service versus 15 (38%) among those without distress (Table 3 and Figure 2). The number of women with "no", "met", and "unmet" rehabilitation needs for the total population, and grouped by distress of four or more and less than four, is shown in Table 3.

After going through responses to the NCCN DTPL and discussing the potential need for referrals, the doctors referred 29 (32%) of the 92 included to various rehabilitation services (Table 4). Of the 29 referred women, 20 (69%) reported distress (data not shown).

4 | DISCUSSION

In this study among gynecological cancer survivors, more than half of the women reported distress. The most prevalent reported

problems from the PL were fatigue, tingling in hands/feet, worry, and problem with memory/concentration. Problems associated with distress were dealing with partner, all emotional problems, appearance, memory/concentration, pain, sexual function, sleep, and problems with physical endurance and muscle strength. More than half of the women reported unmet needs for rehabilitation services. The proportion of women with unmet rehabilitation needs was higher among those with distress compared with the non-distressed group. One-third of the participants were referred to various rehabilitation services.

The prevalence of distress observed in our study is in line with previous studies among women with gynecological cancer examined before, during, and after treatment, reporting prevalence between 30% and 66%.[10–14] In studies with mixed cancer diagnoses and lung cancer, distress has been reported in between 23% and 62% of participants.[16–19] The mean level of distress in this study was 4.0, whereas three previous studies in gynecological cancer patients have reported a mean level of 2.7–3.7.[12,14,20,21] Further, in a large German multicenter study including cancer patients at various time points of the treatment trajectory, the subgroup of women with gynecological cancer ($n = 296$) had a mean distress level of 5.1.[22] However, these estimates are similar considering the statistical variation in data and potential differences among included patients. The participants in our study responded to the questionnaire during the weeks just before the follow-up visit at the hospital. As many patients often experience worries in the weeks before these visits, the prevalence and level of distress reported in our study may be overestimated compared with other studies.

The most commonly reported problems on the PL in our study were fatigue, tingling in hands/feet, worry, and problems with memory/concentration. Fatigue, worry, and tingling were also the three most common problems in the American cohort study of women

TABLE 2 Prevalence of problems on the National Comprehensive Network Problem List grouped by distress four or more versus distress less than four

	Distress ≥4 n = 52	Distress <4 n = 40	p value between groups[a]
Number of problems			
Mean (SD)	11.0 (5.0)	5.2 (5.0)	<0.001
Median (range)	10 (0–23)	4 (0–23)	
Practical problems	n (%)	n (%)	
Childcare	2 (4)		0.503
Housing	4 (8)	1 (3)	0.383
Insurance/financial	5 (10)	3 (8)	1.000
Transportation	6 (12)	1 (3)	0.133
Work/school	9 (17)	5 (13)	0.731
Treatment decisions	8 (15)	1 (3)	0.072
Family problems			
Dealing with children	5 (10)	1 (3)	0.228
Dealing with partner	11 (21)	1 (3)	**0.020**
Ability to have children	7 (14)	1 (3)	0.131
Family health issues	12 (23)	4 (10)	0.173
Emotional problems			
Depression	13 (25)	2 (5)	**0.022**
Fears	27 (52)	5 (13)	**<0.001**
Nervousness	28 (54)	8 (20)	**0.002**
Sadness	29 (56)	7 (18)	**<0.001**
Worry	37 (71)	12 (30)	**<0.001**
Loss of interest in usual activities	21 (40)	5 (13)	**0.007**
Spiritual/religious concerns	2 (4)		0.503
Physical problems			
Appearance	21 (40)	6 (15)	**0.016**
Bathing/dressing	8 (15)	1 (3)	0.072
Breathing	14 (27)	5 (13)	0.151
Changes in urination	13 (25)	8 (20)	0.752
Constipation	10 (19)	5 (13)	0.561
Diarrhea	11 (21)	7 (18)	0.863
Eating	11 (21)	2 (5)	0.057
Fatigue	35 (67)	18 (45)	0.053
Feeling swollen	20 (39)	12 (30)	0.533
Fevers		1 (3)	0.435
Getting around	12 (23)	4 (10)	0.173
Indigestion	11 (21)	5 (13)	0.419
Memory/concentration	33 (64)	13 (33)	**0.006**
Mouth sores	8 (15)	3 (8)	0.338
Nausea	11 (21)	3 (8)	0.130
Nose dry/congested	14 (27)	8 (20)	0.599
Pain	24 (46)	8 (20)	**0.017**
Sexual function	19 (37)	5 (13)	**0.018**
Skin dry/itchy	12 (23)	8 (20)	0.921
Sleep	26 (50)	10 (25)	**0.026**
Substance abuse		2 (5)	0.186
Tingling in hands/feet	33 (64)	17 (43)	0.073

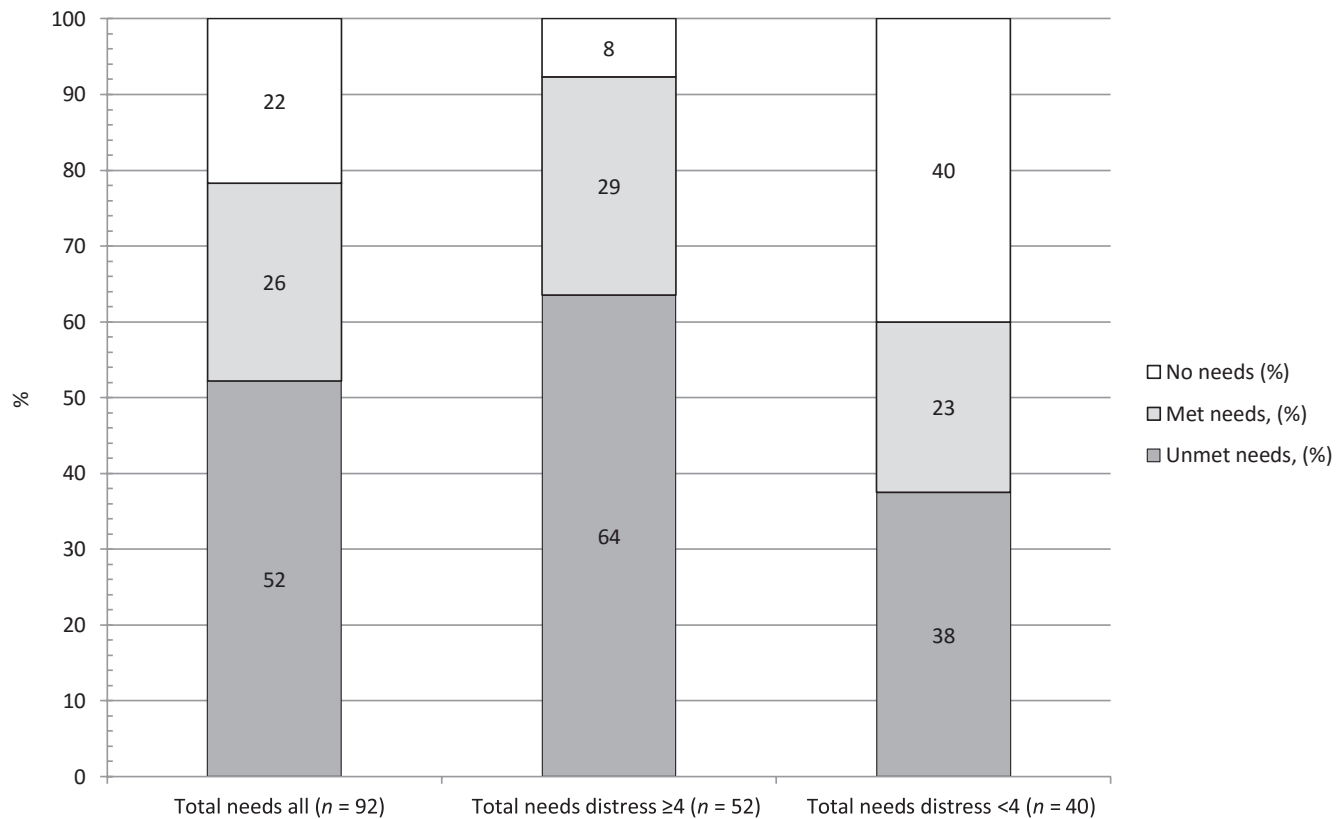[a]Independent-samples t test, chi-squared test, and Fisher's exact test.

FIGURE 2 Percentages of participants with met, unmet and no rehabilitation needs among all patients and grouped by distress four or more and distress less than four

with gynecological cancer.[14] In an American study before surgery, worry and fatigue were also among the four most commonly reported problems.[10] The high prevalence of neuropathy and cognitive problems in our study might be attributable to a high proportion of women who had been treated with chemotherapy, as opposed to the participants in the American study who were included before surgery.[10] As a result of the relatively short observation time since the last treatment in this study (mean 6.8 months), some of the patients might still be experiencing acute side effects of cancer treatment.

Earlier studies have reported that younger women,[10,13,20] highly educated women,[20] and women living alone[13] to be more likely to be distressed. Although results in the present study are not conclusive to confirm these previous findings, the proportions of these characteristics point in the same direction, and the lack of significant associations might be explained by the limited sample size. Two previous studies have reported cervical cancer[10] and multimodality treatment[21] to be associated with elevated distress. However, our results confirm a recent American study reporting no correlations between disease characteristics and distress.[20]

All emotional problems were associated with distress in bivariate analyses. Problems dealing with partner, problems with appearance, memory/concentration, pain, sexual function, sleep, and problems with physical endurance and muscle strength were also associated with distress. An Australian study among outpatient cancer patients with mixed diagnoses found an association between distress and emotional problems. A range of non-emotional problems such as

pain, transport, breathing, and fatigue were also associated with distress.[23] In an American study including women undergoing chemotherapy for gynecological cancer, emotional distress (worry and fear) was a significant predictor of distress in bivariate analyses.[21] Like us, they found an association between appearance and distress. Other factors associated with distress were concerns about family, nausea, and constipation.[21]

As might be expected, we found a positive association between distress and a greater number of problems, in line with a previous American study including patients before surgery for gynecological cancer.[10]

More than half of the women in this study reported having unmet needs for rehabilitation services for one or more problems. A high prevalence of rehabilitation needs was also found in a Norwegian study including more than 1300 patients with mixed cancer diagnoses. In that study, 40% of the included patients reported unmet needs for rehabilitation services.[24] Although comparisons to our study are limited by different samples, the higher prevalence of rehabilitation needs in our study might be a result of shorter observation time since diagnosis. This theory is supported by a Canadian study in gynecological cancer survivors, which reported that women who had completed treatment more recently had higher unmet needs and a higher desire for help.[25]

In our study, a high proportion of women experienced distress after treatment for gynecological cancer. As distress was not associated with specific subgroups, all gynecological cancer patients should be

TABLE 3 Rehabilitation needs among all participants and grouped by distress four or more versus less than four

Rehabilitation needs	All (N = 92)	Distress ≥4 (n = 52)	Distress <4 (n = 40)	p value between groups[a]
Sum rehabilitation needs[b]				
Unmet need, n (%)	48 (52)	33 (64)	15 (38)	0.001
Met need, n (%)	24 (26)	15 (29)	9 (23)	
No need, n (%)	20 (22)	4 (8)	16 (40)	
Practical problems				
Unmet need, n (%)	4 (4)	4 (8)	0	0.079
Met need, n (%)	9 (10)	7 (14)	2 (5)	
No need, n (%)	79 (86)	41 (79)	38 (95)	
Family problems				
Unmet need, n (%)	4 (4)	4 (8)	0	0.004
Met need, n (%)	7 (8)	7 (14)	0	
No need, n (%)	81 (88)	41 (79)	40 (100)	
Emotional problems				
Unmet need, n (%)	16 (17)	10 (19)	6 (15)	0.012
Met need, n (%)	19 (21)	16 (31)	3 (8)	
No need, n (%)	57 (62)	26 (50)	31 (78)	
Spiritual/religious concerns				
Unmet need, n (%)	0	0	0	1.000
Met need, n (%)	2 (2)	1 (2)	1 (3)	
No need, n (%)	90 (98)	51 (98)	39 (98)	
Physical problems				
Unmet need, n (%)	20 (22)	14 (27)	6 (15)	0.002
Met need, n (%)	36 (39)	26 (50)	10 (25)	
No need, n (%)	36 (39)	12 (23)	24 (60)	
Other problems[c]				
Unmet need, n (%)	35 (38)	25 (48)	10 (25)	0.026
Met need, n (%)	14 (15)	9 (17)	5 (13)	
No need, n (%)	43 (47)	18 (35)	25 (63)	

Note: Percentages may not add up to 100 because of rounding.

[a]Chi-squared and Fisher's exact tests.

[b]Need of rehabilitation for practical, family, emotional, religious, or other problems.

[c]Other problems were problems not included in any of the problem categories on the problem list (mainly problems with physical endurance and muscle strength).

considered at risk. As many women will be in need of follow-up and rehabilitation services, awareness of distress is important among healthcare professionals. In this study, all emotional problems were associated with distress, indicating that psychological interventions are crucial when we aim to diminish distress in gynecological cancer patients. However, the complexity of problems reported highlight the need for multidisciplinary rehabilitation services, including assistance from different healthcare professionals including psychologists, physicians, physiotherapists, sexologists, and social workers. Teaching patients how to self-manage might also be of benefit. In a study in women treated with surgery for gynecological cancer, the effect of conversations with a nurse focusing on the patient's challenges, problems, and self-management skills was tested. After 9 months, a significant effect on physical quality of life, including sleep, fatigue, and pain, was demonstrated.[26]

Although not significant, issues related to treatment decisions were more common among patients with distress of four or more than in patients with distress less than four. One could therefore speculate if these issues might lead to distress in gynecological cancer patients. Patients reporting this as a major cause of distress might benefit from a supplemental consultation with the physician or team responsible for their treatment.

As expected, more women with distress reported rehabilitation needs compared with patients who were not distressed. This indicates that assessing distress by the NCCN DTPL is helpful when assessing the need for rehabilitation services in a busy clinical hospital setting. However, as some women who did not report distress also had unmet rehabilitation needs, the instrument should be used together with a clinical interview. A screening tool adapted for women

TABLE 4 Overview of the rehabilitation services to which 29 of the 92 participants were referred to

Type of rehabilitation service	Number of women referred[a]
Services at Oslo University Hospital	
Fitness Center (for cancer patients)	5
Outpatient rehabilitation facility	8
Sexologist	2
Inpatient rehabilitation facility	4
Muncipal rehabilitation services	
Cancer coordinator	9
Healthy life center	3
Other	2

[a]A total of 29 women were referred; 4 were referred to two services and 25 were referred to one service.

with gynecological cancer and derived from the NCCN DTPL has been developed since this study.[27] The new instrument might be a relevant alternative communication tool for these patients because it is shorter and directed at problems specifically causing distress in women with gynecological cancer.

Although the survey response rate of 81% in our study is good, almost 20% of eligible women declined to participate. Reasons for declining to participate were not systematically assessed, but we consider the risk of response bias to be low as reasons not to participate might be not only related to a high level of distress with for example lack of energy, but also to a low level of distress and no need for rehabilitation.

Further studies with larger and more homogeneous subgroups might be helpful in investigating associations between age-dependent problems, such as problems with work or the ability to have children, and distress.

5 | CONCLUSION

The prevalence of distress in this population of women treated for gynecological cancer was high. The most commonly reported problems on the PL were fatigue, tingling in hands/feet, worry, and problems with memory/concentration. As there was an association between having a high number of problems and distress, and also between unmet rehabilitation needs and distress, the study indicates that the NCCN DTPL might be a helpful tool when assessing need for rehabilitation services in gynecological cancer patients' need for rehabilitation services. The complexity of problems identified warrants a multidisciplinary approach to gynecological cancer rehabilitation services.

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