

Cancer patients' interest in participating in cancer rehabilitation

Emma Ohlsson-Nevo^{a,b}, Ingrid Alkebro^c and Johan Ahlgren^{d,e}

^aDepartment of Surgery, Faculty of Medicine and Health, Örebro University, Örebro, Sweden; ^bFaculty of Medicine and Health, University Health Care Research Center, Örebro University, Örebro, Sweden; ^cDepartment of Oncology, Örebro University Hospital, Örebro, Sweden; ^dDepartment of Oncology, Faculty of Medicine and Health, Örebro University, Örebro, Sweden; ^eRegional Oncological Centre Uppsala-Örebro, Uppsala, Sweden

ABSTRACT

Introduction: Rehabilitation for cancer patients aims at preventing and reducing the physical, mental, social and existential consequences of a cancer disease and its treatment. The aim of this study is to describe the patients' self-perceived interest in participating in cancer rehabilitation (CR).

Material and methods: A total of 1179 cancer patients, diagnosed with 28 different cancer diagnoses, from November 2015 to October 2016, were identified via the national cancer quality registers. A questionnaire was developed for the purpose of this study, the Cancer Rehabilitation Interest. The questionnaire comprises 16 different rehabilitation activities. This study describes what activities the patients are interested to participate in.

Results: The response rate was 62% and the final sample comprised 728 patients. The rehabilitation activities wanted by the cancer patients were *Psychoeducational support group together with others with the same cancer diagnosis*, *Open lectures on cancer*, *Individual weight training with a physiotherapist* and *Personal support from a social worker*. Most interested in cancer rehabilitation were women, younger patients, university educated patients and those who had received their diagnosis ≥ 12 months prior. Patients with a mandatory educational level had the lowest interest in all suggested activities compared with those having medium or high education.

Conclusions: The interest of cancer rehabilitation of all approached patients in this study were 21%. Most interested were women, young patients, university educated and those who received their diagnosis ≥ 12 months earlier. About 30% of the participating cancer patients reported an interest of information and supportive groups, physical training and support from a hospital social worker. Patients with low level of education reported a low interest in CR. There are limitations in rehabilitation accessibility and that might affect a person's motivation to participate in this study.

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Introduction

A growing number of cancer survivors recover and return to a life after the cancer diagnosis. Supportive cancer care strategies and cancer rehabilitation (CR) have been developed to reduce the impact of the disease and its treatment [1,2]. The aim of CR is to optimize daily functioning and quality of life, by addressing adverse physical, psychological and social symptoms that patients may suffer, during and after cancer treatment [3]. The long-term medical, psychological and practical needs along the survivorship trajectory need to be addressed as health problems may occur months or year after treatment [4]. Physical rehabilitation for cancer patients aims at maintaining or obtaining muscular strength and physical endurance and contributes to improved health and physical and functional outcomes [5–7]. Mental rehabilitation involves psychotherapy, psychoeducation and relaxation, which can be effective methods for reaching better psychological functioning as well as better health-related quality of

life (HRQoL) [8,9]. Yoga can be effective in improving HRQoL [5] as well as reducing fatigue, sleep disturbance and depression in breast cancer patients [10]. Specific stress reduction programs for cancer patients can improve HRQoL [5], and online support groups have reduced psychological distress [11]. Psychosocial interventions, including meeting others in the same situation, can help cancer patients to manage uncertainty and existential distress [12].

The need for rehabilitation has in previous studies been found to be 26–70% [13–15]. Studies describing what type of rehabilitation activities patients wants to participate in are scarce. A perceived need is not equivalent to actually wanting to participate in an active rehabilitation. Rehabilitation may involve a change of behavior, such as increased physical activity, that may be demanding after a tiresome cancer treatment. A behavior change needs motivation. The theory of self-determination describes the basis for motivations for all humans as: competence (feel personal active, capable and

CONTACT Emma Ohlsson-Nevo  emma.ohlsson-nevo@regionorebrolan.se  Centre for Health Care Sciences, Örebro University Hospital, P.O. Box 1324, Örebro SE-701 13, Sweden

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confident), relatedness (feeling understood, supported and connected) and autonomy (personal control) [16–19]. The extent these three needs are fulfilled might reflect the interest in participate in CR.

The present study is part of a larger project, the Mid-Sweden Cancer Rehabilitation Survey, with a purpose to investigate HRQoL and the interest of CR for people diagnosed with, and treated for, cancer in the Region of Örebro County, Sweden. The aim of this study is to describe the patients' self-perceived interest in participating in CR.

Material and methods

Study design

The study has a descriptive cross-sectional design. A postal survey was conducted in Region Örebro County, situated centrally in the southern half of Sweden, with a population of 290,000 inhabitants, of whom 250,000 live in a city or a small-town area and 40,000 in rural areas.

Sample

A total of 1179 patients who received a cancer diagnosis between 1 November 2015 and 31 October 2016 were identified through a number of population-based quality registers based on a common IT platform, the Information Network for Cancer (INCA). The quality registers' completeness, when compared with the Swedish Cancer Register (SCR), to which reporting of all tumors is mandated by law, is >95%. The SCR itself has a completeness of close to 100% [20]. The final sample comprised the following diagnoses: breast, upper GI-tract, urological, gynecological, lung, thyroid, colorectal, head and neck, hematological, malignant melanoma, sarcoma and pituitary tumors. Deceased were removed after control with the national population register.

Procedure

A nine-page questionnaire comprising demographic questions, the Stigma-related Social Problems scale, EORTC-QLQ and the informational module INFO, and a screening tool, developed for the purpose of this study; the Cancer Rehabilitation Interest (CRI), were distributed along with an information letter and a prepaid response envelope via regular mail during April 2017. After two weeks, a thank you and reminder card was sent to all 1179 persons. If the questionnaire was not returned after five weeks, a reminding letter and a new questionnaire were sent out. In the present study, the results of the CRI questionnaire are presented.

Data protection

The questionnaires were marked with a study object number, no names or personal security number were present. The key to the numbers were stored in a locked cabinet only accessible for one research group member. The Regional Ethical

Review Board of Uppsala approved of the study (reference Dnr 2016/287).

Questionnaire

Cancer Rehabilitation Inventory (CRI). Interest in participating in CR activities was reported by the questionnaire CRI, comprising 16 items representing rehabilitation activities. The items included physical activity (four items), stress reduction (three items), information (one item), psychosocial support groups (four items), sexual counseling (one item), professional individual support (two items) and smoking cessation (one item). The patients were asked to 'Indicate to what extent you would choose to participate in the following activities'. The response options were ranged on a four-point response scale from 'very likely to attend', 'likely to attend', 'not likely to attend' and 'do not know/do not want attend'. Patients could add their own suggestions for additional activities at the end of the questionnaire. A qualitative pilot test was conducted before this study, with the aims of evaluating the cognitive understanding of the questionnaire [21] and possibly identifying additional items. A total of 16 cancer patients participated and the selection of participants was based on diversity in age, sex and diagnosis. Data were collected via a structured face-to-face interview conducted by one of the authors (IA). The understanding was good and nothing was found to be irrelevant or upsetting. No additional questions were added after the pilot test.

Statistical methods

Socio-demographic data are presented as means and standard deviations (SD) for continuous variables and as frequencies and proportions for categorical variables. Pearson's chi-square test was used to test proportions. Comparisons of three groups or more were tested using Linear-by-Linear Association test. Two-group comparisons were performed with Student's *t*-test for continuous data and the Mann–Whitney U-test for ordinal data.

The response options 'very likely to attend' and 'likely to attend', in the CRI scale, were transformed to 'interested to attend' and is presented as percentage. An activity was arbitrarily considered as an interest if more than 25% of respondents wanted to attend.

Results

Sample characteristics

The final sample consists of 728 patients, which gives a response rate of 62%. Women constituted 43% of the sample and men 57%. The mean age was 67.9 years (range 25–96 years) and the median age was 70 years. There were 64 patients (9%) younger than 50 years of age. Characteristics of the study population such as diagnosis, distribution of educational levels, and time from diagnosis and cancer treatments are given in [Table 1](#).

Table 1. Patients' characteristics.

	No (%)	Prostate	Breast	Colo-rectal	Urinary tracta	Skin	Blood ^b	Lung	GI ^c	Gynecological ^d	Head/neck	Other ^e
Total	728	170 (23.4)	120 (16.5)	96 (13.2)	81 (11.1)	67 (9.0)	51 (7.0)	39 (5.4)	30 (4.1)	27 (3.7)	26 (3.6)	21 (2.9)
Sex												
Woman	316 (43.4)	0	120 (100)	49 (51.0)	16 (19.8)	32 (47.8)	19 (37.3)	17 (43.6)	11 (36.7)	27 (100)	10 (38.5)	14 (66.7)
Man	412 (56.6)	170 (100)	0	47 (49.0)	65 (80.2)	35 (52.2)	32 (62.7)	22 (56.4)	19 (63.3)	0	16 (61.5)	7 (33.3)
Age												
Mean (sd)	67.9 (12.3)	71.4 (7.6)	62.8 (13.3)	72.2 (10.3)	68.8 (13.9)	66.1 (15.0)	65.4 (15.6)	69.2 (7.5)	66.3 (8.1)	68.5 (13.5)	66.3 (13.3)	59.0 (14.5)
Median	70.0	72	63	73	72	68	68	70	66.1	70	67.5	59
Range	25–96	47–89	28–87	39–95	25–95	34–96	27–96	48–85	51–86	28–87	37–86	36–82
20–39	24 (3.3)	0	7 (5.8)	1 (1.0)	4 (4.9)	3 (4.5)	4 (7.8)	0	0	1 (3.7)	1 (3.8)	3 (14.3)
40–49	40 (5.5)	1 (6)	15 (12.5)	2 (2.1)	3 (3.7)	8 (11.9)	3 (5.9)	1 (2.6)	0 (0)	1 (3.7)	3 (11.5)	3 (14.3)
50–59	86 (11.8)	13 (7.6)	22 (18.3)	6 (6.3)	8 (9.9)	10 (14.9)	8 (15.7)	3 (7.7)	5 (16.7)	3 (11.1)	3 (11.5)	5 (23.8)
60–69	213 (29.3)	51 (30.0)	39 (32.5)	30 (31.3)	21 (25.9)	14 (20.9)	11 (21.6)	15 (38.5)	14 (46.7)	7 (25.9)	7 (26.9)	4 (19.0)
70–79	251 (34.5)	83 (48.8)	22 (18.3)	35 (36.5)	29 (35.8)	15 (22.4)	17 (33.3)	18 (46.2)	10 (33.3)	10 (37.0)	8 (30.8)	4 (19.0)
80+	114 (15.7)	22 (12.9)	15 (12.5)	22 (22.9)	16 (19.8)	17 (25.4)	8 (15.7)	2 (5.1)	1 (3.3)	5 (18.5)	4 (15.4)	2 (9.5)
Education												
Mandatory	227 (31.2)	64 (37.6)	20 (16.7)	39 (40.6)	23 (28.4)	14 (20.9)	18 (35.3)	17 (43.6)	11 (36.7)	7 (25.9)	8 (30.8)	6 (28.6)
High school	215 (29.5)	44 (25.9)	35 (29.2)	28 (29.2)	13 (16.0)	21 (31.3)	13 (25.5)	7 (17.9)	10 (33.3)	10 (37.0)	9 (34.6)	5 (23.8)
University	187 (25.7)	33 (19.4)	49 (40.8)	19 (19.8)	33 (40.7)	21 (31.3)	14 (27.5)	9 (23.1)	6 (20.0)	6 (22.2)	8 (30.8)	9 (42.9)
Other	85 (11.7)	27 (15.9)	10 (8.3)	10 (10.4)	10 (12.3)	9 (13.4)	6 (11.8)	4 (10.3)	3 (10.0)	4 (14.8)	1 (3.8)	1 (4.8)
Missing	14 (1.9)	2 (1.2)	6 (5.0)	0 (0)	2 (2.5)	2 (3.0)	0	2 (5.1)	0	0	0	0
Months from diagnosis												
6	51 (7.0)	15 (8.8)	3 (2.5)	5 (5.2)	4 (6.0)	4 (6.0)	5 (10.4)	5 (12.8)	2 (6.7)	0	6 (23.1)	0
7–9	173 (23.8)	41 (24.1)	33 (27.5)	28 (29.2)	19 (23.5)	8 (11.9)	14 (29.2)	14 (35.9)	8 (26.7)	3 (11.1)	3 (11.5)	2 (10.5)
10–12	184 (25.3)	33 (19.4)	34 (28.3)	23 (24.0)	23 (28.4)	21 (31.3)	13 (27.1)	6 (15.4)	12 (40.0)	10 (37.0)	6 (23.1)	3 (15.8)
13–15	191 (26.2)	50 (29.4)	29 (24.4)	25 (26.0)	20 (24.7)	22 (32.8)	9 (18.8)	6 (15.4)	6 (20.0)	9 (33.3)	7 (26.9)	8 (42.1)
16–18	124 (17.0)	31 (18.2)	21 (17.5)	15 (15.6)	13 (16.0)	12 (17.9)	7 (14.6)	8 (20.5)	2 (6.7)	5 (18.5)	4 (15.4)	6 (31.6)
Treatment												
Chemo ^f	146 (20.0)	0	52 (43.3)	40 (41.7)	8 (9.9)	0	0	27 (69.2)	13 (43.3)	2 (7.4)	0	4 (19.0)
Radiation ^f	172 (23.6)	43 (25.7)	60 (50)	17 (17.7)	3 (3.7)	0	19 (37.3)	6 (15.4)	0	1 (3.7)	16 (61.5)	7 (33.3)
Surgery	472 (64.8)	20 (11.8)	117 (97.5)	84 (87.5)	79 (97.5)	67 (100)	0	17 (43.6)	25	27 (100)	18 (69.2)	18 (85.7)

^aBladder, testicular, penis.^bKLL, KML, lymphoma, myeloma.^cPancreas, liver/gallbladder, ventricle, esophagus.^dCervical, endometrial, ovarian, vaginal- and vulvar cancer.^eBrain tumor, thyroid (gland), sarcoma.^fPlanned or given.

Table 2. Diagnosis and rehabilitation participation, n (%)

	Total	Prostate	Breast	Colorectal	Urinarytract ^a	Skin	Blood ^b	Lung	GI ^c	Gynae-cologic ^d	Head/neck	Other ³
<i>n</i>	728	170	120	96	81	67	51	39	30	27	26	21
Psychoeducational / same	248 (34)	54 (32)	51 (43)	35 (38)	16 (23)	20 (30)	21 (41)	11 (30)	11 (39)	11 (41)	9 (35)	9 (45)
Open lectures about cancer	222 (30)	50 (30)	40 (34)	36 (39)	14 (19)	26 (39)	15 (30)	6 (16)	11 (39)	12 (44)	6 (23)	6 (30)
Social worker	212 (29)	49 (29)	54 (46)	19 (21)	16 (21)	24 (36)	14 (28)	10 (27)	6 (21)	7 (26)	5 (19)	8 (40)
Weight training / individual PT	216 (29)	42 (25)	45 (38)	25 (27)	17 (22)	27 (41)	18 (36)	9 (24)	9 (32)	9 (33)	4 (15)	9 (45)
Cardio / individual PT	202 (28)	42 (25)	47 (40)	18 (19)	16 (21)	21 (32)	17 (34)	11 (31)	11 (38)	9 (33)	3 (12)	2 (10)
Online support group / same	198 (27)	46 (27)	33 (28)	28 (31)	12 (16)	24 (36)	14 (28)	8 (22)	10 (34)	9 (33)	7 (27)	7 (35)
Medical yoga	164 (22)	18 (11)	54 (46)	17 (18)	11 (15)	14 (21)	9 (18)	7 (19)	8 (28)	13 (48)	5 (19)	8 (40)
Psychologist	155 (21)	26 (15)	39 (33)	15 (16)	12 (16)	18 (27)	15 (29)	6 (17)	6 (21)	4 (15)	5 (19)	9 (45)
Stress reducing / individual	142 (19)	21 (13)	37 (32)	14 (15)	11 (15)	20 (31)	9 (18)	7 (19)	5 (17)	5 (18)	4 (15)	9 (45)
Cardio / group	134 (18)	23 (14)	35 (29)	15 (16)	10 (13)	12 (18)	12 (24)	9 (25)	6 (20)	9 (33)	1 (4)	7 (37)
Strength training / group	118 (16)	20 (12)	30 (25)	14 (15)	11 (15)	13 (19)	9 (18)	4 (11)	7 (25)	7 (26)	1 (4)	8 (40)
Psychoeducational / mix	106 (15)	25 (15)	18 (15)	16 (17)	8 (11)	11 (17)	6 (12)	2 (5)	6 (21)	7 (26)	3 (12)	4 (20)
Web info group / mix	88 (12)	19 (11)	9 (7)	11 (12)	6 (8)	9 (14)	7 (14)	7 (19)	4 (14)	6 (22)	4 (15)	6 (30)
Sexual counseling	89 (12)	35 (21)	12 (10)	9 (10)	9 (12)	5 (8)	6 (12)	3 (8)	3 (11)	5 (18)	1 (4)	1 (5)
Stress reducing / group	82 (11)	13 (8)	23 (20)	8 (8)	6 (8)	11 (17)	5 (10)	1 (3)	4 (15)	14 (15)	3 (11)	4 (20)
Smoke cessation	22 (3)	6 (4)	5 (4)	2 (2)	3 (4)	1 (1)	1 (2)	2 (6)	1 (4)	1 (4)	0	0
Activities wanted by more than 25%	6	4	10	5	0	8	7	3	6	10	2	10

Numbers in bold denote most wanted activity per diagnosis.

Yellow denotes wanted by ≥25%.

^aBladder, testicular, penis.

^bKLL, KML, AML, lymphoma, myeloma.

^cGastrointestinal; pancreas, liver, gallbladder, ventricle, esophagus.

^dCervical, endometrial, ovarian, vaginal and vulvar.

^eBrain tumor, thyroid (gland), sarcoma.

Cancer rehabilitation

The most wanted CR activities were Psychoeducational support group together with others with the same cancer diagnosis (Psychoeducational SGs), wanted by 34%; Open lectures on cancer, 30%; Individual weight training assisted by a physiotherapist, 29%; and Personal support from a social worker, 29% (Table 2). As only 23 patients (3%) were interested in support for smoking cessation, it will not be further reported in this study.

Physical training (cardio and weight) was wanted by 16–29%, informational sessions and support groups by 12–34% (psychoeducational, lectures, online); visits to a social worker or psychologist by 21–29%; stress management including medical yoga by 11–22%; and sexual counseling by 12% (Table 2). The interest in CR according to sex, age, education, time from diagnosis and treatment is shown in Table 3.

Men and women

There were significant differences between men and women in 11 of the activities ($p < .02$). More than 25% of the women wanted to participate in 10/16 activities, whereas three activities were wanted by more than 25% of the men. The only activity that interested men more than women was Sexual counseling (17% vs 7%, ($p < .00$). The most popular activities for women were Psychoeducational SGs ($n = 129$, 42%), Medical yoga ($n = 120$, 39%) and Support from a social worker ($n = 111$, 36%). Men wanted Psychoeducational SGs ($n = 119$, 30%), Open lectures on cancer ($n = 121$, 30%), and Individual weight training assisted by a physiotherapist ($n = 106$, 26%).

Age

The interest in organized CR decreased significantly with increasing age for all types of activities (Table 3). Twelve of the activities were wanted by >25%, and of these, eight

activities attracted more than half of persons in the ages 20–39 years.

The three most wanted activities among the youngest were Individual stress management ($n = 89$, 67%), Support from a social worker ($n = 16$, 67%) and Medical yoga ($n = 15$, 62%). The youngest age group differed from all other sub-groups in this study, as a large proportion (67%) wanted Support from a social worker. Patients younger than 70 years were interested in participating in 7 to 12 activities. The largest age group, 70–79 years ($n = 251$), were interested in two activities, Open lectures about cancer ($n = 63$, 26%) and Psychoeducational SGs ($n = 70$, 29%). In the oldest age group (80+ years), there was no rehabilitation activity wanted by more than 25%, although 20% were interested in Individual weight training with a physiotherapist and 22% in seeing a psychologist.

Education level

Interest in organized increased significantly with higher educational levels (Table 3). Among persons with university education, >25% wanted to participate in 10 activities compared with 9% among those with high school education. Patients with only the mandatory level of education reported lower interest; 4–22% reported an interest in rehabilitation. The most wanted activity for both the university- and high school-educated respondents was Psychoeducational SGs (39–47%). About 40% of the university educated wanted to participate in Individual weight training with a physiotherapist, Open lectures about cancer and Online support groups including people with the same diagnosis (Online SGs).

Time from diagnosis

Interest in rehabilitation activities significantly increased with time from diagnosis in two activities (Individual weight training and Cardio individually with physiotherapist) ($p = < .003$).

Table 3. Wanted rehabilitation activities by sex, age and education (number and proportion yes)

	Cardio in individ.. group		Weight training with PT Individ.		Stress management group		Stress management individ..		Medical yoga about cancer		Psychoeducational support (mixed)		Psychoeducational support (same)		Online Group (Mixed)		Online Group (same)		Social worker		Psychologist counselling		Sexual		Smoke cessation	
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Total	728	134 (18)	202 (28)	118 (16)	82 (11)	142 (19)	164 (22)	222 (30)	106 (15)	248 (34) ^a	88 (12)	198 (27)	212 (29)	155 (21)	89 (12)	23 (3)										
Sex																										
Woman	316	79 (26)	103 (34)	67 (22)	51 (17)	89 (30)	120 (39)	102 (33)	51 (17)	129 (42) ^a	39 (13)	98 (32)	111 (36)	92 (30)	22 (7)	10 (3)										
Man	412	55 (14)	99 (25)	51 (13)	31 (8)	53 (13)	44 (11)	121 (30)	55 (14)	119 (30) ^a	49 (12)	100 (25)	100 (25)	63 (16)	67 (17)	12 (3)										
p^1	.00	.00	.13	.00	.00	.00	.36	.28	.00	.00	.82	.02	.00	.00	.00	.82										
Age (year)																										
20-39	24	8 (33)	11 (46)	8 (33)	6 (25)	16 (67) ^a	15 (62)	14 (58)	5 (21)	14 (58)	8 (33)	14 (58)	16 (67) ^a	14 (58)	4 (17)	2 (8)										
40-49	40	11 (28)	18 (45)	8 (20)	8 (20)	22 (55)	20 (50)	17 (42)	8 (20)	22 (55)	10 (25)	22 (55)	26 (65) ^a	8 (20)	1 (2)											
50-59	86	33(38)	35 (41)	26 (30)	22 (25)	25 (29)	29 (34)	32 (37)	21 (24)	42 (49) ^a	15 (17)	38 (44)	36 (42)	21 (24)	4 (5)											
60-69	213	33(16)	66 (31)	31 (15)	22 (11)	47 (22)	60 (28)	76 (36)	36 (17)	82 (39) ^a	31 (15)	67 (32)	64 (31)	50 (24)	25 (12)	12 (6)										
70-79	251	37 (15)	54 (22)	36 (15)	19 (8)	22 (9)	35 (14)	63 (26)	27 (11)	70 (29) ^a	20 (8)	49 (20)	51 (21)	32 (13)	28 (11)	2 (1)										
80+	114	12 (11)	18 (17)	9 (8)	5 (7)	10 (9)	5 (5)	20 (19)	9 (8)	18 (16)	4 (4)	8 (7)	19 (18)	9 (22)	3 (3)	1 (1)										
p^2	<.00	<.00	<.00	<.00	<.00	<.00	<.00	<.00	.001	<.00	<.00	<.00	<.00	<.00	<.00	.01										
Education																										
Mandatory	227	27 (12)	36 (17)	24 (11)	10 (4)	18 (8)	23 (10)	50 (23) ^a	22 (10)	48 (22)	16 (7)	32 (15)	42 (19)	24 (11)	17 (8)	7 (3)										
High school	215	41 (19)	66 (31)	37 (17)	32 (15)	56 (26)	55 (26)	73 (34)	41 (19)	84 (39) ^a	35 (16)	73 (34)	71 (38)	56 (26)	29 (14)	10 (5)										
University	187	50 (27)	71 (38)	39 (21)	31 (17)	53 (29)	67 (36)	74 (40)	34 (18)	89 (47) ^a	27 (15)	76 (41)	71 (34)	61 (33)	28 (15)	5 (3)										
Other	85	14 (17)	24 (30)	16 (20)	7 (9)	12 (15)	18 (22)	22 (28)	8 (10)	24 (30)	10 (12)	16 (20)	23 (28)	11 (14)	15 (18)	0										
p^2	<.00	<.00	<.00	<.00	.001	<.00	<.00	.001	.09	<.00	<.00	<.00	<.00	<.00	<.00	.416										
Time from diagnosis (months)																										
6	51	4 (8)	10 (20)	2 (4)	6 (13)	9 (18)	7 (14)	10 (21)	5 (10)	14 (29)	8 (17)	15 (31)	11 (23)	7 (15)	6 (12)	2 (9)										
7-9	173	25 (15)	40 (24)	20 (12)	11 (6)	31 (19)	34 (20)	47 (28)	27 (16)	55 (32) ^a	22 (13)	42 (25)	51 (30)	33 (20)	20 (12)	7 (4)										
10-12	184	34 (19)	57 (32)	31 (17)	27 (15)	46 (25)	53 (29)	56 (31)	26 (14)	65 (36) ^a	19 (10)	44 (24)	50 (28)	44 (24)	31 (17)	6 (3)										
13-15	191	41 (22)	58 (32)	38 (20)	25 (13)	33 (18)	46 (25)	70 (38) ^a	31 (17)	69 (37)	21 (11)	57 (31)	59 (32)	40 (22)	18 (10)	3 (2)										
16-18	124	30 (25)	36 (30)	27 (22)	13 (11)	23 (19)	24 (20)	39 (32)	17 (14)	45 (37)	17 (14)	39 (39) ^a	41 (34)	31 (26)	14 (12)	4 (3)										
missing	22	3 (3)	26 (4)	24 (3)	27 (4)	29 (4)	23 (3)	28 (4)	28 (4)	22 (3)	22 (3)	26 (4)	25 (3)	30 (4)	48 (7)											
p^2	0.003	0.11	0.001	0.49	0.79	0.39	0.51.	0.47	0.72	0.21	0.79	0.21	0.18	0.15	0.55	0.31										
Treatment																										
Chemotherapy	146	38 (26)	50 (35)	35 (24)	22 (15)	34 (24)	49 (34)	55 (38)	20 (14)	62 (43) ^a	16 (11)	49 (34)	51 (36)	38 (27)	17 (12)	7 (5)										
Radiation	172	29 (17)	46 (27)	23 (13)	16 (9)	31 (18)	43 (25)	44 (26)	23 (14)	53 (31) ^a	18 (11)	39 (23)	49 (29)	38 (22)	12 (7)	2 (1)										
Surgery	472	95 (21)	131(29)	89 (19)	63 (14)	106 (23)	132 (29)	156 (34)	74 (16)	169 (37) ^a	62 (14)	136 (30)	148 (32)	111 (24)	53 (12)	14 (3)										

p^1 = Chi2; p^2 = Linear-by-Linear association; PT: physiotherapist; yellow >50%; green 26-50%.
^aHighest value in the row.

Those six months post diagnosis were interested in two activities, *Psychoeducational SGs* (29%) and *Online SGs* (31%). Patients 7–9 months post diagnosis wanted four activities and those 10–15 months after diagnosis wanted six activities. Patients with the longest time span from the cancer diagnosis (16–18 months) wanted to participate in seven of 16 activities.

Diagnosis

The interest in participation in different activities by diagnosis is shown in Table 2. There were significant differences between the diagnoses in the proportion of patients wanting to participate in *Cardio in a group*, ($p < .02$), *Individual stress management* ($p < .00$), *Medical Yoga* ($p < .00$), *Open lectures on cancer* ($p < .04$), *Support from a social worker* ($p < .004$) and *Session with a psychologist* ($p < .00$). Patients diagnosed with gynecologic or breast cancer were most interested in CR, followed by others (brain tumor, thyroid, sarcoma), blood, skin and gastrointestinal cancer.

Discussion

This is the first study that evaluates the interest in participating in 16 rehabilitation activities for cancer patients. The main findings from this study are that informational and supportive activities were the most wanted, followed by support from a social worker and physical activities. The patients in this study preferred psychoeducational support with patients with the same diagnosis. The presence of others that are going through similar experiences and sharing the same problems can alleviate loneliness and give a new belonging [19]. The group support has been described as being supportive in a way that is different from the support one can get from other friends, sometimes described as ‘closeness without words’ [22]. It is possible that group support with other diagnoses are suspected to be too diverse to give adequate support.

The patients in the present study seem to prefer individual support with physical activities. A previous study, support these findings concluding a preference of receiving personalized information as well as individualized interventions to increase motivation and engagement in physical activities [23].

The interest in participating in CR in this study varied. For the whole group of 728 patients, six of the activities were wanted by more than 25% of the patients. In some subgroups, the interest was greater. Women were highly interested in rehabilitation which corresponds with the review by Mirosevic [24] and with a Danish study where women were more likely to express a need for rehabilitation treatment [13]. The younger patients had a large interest in CR in our study and the findings are similar to other studies, who find a higher number of unmet needs among young patients [13,24].

Our study differs from the result of Mirosevic [24] as those with the longest time elapsed since the diagnosis reported a higher interest in participating in rehabilitation than those

more recently diagnosed. Another Scandinavian study supports our findings as 30% of the patients expressed a rehabilitation need 14 months after treatment [13]. Health problem and side effects can arise months and years after active treatment, and patients may need support [4] and rehabilitation [15,25–29].

A structured assessment of rehabilitation needs, including evaluating symptoms and side effects, needs to be performed repeatedly, to discover and help to reduce discomforts that might burden the patients.

An interesting finding was that among those with only mandatory-level education, rehabilitation activities attracted only 3–23%. Earlier studies have shown that low education is associated with low health literacy [30,31]. Health literacy corresponds to the degree to which individuals have the capacity to obtain, process and understand health information needed to make appropriate health decisions [32]. Patients with low health literacy ask fewer questions [33] and may not understand information well enough to ask and engage actively in their care [34]. Low health literacy can be an explanation to why there was a low interest in participating in CR, among those with only mandatory education, in the present study. It was somehow surprising that despite the variety of activities (both physical activities as well as informational support), few with only mandatory education wanted to participate. This is also an important finding, since health literacy is independently associated with HRQoL among cancer patients [35]. Educational DVDs [36], individual decision aids [37] as well as simplification of information [38] have shown promising results in overcoming the barriers of low health literacy, although interventions to increase participation in rehabilitation are scarce in the literature.

The higher interest in CR among women, younger patients and those with higher education in this study can be explained by previous studies reporting that these groups have a high need of information [39] and are shown to be active information seekers [40]. Information seekers might have knowledge of the importance of physical activity for cancer patients as well. rehabilitation activities they wanted to attend.

An interest in CR may reflect a personal motivation to commit and engage in activities. Without knowledge about the expected benefits of rehabilitation, skills and experiences, the variable for self-determination competence is not fulfilled. Without support and feeling of belonging, the relatedness is missing as well. There are differences in accessibility and information about CR in Sweden. Only a few cities have rehabilitation centers [41] and the questions could have been experienced as hypothetical as some of the activities felt out of reach. Despite the supportive care strategies described in policy document and legislation (national cancer strategy and patient act) there are several patients who report not being offered stimulated support [42].

Of the 728 participants in this study, 89/248 patients were interested in educational, mental or physical support in a county with 290,000 inhabitants. The result can help health care services to tailor rehabilitation activities for cancer patients.

A strength of this study was that all patients in the county who were diagnosed with cancer during a 12-month period and registered in an INCA-based quality register were asked to participate in the study. The result gives an indication of which diagnoses or subgroups are interested in participating in CR. The low response rate (62%) can be seen as a limitation, although one might assume that those interested in CR did participate in the study, which means that the rather low interest in rehabilitation is more likely to be under- than over-estimated. The most wanted activity, Psychoeducational support groups including patients with the same cancer diagnosis was wanted by 248 of all approached patients, which is 34% of responding patients but 21% of all patients approached.

It was a rather low proportion of patients who were interested in the 16 types of CR in our study, although more than 200 patients wanted to participate in five of the activities. The result of this study indicates that health care services have to develop accessible rehabilitation activities in close cooperation with the patients. The low proportion of patients interested in some rehabilitation activities could reflect that some groups of patients have a low degree of anxiety and depression [43]. In an interventional Swedish breast cancer study, around half of the 821 patients who were asked to participate declined [44]. The most common reasons were that they did not feel distressed (31%), they had other commitments (19%) or they had too far to travel (18%). These types of reasons could well have played a role in our study as well, since the catchment areas of the two studies are quite similar.

The patients' interest in rehabilitation more than 18 months after diagnosis was not addressed in our study. The extent of long-term need of rehabilitation should be the subject of further studies. Whether a structured assessment of CR need can enhance recovery, reduce long-term consequences or influence patients' working capacity is yet to be proven.

Conclusions

The interest of all approached patients in this study was 21%. The interest in CR varied, and most interested were women, young patients, university educated and those who received their diagnosis ≥ 12 months earlier. About 30% of the participating cancer patients reported an interest in information and supportive groups, physical training and support from a hospital social worker.

Patients with a self-assessed low level of education reported a low interest in CR. Limitations in CR accessibility might affect patients' motivation to participate.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Disclosure statement

The authors have no conflict of interest to disclose.

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