



Cancer worry is associated with increased use of supportive health care—results from the multinational InCHARGE study

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Abstract

Purpose To assess use of health care following a diagnosis of endometrial, cervical, and ovarian cancer in the Netherlands, Norway, and Denmark. Furthermore, to analyze the association between cancer worry and use of supportive care.

Methods An international multicenter cross-sectional questionnaire study was undertaken among female cancer survivors with endometrial, cervical, or ovarian cancer 1–7 years post diagnosis. We investigated different aspects of cancer survivorship and follow-up care. Health care use included information on the use of supportive health care, general practitioner (GP), and follow-up visits to the department of gynecology. Cancer worry was assessed with the Impact of Cancer (IoCv2) questionnaire.

Results A total of 1433 women completed the questionnaire. Health care use decreased from time of diagnosis and was higher among cervical and ovarian cancer survivors than endometrial cancer survivors. Twenty-five percent of the women with ovarian cancer reported severe cancer worry, in contrast to 10 and 15% of women diagnosed with endometrial and cervical cancer, respectively. Women with severe worry had significantly higher use of supportive care activities. In a multivariable regression analysis, cancer worry remained a significant correlate for use of supportive health care services irrespective of disease severity or prognosis. The strongest association was found for use of a psychologist (OR 2.1 [1.71–2.58]).

Conclusion Cancer worry is associated with increased use of supportive care.

Implications for Cancer Survivors Targeted, timely, and accessible psychological support aimed at severe cancer worry may improve survivorship care and ensure optimal referral of patients in need of additional care.

Keywords Gynecologic cancer · Gynecologic malignancy · Cancer worry · Health care use

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Introduction

In recent years, the management and organization of survivorship care following gynecologic malignancies has been reorganized in several countries [1–3]. Formalized follow-up with scheduled specialist visits is increasingly replaced or supplemented with individualized survivorship care plans, patient-initiated follow-up, and telephone-led follow-up performed by nurses [4–7]. These approaches partly depend on the patient's ability to self-manage, and require appropriate support and education from the health care staff to succeed [8]. This transformation of follow-up care represents a paradigm shift and may enhance a more qualified and needs-directed use of specialist services, general practitioner (GP), and additional follow-up care. Further, this approach may improve quality of life for cancer survivors and increase the cost-effectiveness for the health care system [9]. However, randomized trials assessing the use of survivorship care plans and patient-initiated follow-up have also demonstrated increased disease concerns compared to standard care which may increase health care use [4, 6, 10].

Cancer worry includes fear of recurrence, i.e., worry that the cancer will return or progress, but also health concerns in general as well as concerns about the future [11, 12]. Cancer worry is a frequent and persistent concern among cancer survivors. In a systematic review by Simard et al. [13], fear of recurrence was reported by 38–97% of cancer survivors. It can be considered a rational response to the threat of recurrence, but high levels of worry are associated with increased perceived symptom burden that can lead to psychological distress, impairments in functioning, lower quality of life, and changes in use of health care [14, 15]. In a study by Lebel et al. [15], a high level of cancer worry predicted an increased use of emergency room and outpatient visits. Similarly, Nicolaije et al. demonstrated that overconsumption of follow-up visits after endometrial cancer was associated with high levels of cancer worry [16]. Previous studies also report an association between health anxiety and negative illness perceptions with increased GP visits [17, 18]. Hence, the impact of cancer worry on health care use seems plausible though more knowledge is needed regarding the type and extent of health care use to support and align future interventions.

The aim of this paper was to (1) compare the use of supportive health care (such as psychologists and physical therapists), GP and follow-up visits at the department of gynecology in patients with a diagnosis of endometrial, cervical, or ovarian cancer across three European countries and (2) to analyze the association between cancer worry and the use of these health care services.

We hypothesize that any association between cancer worry and health care use will be universal across the three countries. Hence, we present international data to enhance generalizability of the results.

Methods

Design

The paper is based on data from the InCHARGE study (International Collaboration of Healthcare professionals and Researchers for Gynecologic Cancer Survivors' Empowerment) [19], a multicenter, cross-sectional study examining aspects of cancer survivorship and follow-up care in the Netherlands, Norway, and Denmark.

Population

We included women diagnosed with endometrial, cervical, or ovarian cancer between January 1, 2011, and December 31, 2016, who were 1 to 7 years post diagnosis. The women were included from the Netherlands, Norway, and Denmark, and all disease stages were included. Women were excluded if they were younger than 18 years or were unable to complete the questionnaire. The method for inclusion varied between countries: In the Netherlands, survivors were sampled from the population-based Netherlands Cancer Registry and recruited from four hospitals. The women were invited to participate by postal mail from their gynecologist. In Norway, the women were recruited through the electronic patient system at six departments of gynecology and were contacted by mail by their gynecologist. In the Netherlands as well as in Norway, the women received a secure link to an online questionnaire, but they could request a paper questionnaire if preferred. In Denmark, a nationwide cohort was created with all women alive and diagnosed with endometrial, ovarian, or cervical cancer between January 1, 2013 and December 31, 2016. The cohort was identified from the Danish National Patient Register [20]. The women were contacted with an electronic questionnaire in a national e-box system, a Danish online mailbox that works as a secure source of communication between public services and Danish citizens. Approximately 20% of the identified women did not a priori accept the e-box system, and hence did not receive a questionnaire. The women without the e-box system typically represent older adults with cognitive impairments, who would be underrepresented in the Danish population. As this group is often less inclined to participate in questionnaire studies, they would most likely be underrepresented in the Dutch and Norwegian sample as well. Furthermore, 850 randomly

selected women diagnosed with ovarian or endometrial cancer were enrolled in another Danish questionnaire study and thus excluded from this study.

To ensure balance in the number of included women from Denmark in comparison with the Dutch and Norwegian inclusion, we randomly selected 200 endometrial and 150 cervical cancer patients from the Danish cohort to be included in the InCHARGE study. All included ovarian cancer ($N = 149$) survivors from Denmark were included in the InCHARGE study.

Outcome measures

The study outcomes were collected using a combination of questionnaires and national disease or cancer registries.

Cancer worry was assessed using the worry scale from the Impact of Cancer version 2 (IOCv2) questionnaire [21]. The scale consists of seven items regarding fear of recurrence and uncertainties about the future. The items are scored on a 5-point Likert scale from 1 to 5 with a high score indicating high levels of worry. The instrument has been psychometrically validated with Cronbach alpha coefficients of 0.89 [21] and has been widely used in Norwegian and Dutch oncology settings [22–24].

Information on health care use was collected through the following questions: “How often have you visited your GP in the past 12 months?” “How often were these visits related to the cancer diagnosis?” “How often did you attend gynecological specialist follow-up during the past 12 months?” Finally, the women were asked to indicate whether they had received additional care due to their cancer diagnosis from other sources? (yes/no), including a psychologist, physical therapist, sexologist, oncological revalidation, social worker, spiritual coaching, oncology nurse, or dietician.

Questionnaire items were developed to collect sociodemographic, clinical, and lifestyle information, i.e., comorbidity, recurrence, education, employment status, marital status, height, and weight. Information on treatment and FIGO stage was collected from the Netherlands Cancer Registry, from medical charts in Norway, and from the Danish gynecological cancer database [25, 26]. The exact date of diagnosis was obtained from cancer registries in the Netherlands and Denmark, while the year of diagnosis was self-reported by the women included in Norway.

Health literacy was assessed by a single item developed and validated by Chew et al. [27]: “How confident do you feel completing medical forms?” It was scored on a Likert scale from 1 to 5 with a low score indicating high health literacy.

Statistical analyses

We used frequencies with percentages, means with standard deviations, or medians with interquartile ranges (non-normal continuous) to describe the cohort and health care use. The level of cancer worry was reported as a mean sum score according to the questionnaire scoring manual [21], and further qualitatively categorized by the authors into three groups based on the response categories: no worry (mean < 2), intermediate worry (mean 2–< 4), and severe worry (mean 4 or more). Differences in worry between diagnoses were evaluated using a Pearson chi-squared test or one way ANOVA.

Multiple logistic regression models were designed to evaluate the association between cancer worry (mean sum score) and use of GP, specialist (gynecologist), psychologist, physical therapist, sexologist, oncological revalidation, social worker, spiritual coaching, oncology nurse, and dietician. Specialist use (i.e., visits to the gynecologist) was dichotomized as over-users yes/no based on the country-specific guidelines as explained in a previous publication by Skorstad et al. [19]. In short, Danish and Norwegian survivors were categorized as over-users if they had more than 4 specialist visits per year, in years 1–2 after diagnosis, and more than 2 visits per year, in years 3–5. Dutch ovarian and endometrial cancer survivors were over-users when they had more than 4 visits per year, in years 1–2, more than 3 visits per year, in year 3 and more than 2 visits per year, in years 4–5 post-diagnosis. Dutch cervical cancer survivors diagnosed before 2017 were defined as over-users when they had more than 4 visits in years 1 and 2 post diagnosis and in case of any visits from year 3. Women with recurrence and with more than 5 years after diagnosis were not included in this analysis.

For all types of health care use, univariate analyses were used to identify relevant covariates that should be adjusted for in the models. Factors tested were country, disease, FIGO stage, treatment modality, recurrence (except in analyses on specialist over-use as recurrent cases were excluded from these analyses), years since diagnosis, age, health literacy, number of comorbidities, and marital status. Factors with a p value < 0.10 were included using a forward inclusion approach. To ensure that models were not over-fitted, we required 10 outcome events per included variable [28]. Hence, models for use of sexologist, social worker, and spiritual coaching were only adjusted for years since diagnosis, and use of dietician for country, years since diagnosis, and tumor stage, as these were considered the most important covariates from a clinical standpoint.

Results from the multivariable models were presented as odds ratios (OR) with 95% confidence intervals (95% CIs). When a statistically significant association between worry level and health care use was found, the predicted probabilities were presented graphically using the predictive margins with 95% CI.

Results

Population

A total of 1433 women completed the study questionnaire; 699 women diagnosed with endometrial cancer, 403 with ovarian cancer, and 331 with cervical cancer (see flowchart in supplementary material). Participation rates were 47% in the Netherlands, 56% in Denmark, and 60% in Norway. Worry scores were available from 1401 women (98%).

Health care use

The median number of cancer-related GP visits and specialist follow-up visits with interquartile ranges is presented in Table 1.

Overall, we report a trend of decreasing health care use with years from initial diagnosis. Women diagnosed with endometrial cancer had significantly fewer visits to the GP compared to ovarian and cervical cancer in years 1, 2, 3, and 4 after diagnosis. Even so, after 3 years of follow-up, the median number of cancer-related GP visits was 0 for all three diagnoses. In total, 20% of the women diagnosed with endometrial cancer had one or more cancer-related GP visits during the overall follow-up period, whereas this number was 45 and 40% for ovarian and cervical cancer survivors, respectively ($p < 0.01$). Use of GP was similar across the three countries.

In accordance with this finding, women diagnosed with endometrial cancer attended significantly fewer specialist

Table 1 Cancer-related use of general practitioner, specialist follow-up, and additional health care

	Endometrial <i>n</i> = 699	Ovarian <i>n</i> = 403	Cervical <i>n</i> = 331	<i>p</i>
Cancer-related GP use, median (IQR)				
Years 1 and 2	0 (0–1)	1 (0–4)	1 (0–4)	< 0.01
Third year	0 (0–0)	0 (0–3)	0 (0–1)	0.01
Fourth year	0 (0–0)	0 (0–1)	0 (0–1)	< 0.01
Fifth year	0 (0–0)	0 (0–1)	0 (0–0)	0.10
> 5 years	0 (0–0)	0 (0–1.5)	0 (0–1)	0.17
Any GP use, <i>n</i> (%)	130 (20)*	175 (45)**	131 (40)***	< 0.01
Specialist use, median (IQR)				
Years 1 and 2	3 (2–4)	3 (2–4)	4 (3–4)	< 0.01
Third year	2 (1–2)	3 (2–4)	2 (1–3)	< 0.01
Fourth year	1 (0–2)	2 (1–3)	1 (0.5–2)	< 0.01
Fifth year	1 (0–1)	2 (1–3)	1 (1–1.5)	< 0.01
> 5 years	0 (0–1)	1 (0–2)	1 (0–1)	0.01
Specialist over-use, <i>n</i> (%)	48 (9)	54 (21)	47 (18)	< 0.01
Additional health care, <i>n</i> (%)				
Psychologist	38 (5.4)	57 (14)	67 (20)	< 0.01
Physiotherapist	86 (12)	96 (24)	70 (21)	< 0.01
Sexologist	11 (1.6)	4 (0.99)	28 (8.5)	< 0.01
Oncological revalidation	50 (7.2)	79 (20)	49 (15)	< 0.01
Social worker	9 (1.3)	15 (3.7)	7 (2.1)	0.03
Spiritual coaching	8 (1.1)	13 (3.2)	9 (2.7)	0.045
Oncology nurse	64 (9.2)	55 (14)	36 (11)	0.07
Dietician	23 (3.3)	30 (7.4)	26 (7.9)	< 0.01

GP and specialist use is reported as medians with interquartile ranges. Use of additional health care is reported as frequencies with percentages. Test for differences is done with the chi2 test

*Fifty-one missing values

**Eleven missing values

***Three missing values

follow-up examinations compared to women diagnosed with ovarian and cervical cancer. The difference remained significant beyond 5 years of follow-up. Women diagnosed with ovarian and cervical cancer still had a median of 1 visit per year, 5 years after diagnosis. Over-use of follow-up visits according to the recommended guidelines was significantly higher in women with a diagnosis of ovarian (21%) and cervical cancer (18%) as compared to endometrial cancer (9%).

Table 1 also presents the number and proportion of women using supportive care following their cancer diagnosis. Women with endometrial cancer had a significantly lower use of additional health care compared to cervical and ovarian cancer although we found no difference in number of visits to an oncology nurse or social worker (see Table 1). The women most frequently visited a physical therapist (24% ovarian, 21% cervical, 12% endometrial), psychologist (14% ovarian, 20% cervical, 5% endometrial), and oncological revalidation (20% ovarian, 1% cervical, 7% endometrial). Women diagnosed with cervical cancer had a significantly higher use of sexologist compared to endometrial and ovarian cancer (9% vs. 1% ovarian and 2% endometrial, $p < 0.01$).

Cancer worry and health care use

In the population of 1401 gynecologic cancer survivors, 22% presented with no/very little worry, 63% with intermediate worry and 15% with severe worry (Table 2). Cancer worry varied significantly with diagnosis and the highest level of cancer worry was reported by ovarian cancer patients; one in four (97/396) women with ovarian cancer reported severe cancer worry, compared to 10% (69/675) of women diagnosed with endometrial cancer. Severe worry was significantly associated with more advanced disease stage ($p < 0.01$), chemotherapy and radiation therapy ($p < 0.01$ and 0.02, respectively), recurrent disease ($p < 0.01$), presence of at least one comorbid condition ($p = 0.03$), younger age ($p < 0.01$), and lower levels of health literacy ($p = 0.02$). No difference in the level of worry was found between the three countries.

Figure 1 depicts the association between additional health care use and the level of worry. Women with severe worry had a significantly higher use of all types of additional health care.

In the multivariable logistic regression analyses, mean cancer worry remained a significant variable associated with all types of health care services, except specialist over-use and spiritual coaching, when adjusting for relevant covariates (Table 3). The strongest association was found for use of psychologist, where an increase of 1 point in the mean level of worry would lead to a 2.1-fold increase in the odds of visiting a psychologist (OR 2.1 [95% CI 1.71–2.58]). The model was adjusted for country, time since diagnosis, use of

chemotherapy, and age, as these were significant factors in the univariate analysis.

Based on the logistic regression models, Fig. 2 depicts the predicted probabilities of using additional health care by the mean level of worry. The figures show that the probability of using additional care services increased with the mean worry score, e.g., from 22.5% at mean score 2 to 43.2% at mean score 4 for use of GP or from 2.7% at mean score 2 to 18.1% at mean score 4 for use of psychologist.

Discussion

In this study of women from three different countries, use of health care after a gynecologic cancer diagnosis decreased over time from initial diagnosis and varied with the type of cancer, i.e., women with ovarian and cervical cancer reported a higher use of health care compared to endometrial cancer survivors. Aside from specialist provided follow-up examinations, the GP was the most frequent supportive care provider independent of diagnosis. This finding suggests that the GP is an important gatekeeper who provides support for women after cancer treatment. The GP represents continuous and coordinated care provision that may result in improved survivorship care and more personalized care [29]. In a previous study of health care use after endometrial cancer, the women had a mean of one cancer-related GP visit during the past 12 months and younger women were more likely to visit the GP [30]. In a cross-sectional study of GP use in prostate cancer survivors, 42% of the population reported cancer-related contact to their GP. This corresponds well with our previous findings in cervical and ovarian cancer [31]. Those with a higher educational level, treated with surgery or hormonal therapy, with symptoms from their cancer or treatment, and those who were satisfied with their GP, were more likely to contact their GP [31]. Indeed, in previous studies, GP-led follow-up after breast and colon cancer was a feasible alternative to specialist follow-up [32, 33], and GPs as well as patients support and advocate for a greater role for the GP in cancer follow-up care [34].

In this study, cancer worry was associated with increased use of health care. This finding is recognized in previous literature. In the population-based study by Thong et al. [18], negative illness perceptions, including concern, were associated with a higher health care use in endometrial cancer patients and over-consumption of endometrial cancer follow-up examinations was associated with high levels of cancer worry in the study by Nicolaije et al. [16]. Furthermore, Cannon et al. [35] found a significant association between worry and contact to follow-up providers in a mixed population of cancer survivors. In

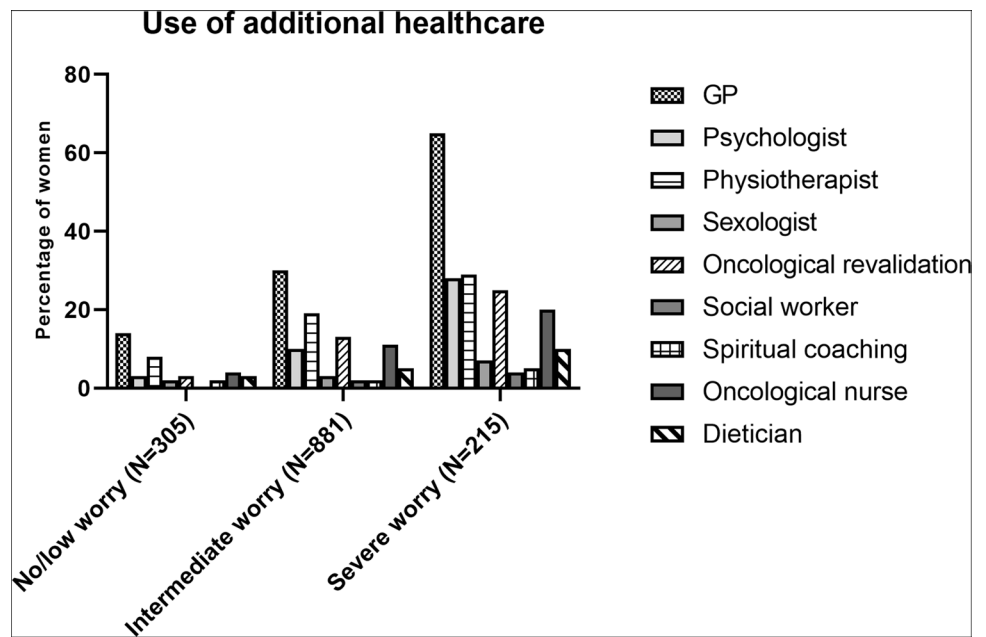
Table 2 Baseline characteristics by the levels of worry

	Levels of worry			<i>p</i>
	No/very little <i>N</i> =305 (%)	Intermediate <i>N</i> =881 (%)	Severe <i>N</i> =215 (%)	
Disease				
- Endometrial	200 (66)	406 (46)	69 (32)	
- Cervical	49 (16)	232 (26)	49 (23)	
- Ovarian	56 (18)	243 (28)	97 (45)	<0.01
Country				
- The Netherlands	131 (43)	326 (37)	76 (35)	
- Norway	84 (28)	233 (26)	52 (24)	
- Denmark	90 (30)	322 (37)	87 (40)	0.09
Stage				
- I	241 (82)	567 (67)	97 (47)	
- II	21 (7)	109 (13)	25 (12)	
- III	27 (9)	131 (15)	68 (33)	
- IV	6 (2)	40 (5)	16 (8)	<0.01
Primary treatment*				
- Surgery	285 (93)	791 (90)	192 (89)	0.14
- Chemotherapy	69 (23)	364 (41)	136 (63)	<0.01
- Radiotherapy	45 (15)	194 (22)	46 (21)	0.02
- Hormonal treatment	9 (3)	36 (4)	11 (5)	0.45
Recurrence				
Years since diagnosis, mean (SD)	4.2 (1.9)	3.9 (2.0)	3.7 (1.7)	0.04
Age, mean (SD)	66.0 (11.7)	61.6 (13.9)	58.4 (13.5)	<0.01
Marital status				
- Married/cohabiting	206 (68)	580 (67)	147 (70)	
- Divorced/separated	25 (8)	79 (9)	20 (10)	
- Widowed	48 (16)	131 (15)	28 (13)	
- Single	24 (8)	82 (9)	15 (7)	0.88
Educational level				
- Primary	54 (18)	121 (14)	30 (14)	
- Secondary	92 (30)	283 (32)	58 (27)	
- Medium	93 (31)	284 (32)	76 (36)	
- Higher	64 (21)	188 (21)	50 (23)	0.50
Employed (%yes)	107 (35)	359 (41)	89 (41)	0.21
Comorbidity				
- None	101 (33)	269 (31)	54 (25)	
- 1	105 (35)	277 (31)	62 (29)	
- 2 or more	98 (32)	335 (38)	99 (46)	0.03
BMI, mean (SD)	27.9 (6.3)	27.6 (6.2)	27.5 (5.8)	0.45
Smoking status				
- Never	156 (51)	421 (48)	105 (49)	
- Former	127 (42)	370 (42)	87 (41)	
- Current	21 (7)	89 (10)	22 (10)	0.51
Health literacy	1.42 (0.8)	1.6 (0.7)	1.6 (0.8)	0.02

Categorical variables are presented with frequencies and compared using Pearson chi2 test. Continuous variables are presented with means and standard deviations and compared with a one-way ANOVA test

*More treatment modalities are possible per patient

Fig. 1 Use of additional health care stratified according to worry



The differences in use of additional health care according to worry level were statistically significant with $p < 0.05$ for all types of health care (chi-squared test). No worry (mean < 2), intermediate worry (mean $2 - < 4$), and severe worry (mean 4 or more).

Table 3 The association between cancer worry and health care use (dependent variable) assessed by logistic regression analysis

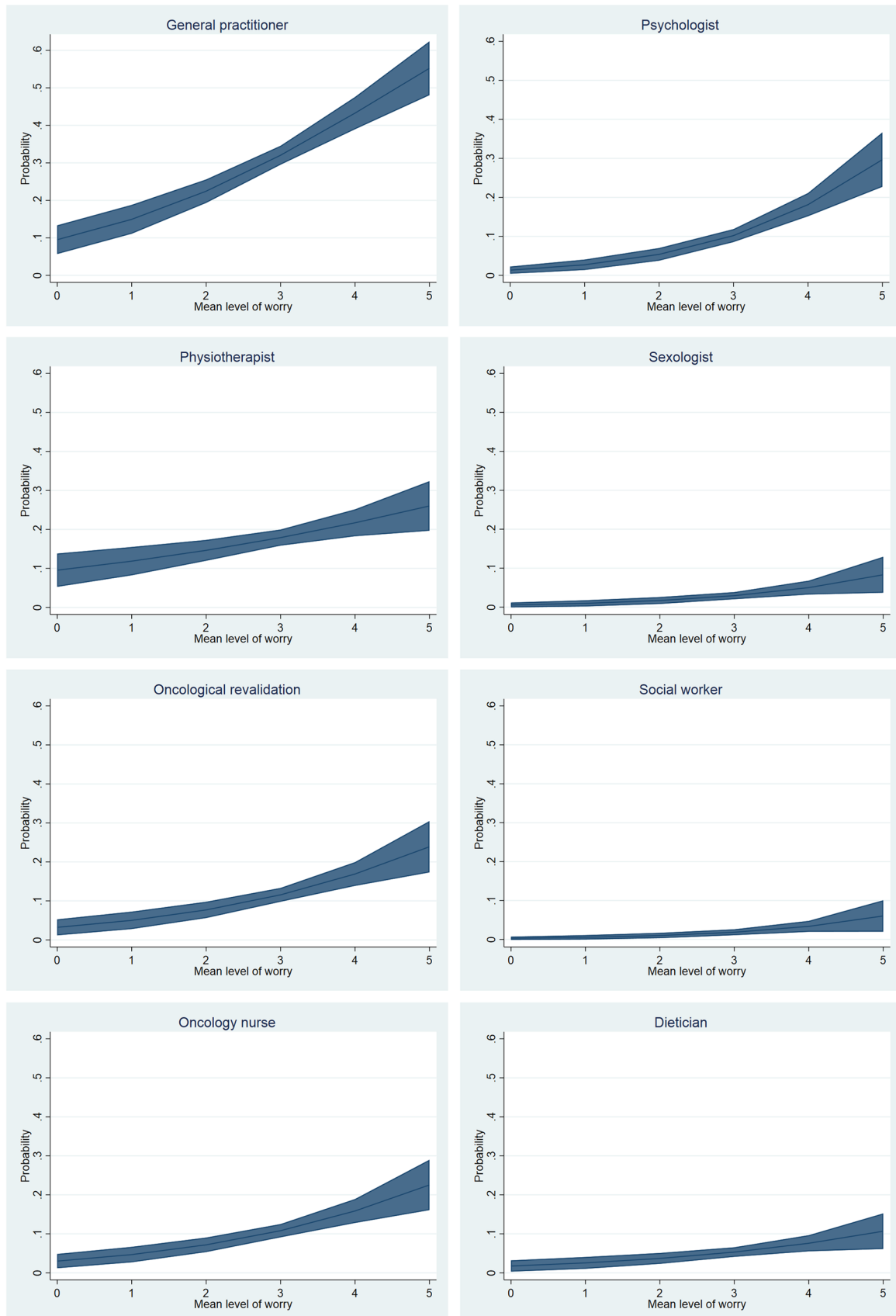
Type of health care	Mean score (SD) + health care use	Cancer worry		
		Mean score (SD) No health care use	OR	95% CI
Cancer-related GP use	3.3 (1.0)	2.6 (1.0)	1.76	1.52–2.05
Specialist over-use	2.9 (1.1)	2.7 (1.0)	1.09	0.90–1.32
Psychologist	3.5 (0.9)	2.7 (1.0)	2.10	1.71–2.58
Physiotherapist	3.2 (1.0)	2.7 (1.0)	1.28	1.10–1.50
Sexologist	3.3 (1.0)	2.8 (1.0)	1.77	1.27–2.47
Oncological revalidation	3.4 (0.9)	2.7 (1.0)	1.60	1.32–1.95
Social worker	3.5 (0.8)	2.8 (1.0)	1.85	1.25–2.73
Spiritual coaching	3.2 (1.1)	2.8 (1.0)	1.33	0.92–1.92
Oncology nurse	3.3 (1.0)	2.7 (1.0)	1.60	1.32–1.94
Dietician	3.3 (1.0)	2.8 (1.0)	1.48	1.15–1.89

Cancer worry was analyzed as a continuous variable. ORs of 1.00 represent the reference category. Significant ORs are highlighted in bold

our study, the strongest association was found for use of psychologist which may indicate a relevant referral pattern and/or efficient self-capacity to seek out relevant supportive care to help alleviate worry. Even so, in this population of women 1–7 years post-diagnosis, severe worry still persisted among 10 to 25% of the women.

In this study, cancer worry was associated with more advanced disease stage, chemotherapy and radiation therapy, recurrent disease, presence of comorbid condition, younger age, and lower levels of health literacy. Cancer worry can be considered a rational response to a cancer

diagnosis. However, high and persistent levels of cancer worry may be a symptom of more serious psychological and functioning impairments. In a study by Smith et al. [36], severe fear of recurrence was associated with post-traumatic stress symptoms in a population of breast, colorectal, and melanoma cancer survivors. Furthermore, Hanprasertpong et al. [37] demonstrated an association between cancer worry and anxiety disorder and low quality of life in cervical cancer survivors. Hence, cancer worry is an important late effect to gynecological cancer and its treatment which should be treated with relevant



The figures display the predictive margins with 95% CI. Over-use of specialist and use of spiritual coaching was not included, as the association with worry was not significant in the logistic regression analysis.

Fig. 2 The predicted probabilities of using additional health care according to the mean worry score

psychological and therapeutic interventions. Furthermore, providing patients with proper education on risk and symptoms of recurrence is important to help the woman manage the feeling of worry and master the situation.

There is limited knowledge of efficient interventions aimed at reducing cancer worry [38]. Helpful therapeutic aims include normalization, psychoeducation, and self-efficacy. Normalization helps the patient understand when the fear is not normal, and psycho-education gives the patient an understanding of the bodily reactions to fear [38]. In a study of breast cancer survivors, Ziner et al. demonstrated an association between high self-efficacy and low fear of recurrence [39]. Cognitive behavioral therapy that incorporates these mechanisms seems a promising treatment option [13, 40]. Future trials will help increase our understanding of this type of interventions and their efficacy in treating cancer worry [38].

In all three countries participating in this study, access to a psychologist with government subsidy requires severe pathology and referral from the general practitioner or specialist. Furthermore, there is a shortage of psychologists in general, and women may have to wait several months to get an appointment. This system may be a barrier for the women to seek help, and easier access to care may help reduce psychological concerns. In line with this, barriers exist across several types of health care services, including use of dietician, sexologists, etc. Hence, women without “severe pathology” may go unseen, and the need of supportive care may be underestimated in this paper as the use of additional services is limited by availability.

Screening for distress may ensure supportive care for the right patients. A useful instrument is the distress thermometer which consists of a VAS indicating the level of distress. It is furthermore accompanied by a problem list including 35 items that help indicate the source of distress: practical, family/social, emotional, spiritual, and physical. It has been studied as a screening tool [41], and though it does not perform as a diagnostic tool, it has demonstrated effective in ruling out elevated distress [42]. Hence, it may be useful as a first-hand screening tool to help guide referral of the right patient to the right type of supportive care.

In this study, less than 10% of the women with cervical cancer and only 1% with ovarian and endometrial cancer consulted a sexologist. Several longitudinal studies [20–23] have described the impact of treatment on sexuality in cervical cancer patients including dyspareunia, lack of lubrication, vaginal shortness, and decreased sexual activity. It is likely that women with these issues

would benefit from consulting a sexologist, and it is essential that sexual difficulties are addressed during follow-up, and help is provided to avoid long-term sequelae. In an ongoing trial from the Netherlands, women diagnosed with a gynecologic cancer and undergoing radiotherapy are randomized to a nurse-led sexual rehabilitation intervention to improve sexual recovery (SPARC: NTR7175). In the intervention, the women receive four 1-h sessions with an oncology nurse trained in sexology. Findings from the pilot study indicate that this intervention is helpful for the women to resume sexual activity [43].

The strengths of this study include the large sample size and the fact that it includes data on health care use and cancer worry across three different countries. No difference in the level of worry or use of GP was found across the three countries; hence, pooling of the data across countries was deemed appropriate for the purpose of this paper.

Some limitations are present. Health care use was investigated in three different countries, and access to care may vary, i.e., in Denmark, the use of additional health care relies on referral by the general practitioner whereas in the Netherlands, and in Norway, the gynecologist can refer patients to additional care as well. Even so, we consider these differences minor with minimal effect on the reported associations. It does however mean that each additional care visit would also be related to a GP/specialist visit, i.e., two visits per need. This study uses a cross-sectional design, and we cannot with certainty conclude on the causality on the reported associations. The participation rate for the study was 47–60% depending on country, which is to be expected of this study design. Even so, we cannot rule out selection bias, i.e., women with more problems post diagnosis may not have had the energy to participate, and it is possible that the reported health care use and cancer worry levels are underestimated. On the other hand, those with the most symptoms may wish to report them, thus leading to overestimation [44, 45]. In the Danish population, women without the e-box system were not invited to participate in the study. This may lead to a selection bias towards younger/more educated patients in the Danish sample. Information on health care use was self-reported, and recall bias may be present. Furthermore, the women were asked to indicate whether the use of additional care was related to the cancer diagnosis. This can be challenging for women with multiple comorbidities, and some information bias may be present.

In our study, we report an association between cancer worry and low levels of health literacy. Health literacy was measured by a single item developed and validated in a population of veterans in a primary care setting and generalizability to a female population could be questioned [27]. However, the item was also accurate in detecting limited health literacy in a population of 205 women attending hospital outpatient visits [46], and use of the multi-item scale did not perform better than the single item [27].

Conclusions

Women treated for a gynecologic malignancy use a variety of health care following diagnosis, including specialist care, GP, physical therapy, psychologists, and oncological revalidation. Severe cancer worry is reported in 10–25% of survivors and associated with increased use of additional health care services, even after adjustment for disease stage and treatment. The strongest association with cancer worry was found for use of psychologist. Even so, a considerable proportion of patients with severe worry do not receive supportive care aside from their GP.

Individualized information on risk and symptoms of recurrence and easier access to psychologists is important to help survivors manage severe cancer worry. Screening for worry could facilitate targeted and timely interventions and improve survivorship care.

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Author contribution Authors MMJ, SHB, BR, MS, NE, LF, IV, and PTJ designed the study. All authors were involved in the data collection. MMJ, SHB, BR, and PTJ performed the data analyses. MMJ wrote the manuscript and all authors discussed the results and contributed to the final manuscript.

Data availability The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Competing interests The authors declare no competing interests.

Ethics approval The InCHARGE study was approved by the Regional Committee of Medical Research Ethics in Norway (2018/441) and the Danish Data Protection Agency (18/39742). In the Netherlands, the Medical Ethical Committee provided declarations that ethical evaluation was not needed, as the study does not fall under the Medical Research Involving Human Subjects Act (NW2018-38). Data from the three countries were anonymized before pooling and analyses.

Consent to participate Informed consent was obtained from all individual participants included in the study.

Conflict of interest The authors declare no competing interests.

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