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Research in Danish cancer rehabilitation: Social characteristics and late effects of cancer among participants in the FOCARE research project

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Abstract

Worldwide, the number of cancer survivors is increasing, owing to improvements in cancer therapy, resulting in an increased need to address the physical and mental sequelae of cancer. This paper introduces a Danish psychosocial cancer intervention and presents the baseline characteristics of the cancer survivors with respect to cancer site, sociodemographic variables, social network, lifestyle, self-rated health and the prevalence of cancer-related late effects. The study is part of the FOCARE research project, in which the long-term effects of the rehabilitation programme are evaluated systematically. The study is based on data from a self-administered baseline questionnaire filled in by 2 174 cancer survivors who registered for a 1-week, publicly paid rehabilitation retreat and were invited to participate in the FOCARE study in the period 25 November 2002 to 31 December 2005. The response rate at baseline was 86% (n = 1876). Most participants were younger women with breast cancer. They were generally well educated and working. The cancer survivors reported having comprehensive social networks and being physically active. Several cancer-related symptoms were reported by women with cancers at selected sites, of which fatigue was the most prevalent. More than half reported good-to-excellent self-rated health, while fair-to-poor health was reported by 40%, most of whom were survivors of lung (56%) and haematological (48%) cancers. The results indicate that Danish cancer survivors experience considerably reduced physical health, possibly as late physical effects of treatment. The problems reported by the cancer survivors suggest that cancer rehabilitation should include these aspects of living after cancer and take account of differences among cancer survivors with regard to cancer site, sex, age, family, working status and social position. These challenges might be addressed optimally in multi-dimensional rehabilitation programmes.

Worldwide, the number of cancer survivors is increasing, probably due to earlier diagnosis, improvements in cancer therapy and better general health [1]. In the Danish population of 5.4 million people, more than 300 000 are cancer survivors [2]. Several studies have shown that both cancer itself as well as the primary treatment can result in a wide range of physical, psychological and social late effects [3–9], suggesting a straightforward explanation for the high levels of distress that have been associated with cancers at many different sites [10].

After diagnosis and initial treatment, cancer patients must cope with considerable life changes, including physical, psychological and existential issues. Rehabilitation can begin when decisions have been taken about treatment, as it plays a key role in enabling cancer survivors to adjust to their situation and return to as normal a life as possible. The programmes are often multi-focused and include physical as well as psychosocial and educational interventions [11,12]. They are designed not only to alleviate the effects of cancer but also to influence and perhaps change the lifestyle and health behaviour of cancer survivors. Previous studies have shown positive effects on important aspects such as quality of life and level of depression [13]. In

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addition, rehabilitation programmes can have socio-economic benefits, reducing the use of public or insurance-paid health system services and increasing the probability of cancer survivors returning to work [14]. Most studies published so far, however, have been limited by small numbers, a cross-sectional design, lack of detailed tumour characteristics and no clear description of the rehabilitation programme offered [13].

The aim of the FOCARE research project is to evaluate systematically the long-term effects of a well-defined psychosocial intervention programme provided at the Rehabilitation Centre Dallund. In the present paper, we introduce this programme and give detailed information about the intervention provided and the baseline characteristics of the participants with respect to cancer site, socio-demographic variables, social network, lifestyle, self-rated health and the prevalence of cancer-related late effects.

Material and methods

Between November 25, 2002 and December 31, 2005, 2 174 cancer survivors who registered for a 1-week rehabilitation retreat at the Rehabilitation Centre Dallund were invited to participate in the FOCARE study. Inclusion in the study was based on the general criteria for attending the rehabilitation retreat: all persons with cancer who had completed primary treatment, who needed rehabilitation and who were able to participate physically in the activities offered. There were no restrictions with respect to time since diagnosis. All participants in this study had applied for the intervention and thereby represent a selected population of cancer survivors.

Intervention

Each week, 20 cancer survivors are offered a 6-day retreat in a fully restored mediaeval castle. The retreat consists of a combination of lectures and patient group work on themes such as the treatment of cancer, psychological reactions, spirituality, sexuality, working life and lifestyle. The programme is conducted by a multi-disciplinary team consisting of a medical doctor, two nurses, a physiotherapist, a social worker, a psychologist and a number of free-lance experts (e.g. a dietician and a vicar or theologian) who are affiliated with the rehabilitation centre. Each day, participants are involved in a combination of physical activities and lectures on the above themes. Individual consultations can be held with all the experts. The daily menu represents a healthy diet.

The intervention aims at strengthening each individual's understanding of his or her situation and, by increasing freedom of action, encouraging joy of living, hope and belief in the future. The organizers consider that this programme helps cancer survivors to achieve the best possible levels of physical, mental and social functioning. At the end of the course, each participant produces a personal, specific 'action plan', which is intended to serve as a 'booster' to support the 'action points' that each cancer survivor has chosen to focus on in their rehabilitation after returning to daily life.

Questionnaire

All 2 174 participants were asked to fill in four self-administered questionnaires at baseline and 1, 6 and 12 months after finishing their rehabilitation course. Before each follow-up questionnaire was mailed out, the vital status of each participant was checked in the Central Population Register through the unique 10-digit personal identification number assigned to all Danish residents since 1968, which includes gender and date of birth.

The content of the four questionnaires was similar, except that participants reported socio-demographic information (marital status, education, employment history before the cancer diagnosis and annual household income) only at baseline. We classified all participants as married or cohabiting or living alone (divorced, widowed or single). Educational level was classified according to the International Standard of Education [15] into basic education (basic school), youth education (high school and vocational training) and higher education (college and university). The employment status of the participants was categorised as working, on sick leave or unemployed or on any kind of pension; household income was classified as low (EUR 0–31 000), medium (EUR 31 500–70 000) or high (EUR $\geq$ 70 500).

The participants also reported lifestyle habits such as alcohol consumption, tobacco smoking, physical activity, eating habits and the structure of their social network. Alcohol consumption was reported in units consumed per day within the past week and summarised as units per week. The number of reported alcohol abstainers was subtracted in the calculation of median number of units. Further, participants were divided into those who smoked every day, occasionally (weekly or less than weekly), previously or never. All current smokers, regardless of smoking frequency, were classified as smokers. Physical activity was reported as hours per week spent on recreational activity (walking, biking and other sports) and household activity (cleaning, shopping,

gardening, household maintenance). Participants stated whether their eating habits were healthy and were given ten options to characterise the types of healthy foods consumed. In this paper, we report the five most frequently chosen options. The structure of the social network was assessed by the presence of various relationships and the frequency of face-to-face or telephone contact with these persons. Self-rated global health was categorised as excellent/very good, good or fair/poor. Actual physical status was measured as a self-reported comparison with persons of the same age in relation to fitness and muscular strength. Further, the participants reported their perception of the importance of their efforts to preserve their health and whether such efforts were made.

Finally, the participants reported a number of physical and cognitive symptoms related to their treatment for cancer on a symptom check-list, specifying whether the symptom was present and, if so, whether it had been present before the diagnosis of cancer. The present report covers the 14 most frequently reported symptoms in relation to cancers of the breast, female genital organs, colon and rectum, prostate and lung as well as haematological malignancies.

Statistical analysis

We applied a multiple regression model with gender or participation as the dependent variable. All models were adjusted for age. The FREQ, UNIVARIATE and GLM procedures in SAS release 9.1 was used for the analyses.

Results

Of the 2 174 cancer survivors invited to participate in the study, 1 876 (86%) returned the baseline questionnaire and a signed informed consent form. Most of the participants were women (85%; n = 1586) (Table I), and they were significantly younger than the men (median age, 55 vs. 59 years). Most of the women had had breast cancer, whereas prostate cancer, colorectal cancer and haematological malignancies were the most prevalent cancers for the men. Generally, the participants were well educated, although more men had had vocational education (39% vs. 29%) and more women had had higher education (49% vs. 39%). Most of the participants were working (61%), only 7% being on sick leave or unemployed. When age was accounted for, there was no difference in employment status between men and women (Table I).

Women reported a higher frequency of contacts than men; for both sexes, contact with friends was the most frequent (Table II). Men reported a significantly higher level of recreational activity than women. Further, significantly more men were smokers and had a higher median alcohol consumption (9 units per week). Significantly more women reported healthy habits, although in general the level was high for both men and women (90% vs. 96%) (Table II).

Slightly more men (43%) than women (39%) rated themselves in poor-to-fair health, but the overall difference in self-rated health was not significant (Table III). Significantly more men than women assessed their physical status as 'somewhat worse to worse' than that of persons of the same age. Although 88% (n = 1649) of all participants considered their own efforts to preserve or improve their health important, significantly more women than men reported that they made an effort (Table III).

Several symptoms often associated with cancer or its treatment were reported across all sites (Table IV), such as fatigue, lack of concentration, sleep interruption, sensory disturbances in the hands, dry mucous membranes, pain in joints or muscles and weight changes. Some symptoms were, however, more prevalent in survivors of cancers at specific sites, like sexual problems and urinary problems in survivors of prostate cancer, swelling of the limbs in women who had had breast cancer and an altered sense of taste or smell in survivors of haematological malignancies. Hot flushes were reported frequently in survivors of breast, prostate and female genital cancers, while digestive problems were reported by survivors of colorectal, haematological and female genital cancers. Dyspnoea was reported by survivors of both lung cancer and haematological malignancies. Self-rated health status was rated good to excellent by more than 60% of survivors of cancers at most of the selected sites, except for lung cancer and haematological malignancies, where 56% and 48% respectively, reported poor-to-fair health (Table IV).

We compared the 298 non-responders in the FOCARE study to the 1 876 participants with respect to age and gender and cancer diagnoses acquired from reference sheets. No age difference was found between the two groups, but significantly more of the non-responders were men. Fewer non-responders were survivors of breast cancer, whereas more survivors of head-and-neck cancers and lung cancer chose not to participate in the study (Table V).

Discussion

Fatigue was the symptom most often reported by the 1 876 cancer survivors. Although we cannot be sure

Table I. Socio-demographic characteristics at baseline of 1 876 participants in the FOCARE study of cancer rehabilitation, Denmark, 2002–2005.

Characteristic	290 men n (%)	1586 women n (%)	Age adjusted p-value
Median age (years) (5–95%)	59 (35–75)	55 (36–72)	<0.0001
Cancer site			<0.0001
Breast	0 (0)	1 051 (66)	
Colon and rectum	44 (15)	78 (5)	
Head and neck	42 (14)	38 (2)	
Haematological malignancy	44 (15)	99 (6)	
Female genital organs	0 (0)	185 (12)	
Upper gastrointestinal tract	18 (6)	14 (1)	
Lung	34 (12)	51 (3)	
Prostate	49 (17)	0 (0)	
Skin	10 (3)	23 (1)	
Urinary tract	10 (3)	11 (1)	
Brain	10 (3)	14 (1)	
Other	21 (7)	18 (1)	
Unknown	8 (3)	4 (0)	
Education[a]			0.02
Basic	36 (12)	182 (11)	
Youth	141 (49)	617 (39)	
Higher	112 (39)	780 (49)	
Unknown	1 (0)	7 (0)	
Employment status			0.91
Working	157 (54)	991 (62)	
Pensioner/other[c]	113 (39)	457 (29)	
Sick leave/unemployed	19 (7)	116 (7)	
Unknown	1 (0)	22 (1)	
Annual household income (DKK)			0.01
Low (0–249 000)	103 (36)	553 (35)	
Medium (250 000–549 000)	138 (46)	629 (40)	
High (≥550 000)	40 (14)	309 (19)	
Do not wish to answer	9 (3)	95 (6)	
Marital status			<0.01
Married or co-habiting	196 (68)	971 (61)	
Living alone[b]	94 (33)	615 (39)	

Head-and-neck cancer includes cancers of the mouth, pharynx, larynx and thyroid gland; haematological malignancies include leukaemia, lymphoma and myelomatosis; cancer of the female genital organs includes cancers of the uterus, cervix and ovary; upper gastrointestinal tract cancer includes cancers of the oesophagus and stomach; urinary tract cancer includes cancers of the kidney and bladder; other cancers include cancers of the testis, liver and male breast, sarcoma, carcinoma and cancers at unspecified sites.

[a]Highest educational level achieved; classified by International Standard Classification of Education.

[b]'Living alone' includes divorced, widowed and single.

[c]Other includes persons not affiliated to a work place for reasons other than unemployment or illness; e.g. housewife, student, maternity leave.

that the fatigue was due solely to the cancer, this finding is in line with those of previous studies [4,5,9,16], which showed that fatigue is a multifactorial effect of cancer. A randomised clinical trial of the quality of life of 247 survivors of early-stage Hodgkin lymphoma who had received either subtotal lymphoid irradiation or combined modality treatment showed that the type of treatment influenced the reported level of fatigue [5]. In a longitudinal study of 885 survivors of high-risk breast cancer who were randomly assigned to either standard or high-dose chemotherapy, both followed by radiotherapy and tamoxifen, no difference in level of fatigue was found; however, poor mental health and, to a lesser extent, anaemia were related to fatigue [16]. In a cross-sectional survey of 1 957 breast cancer survivors who had received various treatment regimens, one-third reported severe fatigue, which was correlated with high levels of depression and pain, as compared with age-matched women in the general population [4]. In another study, fatigue was more likely in breast cancer survivors who had received chemotherapy [4]. A survey of 3 095 survivors of cancers at various sites likewise found high levels of fatigue, mainly related to distress [9]. These findings point to the difficulty in concluding

Table II. Lifestyle characteristics at baseline of 1 876 participants in the FOCARE study of cancer rehabilitation, Denmark, 2002–2005.

Characteristic	290 men n (%)	1586 women n (%)	Age adjusted p-value
Social network			
Being together / in contact with:			
Children (own or partners)			<0.001
Frequent	187 (64)	1 103 (70)	
Rare/Never	13 (4)	38 (2)	
Have none	31 (11)	194 (12)	
Unknown	59 (20)	251 (15)	
Family			<0.01
Frequent	216 (74)	1 355 (85)	
Rare/Never	20 (7)	72 (5)	
Have none	8 (3)	20 (1)	
Unknown	46 (16)	139 (9)	
Friends			0.01
Frequent	234 (81)	1 392 (88)	
Rare/Never	17 (6)	79 (5)	
Have none	2 (1)	7 (0)	
Unknown	37 (13)	108 (7)	
Colleagues (outside work)/ neighbours/others			<0.001
Frequent	63 (22)	431 (27)	
Rare/Never	121 (42)	732 (46)	
Have none	5 (2)	3 (0)	
Unknown	101 (35)	420 (26)	
Physical activity (median hours per week) (5–95%)[a]			
Recreational	5 (1–20)	5 (1–16)	0.01
Household	8 (2–35)	10 (2–31)	0.05
Smoking			
Current	78 (29)	370 (23)	<0.0001
Alcohol consumption (median units per week) (5–95%)[b]	9 (1–35)	5 (1–20)	<0.0001
Abstainer	28 (14)	233 (21)	0.09
Unknown	36 (14)	136 (8)	<0.0001
Healthy eating			
Do you have healthy eating habits?			<0.0001
Yes	261 (90)	1 537 (97)	
No	26 (9)	41 (3)	
Unknown	3 (1)	8 (1)	
Types of healthy food consumed			
Wide variety in foods consumed	212 (73)	1 204 (76)	0.35
Eat fish regularly	165 (57)	978 (62)	0.02
Choose meats with low fat	137 (47)	1 091 (69)	<0.0001
High vegetable intake	134 (46)	1 063 (67)	<0.0001
High fruit intake	126 (43)	1 038 (65)	<0.0001

[a]Frequency based on physical activity among participants reporting physical activity (total population-participants reporting no activity and unknown): Recreational activity: men, n = 262; women, n = 1501. Household activity: men, n = 263; women, n = 1506.
[b]Frequency based on mean alcohol consumption among drinkers (total population-abstainers and unknown): 226 men and 1217 women.

whether fatigue is induced by the cancer and its treatment, leading to i.e. depression, or whether fatigue develops as a consequence of depression [16].

Most of the symptoms reported here might have been related to the treatment regimens, as illustrated by the high prevalence of dyspnoea in lung cancer survivors, the altered sense of taste and smell in survivors of haematological malignancies and the digestive problems reported by survivors of colorectal, haematological and female genital cancers. We did not, however, have information on treatment.

The finding that sexual problems were prevalent in survivors of cancers at all sites suggests that this problem is more multi-factorial. This conclusion is in line with the results of previous studies of long-term cancer survivors, which showed that sexual problems have a number of causes [17–19]. A 3-year follow-up survey of the quality of life and sexuality of

Table III. Self-rated health and health perceptions at baseline of 1 876 participants in the FOCARE study of cancer rehabilitation, Denmark, 2002–2005.

Characteristic	290 men n (%)	1586 women n (%)	Age adjusted p-value
Self-rated health			0.91
Excellent/Very good	36 (12)	237 (15)	
Good	126 (43)	714 (45)	
Fair/Poor	125 (43)	620 (39)	
Unknown	3 (1)	15 (1)	
Self-rated physical status			
Fitness (in comparison with persons of same age)			0.03
Better/Somewhat better	53 (18)	271 (17)	
Similar	65 (22)	458 (29)	
Somewhat worse/ Worse	166 (57)	838 (53)	
Unknown	6 (2)	19 (1)	
Muscular strength (in comparison with persons of same age)		0.01	
Better/ Somewhat better	49 (17)	178 (11)	
Similar	62 (21)	429 (27)	
Somewhat worse/ Worse	174 (60)	927 (58)	
Unknown	5 (2)	52 (3)	
Health perceptions			
Importance of own effort in preserving good health			0.03
Very important/important	255 (88)	1 386 (87)	
Some	27 (9)	179 (12)	
None	2 (1)	7 (1)	
Unknown	6 (2)	14 (1)	
Do you make an effort to preserve or improve health?			0.01
No	40 (14)	159 (10)	
Yes	245 (84)	1 404 (86)	
Unknown	5 (2)	23 (2)	

75 survivors of localized prostate cancer showed persistent impairment of erectile function and measures of social and family well-being in more than half of the participants [17], whereas in a survey of sexual health in 1 134 breast cancer survivors, chemotherapy, vaginal dryness and having a new partner since diagnosis significantly predicted sexual dysfunction. In contrast, high mental health scores, a good body image and having a new partner since diagnosis significantly predicted sexual interest [19].

Although self-rated health was reported good-to-excellent by more than half the participants, 40% considered themselves in fair-to-poor health, including 56% of lung cancer survivors and 48% of survivors of haematological cancers. In a prospective cohort of 181 patients with advanced cancer at various sites, a baseline measure of fair or poor self-rated health correlated with a number of physical effects of cancer, like fatigue, nausea, pain and sleep disturbance [20]. Our finding that the burden of illness and effects of cancer treatment were not distributed equally across the cancer sites represented here indicates that different initiatives should be taken in the course of rehabilitation.

Participants in this study spent a moderate to large amount of time weekly on physical recreational and household activity. We did not obtain an objective measure of the actual physical status of the participants and therefore cannot report details of their actual physical fitness or muscular strength. Still, when the participants rated their physical status, most, regardless of sex, perceived their status as worse than that of persons of the same age. Reduced physical performance was also observed in a study of 89 survivors of chronic myeloid leukaemia who had been alive for more than 10 years after allogenic bone marrow transplantation; the scores in physical performance were lower than those of an age-matched group from the general population, whereas social functioning was equivalent [6]. In a study of quality of life in 5-year disease-free breast cancer survivors, the women reported more difficulties with physical functioning and more physical symptoms than an age-matched control group from the general population [8]. In a prospective study of 78 cancer survivors, in which maximal physical performance was assessed from a tread-mill test, decreased physical performance was significantly related to depression, with an additional strong correlation to fatigue [21]. A randomised study was conducted to evaluate the functional and psychological benefits of a 12-week supervised group exercise programme

Table IV. Self-rated health and self-reported cancer-related late effects at baseline of 1 544 participants by cancer site in the FOCARE study of cancer rehabilitation, Denmark, 2002–2005.

Characteristic	Breast cancer *n = 1051*%	Colorectal cancer *n = 122*%	Prostate cancer *n = 49*%	Haematological malignancy* *n = 143*%	Lung cancer *n = 85*%	Cancer in female genital organs** *n = 185*%
Self-rated health						
Excellent/Very good	18	13	18	10	4	12
Good	46	52	55	41	39	48
Fair/Poor	36	33	24	48	56	39
Fatigue						
Yes	66	66	43	72	79	68
Yes, but also prior to cancer	16	11	16	12	14	12
Lack of concentration						
Yes	46	42	24	49	51	48
Yes, but also prior to cancer	8	7	10	8	11	8
Hot flushes						
Yes	63	29	43	32	26	44
Yes, but also prior to cancer	12	7	4	7	13	9
Sensory disturbances in hands						
Yes	28	25	24	41	39	39
Yes, but also prior to cancer	5	2	4	4	5	3
Sleep interruption						
Yes	50	36	27	48	41	51
Yes, but also prior to cancer	14	16	18	10	15	14
Dry mucous membranes						
Yes	41	31	31	44	29	36
Yes, but also prior to cancer	6	4	6	2	7	5
Digestive problems						
Yes	18	39	8	32	19	35
Yes, but also prior to cancer	12	4	14	4	8	10
Swelling of limbs						
Yes	30	11	6	20	13	23
Yes, but also prior to cancer	8	6	6	4	6	6
Dyspnoea						
Yes	28	30	16	48	62	29
Yes, but also prior to cancer	10	7	8	6	12	9
Pain in joints or muscles						
Yes	49	31	27	52	35	42
Yes, but also prior to cancer	18	12	22	12	19	11
Weight change						
Yes	45	40	24	44	35	38
Yes, but also prior to cancer	8	5	6	3	11	6
Altered sense of taste or smell						
Yes	16	17	6	36	25	13
Yes, but also prior to cancer	1	2	4	1	4	2
Urinary problems						
Yes	11	17	53	9	13	17
Yes, but also prior to cancer	6	3	18	5	2	4
Sexual problems						
Yes	37	35	69	44	29	43
Yes, but also prior to cancer	10	11	14	7	11	6

*Haematological malignancy includes leukaemia, lymphoma and myelomatosis.
**Cancer in female genital organs includes cancers of the uterus, cervix and ovary.

Table V. Demographic characteristics of 2 174 responders and non-responders in the FOCARE study of cancer rehabilitation, Denmark, 2002–2005.

Characteristic	298 non-responders n (%)	1 876 responders n (%)	Age adjusted p-value
Median age (years) (5–95%)	56 (35–76)	55 (36–73)	0.47
Sex			0.02
Men	62 (21)	290 (15)	
Women	236 (79)	1 586 (85)	
Cancer site			0.01
Breast	142 (48)	1 051 (56)	
Colon and rectum	20 (7)	122 (7)	
Head and neck	18 (6)	80 (4)	
Haematological malignancy	25 (8)	143 (8)	
Female genital organs	24 (8)	185 (10)	
Upper gastrointestinal tract	10 (3)	32 (2)	
Lung	24 (8)	85 (5)	
Prostate	3 (1)	49 (3)	
Skin	10 (3)	33 (2)	
Urinary tract	4 (1)	21 (1)	
Brain	6 (2)	24 (1)	
Other	9 (3)	39 (2)	
Unknown	3 (1)	12 (1)	

Head-and-neck cancer includes cancers of the mouth, pharynx, larynx and thyroid gland; haematological malignancies include leukaemia, lymphoma and myelomatosis; cancer of the female genital organs includes cancers of the uterus, cervix and ovary; upper gastrointestinal tract cancer includes cancers of the oesophagus and stomach; urinary tract cancer includes cancers of the kidney and bladder; other cancers include cancers of the testis, liver and male breast, sarcoma, carcinoma and cancers at unspecified sites.

in 177 women during treatment for early-stage breast cancer and found a significant effect on measures of physical fitness by the end of the intervention: Most of the effects were maintained, and an effect of the intervention on quality of life was found at the 6-month follow-up [22]. As decreased self-rated physical status has been observed in cancer survivors, it will be important to incorporate physical exercise into cancer rehabilitation programmes.

Most of the cancer survivors in this study had comprehensive social networks, were living with a partner and were working. This suggest a high level of social functioning in the survivor group studied here but also indicates that rehabilitation programmes should address the challenging issues that survivors with an active family and working life might encounter after their illness. Previous studies have found an association between social network and survival after cancer [23]. In a recent review of five cross-sectional postal surveys of family distress, survivors of cancers at various sites and different lengths of survival reported high levels of family distress as a result of their cancer, showing that the burden of illness is challenging to the whole family [24].

The population of cancer patients in this study was selected with regard to age, gender and site of cancer when compared with all cancer patients alive in Denmark at the time of initiation of the study. The predominance of women in this study primarily reflects the possibility that the offer of residential rehabilitation might appeal more to women. Rehabilitation intervention programmes with a stronger focus on physical activity and without residential obligations have succeeded in attracting more male participants, although they still have a skewed distribution of sex [25].

The comparison of participants with non-participants also showed a significant difference in relation to cancer. This might indicate that participation in this type of study is influenced to some extent by issues of physical health status and general well-being in survivors of cancer at different sites. As our information on the non-responders is limited, we cannot determine the effect of this difference on the results or assess the possible under-representation of certain cancers. Another selection process that affected the external validity relates to the fact that the cancer survivors who attended the rehabilitation course were self-referred and thus did not undergo systematic psychosocial screening before referral. This might mean that their motivation to take part in the rehabilitation intervention was greater than that of the general population of cancer patients, probably further reducing the generalisability of the study results. Other factors such as treatment, time since diagnosis, tumour characteristics, relapse or recurrences and co-morbidity probably influenced the results, but information on these factors was not available.

The advantages of this study include the nationwide, population-based character of the study combined with a public rehabilitation programme offered free of charge to cancer survivors in Denmark. Furthermore, the very high response rate of participants increases the internal validity of the data.

We conclude that this study shows that a large number of symptoms in cancer survivors should be taken into account in their clinical follow-up. The study also illustrates gender-specific aspects of rehabilitation, which should be addressed in programmes. Despite the limited information on treatment-related factors, it can be assumed that at least some of the broad spectrum of symptoms are associated with the treatment received. The availability of more and more treatment options for cancers at many of the major sites illustrates the need for careful recording of potential treatment-related symptoms concurrently with the development of targeted rehabilitation programmes for cancer survivors.

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