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Physical activity among cancer survivors—what is their perception and experience?

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Abstract

Purpose Physical activity (PA) plays an important role relating to cancer. The aim of this study was to investigate the attitude to and experience with the subject of PA in cancer in a large group of tumour patients.

Methods A standardised questionnaire was carried out and distributed to patients online and in printed form.

Results Nine hundred five patients answered the questionnaire. Most tumour patients (60%) received information about PA after their cancer therapy. The Internet was often rated to be inadequate as a source of information. One in two tumour patients were recommended PA by a therapist. During the acute phase, the majority (57% of the 776) did not receive a sport-therapeutic exercise programme. Two thirds (68%) of the 898 patients indicated regularly engaging in PA at least 3 or 5 days per week. In most cases (30% of the 787), 2 to 4 h per week were dedicated to PA. In addition to a desire to increase well-being, enjoyment played a large role. Weakness and lack of willpower are among the most common barriers. Most tumour patients confirmed that PA improved their body awareness (58%) or gave them the feeling that they could do something to better cope with the disease (61%) or feel better (68%).

Conclusion On the one hand, the information requirements of tumour patients with respect to PA have not been adequately taken into account by practitioners. On the other hand, there are still subjective inhibitions on the part of the patients, which keep them from engaging in PA.

Keywords Cancer survivors · Physical activity · Questionnaire · Level of information · Motivation · Barriers

Introduction

Physical exercise is recommended as part of primary prevention in parallel to all medical interventions and to recurrence prophylaxis, as well as for the reduction of side effects.

Thorsten Schmidt and Jutta Hübner contributed equally to this work.

On behalf of the German Cancer Society and of the Federal Association of Cancer Self-help and of the Cancer Nurse in Kiel

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² Comprehensive Cancer Center (CCC) North, University Medical Center Schleswig-Holstein, Campus Kiel, Arnold-Heller-Straße 3, 24105 Kiel, Germany Meanwhile, there is evidence that PA is an important factor in improving overall survival and time to progression [5, 6]. Inactivity, related or not related to cancer treatment, can weaken the skeleton, cause muscle loss and lead to fat gain [1-4]. A meta-analysis with 49.095 breast- and colon carcinoma patients describes a risk reduction for recurrence for the patients with a higher activity level. Various studies confirm the positive effects of PA in the various therapy phases, and also on the physical, emotional and social level. [5-8]. In comparison between the highest and the lowest PA level after breast cancer, a risk reduction of 28% of the breast cancer specific mortality and a reduction of 48% in total mortality can be conducted in the highest PA group. Consideration of the doseresponse-effect of PA after breast cancer reveals that an increase of PA leads to a decrease of breast cancer-specific mortality. An increase of 5, 10 or 15 MET/h/ per week was associated with a decrease of 7, 13 or 19% reduction of total mortality among breast cancer survivors and with 13, 24 or 34% reduction in total mortality. Similar conclusions were found in a comparison of the lowest to the highest level of PA of colorectal cancer and prostate cancer patients [8, 9]. The

American Cancer Society recommended cancer survivor a healthy weight (BMI 18.5–25 kg/m²), healthy food and a regular PA [10]. Nevertheless, often PA is decreased in aftercare [11, 12]. Irwin et al. reported, that breast cancer survivors spend more time in a sedentary state compared to controls and are often overweight or obese [13].

Due to the complexity of recommendations of PA during therapy and in aftercare and the relevance of PA for a reduction of cancer specific mortality and in total mortality, the study was conducted to determine the level of information about PA in cancer patients.

Methods

The questionnaire was developed by the Deutsche Krebsgesellschaft e.V. (DKG) (German Cancer Society) in consultation with the Haus der Krebs-Selbsthilfe Bundesverband e.V. (HKSH-BV) (Federal Association of Cancer Self-help) and has been tested in a small study. The survey took place over a period of 3 months from October to the end of December 2016. The online questionnaire was passed on to the respective group members via the group leaders of the ten federal associations of the HKSH-BV. The group members were also given the opportunity to request the questionnaire in printed form. The 905 questionnaires returned included 77 written questionnaires which had also been distributed via the Cancer Nurse in Kiel from October to December 2016 and had been given to those ambulant patients who visited the Cancer Nurse for out-patient treatment or aftercare of their cancer. In Kiel, the response rate was 85%. Both the data of the online questionnaires and the questionnaires in printed form were collected and evaluated statistically from January to June 2017. The survey objectives and the significance of the questionnaire for the project were explained in its introduction. The participants were also informed about the anonymity of the survey. In addition to demographic data (gender, therapy status), the nine-item questionnaire with open and closed responses (some with an option to provide additional information) collected data as follows:

- Subject area information on cancer and PA, information during or after cancer therapy, the sources of information, the level of information (between very well informed to insufficiently informed)
- Subject area performance of PA, the type and frequency of PA (between physically active at least 5 days per week to rarely or not at all physically active), the duration of PA per week
- Subject area recommendations of PA and stated reasons for supporting or refusing PA

- Subject area sports-therapeutic applications during cancer therapy and in the rehabilitation clinic, the type, frequency and coordination of the applications, references to local rehabilitation sport
- Subject area patients' own assessment of their performance and willingness to perform, their motivation and their barriers (between applies completely to applies not at all). In cases where a rating of the participants was necessary, a gradation according to the Likert scale was performed (e.g. How strongly do you feel burdened by the disease and its consequences? Scale level 1: extremely burdened to Scale level 5: not at all burdened).

IBM SPSS Statistics 24 was used for data analysis of frequencies, tables, figures and associations using chi-square tests, p < 0.05 was considered as significant.

Results

Tumour patients received information after their cancer therapy

Most tumour patients (60% of the 900) received information on physical activity for cancer after their cancer treatment. The most frequent information sources mentioned (among 756) were outpatient or inpatient rehabilitation centres or rehabilitation groups (52.9%), followed by specialists (45.8%) or selfhelp groups (40.5%), regardless of the time at which information was collected *(closed responses*, Table 1).

Of the 882 respondents, only about one in two felt well informed (38%) or very well informed (17.6%). One in six graded the information as inadequate. The majority of the tumour patients (60%) felt very well or well informed when this information was provided by specialists or in rehabilitation. Most of those who did not feel sufficiently informed obtained their information on the Internet (44%, women 54%).

Only one in two tumour patients received a recommendation for PA

For one in two of the 893 tumour patients, the practitioner recommended PA—in most cases during rehabilitation (63%). Only in a very few exceptional cases, the use of PA was discouraged (1%). This was most often the case with the Internet as a source of information (38%). Men more frequently cited reasons such as improvement of performance, condition and fitness, strengthening of the immune system, improvement of cardiac and circulatory parameters or general health for the recommendation of PA by the practitioner. For the women, this tended to be improvement of the course of the disease, better therapy compatibility, promotion of well-being,

Table 1 Information source of cancer survivors (multiple choices possible)

	Responses		Percent of the cases/		
	N	Percent of the sources	patients ($n = 756$)		
of information					
Rehabilitation clinic, outpatient rehabilitation facility or rehabilitation sport group	400	18.8	52.9		
Specialist (e.g. oncologist, gynaecologist or urologist)	346	16.3	45.8		
Self-help group	306	14.4	40.5		
Internet	269	12.6	35.6		
Media (radio, television, brochures, books)	171	8.0	22.6		
Information folder in the hospital		5.9	16.7		
Family doctor	115	5.4	15.2		
Physiotherapist	103	4.8	13.6		
Family and friends	99	4.7	13.1		

56

55

34

27

22

2129

2.6

2.6

1.6

1.3

1.0 100.0 7.4

7.3

4.5

3.6

2.9

281.6

counteracting of fatigue, weight control or risk reduction of tumour recurrence. Fifty-three percent (males 63%) of those who had cited an improvement in cardiovascular parameters as a reason for a recommendation indicated that they were regularly active at least 5 days per week. Fifty-one percent (women 53%) of those who have received a recommendation for better treatment tolerance indicated that they were regularly active at least 3 days per week. Twenty-five percent of women who were recommended PA for weight control regularly follow this advice at least once per week. If the practitioner did not recommend PA (37.7% of the 893), this was mainly due to postoperative physical deficits (27%). Physical limitations, weakness and pain were also the most frequent reasons for being rarely/not at all or only irregularly physically active (open responses, Fig. 1).

Source of information

Psychologist

Nutritionist

Other

Total

Sports scientist

Cancer counselling centre

Only one in two tumour patients received a movement programme during the acute phase

Four hundred forty-two out of the 776 patients (57%) said they had received sports-therapeutic treatments during their cancer treatment, especially physiotherapy (31%) and relaxation methods (23%). In contrast, in 622 of the 660 patients (94.2%), corresponding programmes were carried out in the rehabilitation clinic, mostly as a relaxation method (76%) or in sports groups (68%). One in two rehabilitation patients (out of the 529) indicated having participated in a training programme between one and five times per week, men more frequently than women. The remaining patients indicated having participated in between six and 15 or more training programmes per week, women more frequently than men. Overall, the mean value of women (8.87, median 7.00) is above that of men (6.53, median 5.00).

Tumour patients showed high readiness for PA

Two thirds (68%) of the 898 patients said they were physically active at least 3 to 5 days per week. A majority (30%) of the 787 men and women stated that PA were carried out between 2 and 4 h per week, although women (55%) were more active. Another, third is active between 1 and 2 h (13%) or between 4 and 6 h (17%) per week. Half of the women (59%) and men (56%) who are physically active between 121 and 240 min per week are regularly active at least 3 days per week. While women tend to be more physically active than men, the average weekly mean time of men (409.64 min, standard deviation 504.725, median 240) is approximately 1 h more than that of women (342.60 min, standard deviation 463.202, median 240). The majority of the physically active subjects ride bicycle. Those who are reported being irregularly (38%) or rarely/not at all physically active (54%) take walks. Both men and women reported spending a lot of time on PA at work and in the form of housework and gardening (open responses, Table 2).

The most common reason for the willingness to be physically active was "increase of well-being" (25%) followed by "enjoyment" (14%) or "keeping fit" (13%) (open responses, Fig. 2).

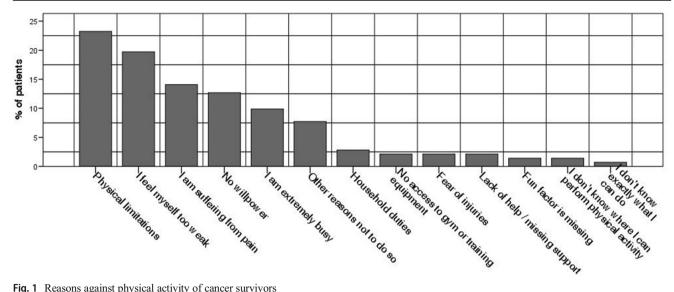


Fig. 1 Reasons against physical activity of cancer survivors

Tumour patients were in need of help

Only one in two (52% of the 834) tumour patients indicated not being unsure of how to be physically active. The majority of patients who were completely or partially unsure of what kind of PA was appropriate for them received no information during or after cancer treatment. Even tumour patients who had received information after the acute phase were to some extent unsure of how they could be physically active or they were unable to correctly classify the information received (p < 0.001, Table 3).

More than two-thirds (71%) of the patients who said they were completely unsure about how they should be physically active received no reference to local rehabilitation sport in the rehabilitation clinic. One in five tumour patients also indicated that contradictory information made them unsure. One in three patients (of the 834) also indicated preferring other activities or finding it difficult to bring oneself to take part in PA. Of those who had indicated exercising rarely or not at all, 44% (women 50%) indicated having difficulties to overcome themselves. The duration of PA has no decisive influence on the problem of not being able to bring oneself to do it.

There is also no significant correlation to the duration of PA when assessing one's own performance. One in four tumour patients confirmed sometimes having difficulties starting because they had not been active before cancer. Furthermore, one in five (of the 832) tumour patients indicated that involvement in PA was problematic. More than half of the patients who reported difficulties had not received any information during or after the cancer treatment. 43% (women 44%) of those who viewed the topic as difficult exercised rarely or not at all. The duration of PA did not have any significant correlation to a difficult beginning or any problems with involvement.

Social aspects were not the focus

One hundred twenty-three (17%) of the 733 patients completely agreed that PA would allow them to meet other cancer patients. A majority of the 284 (39%) denied this.

Tumour patients confirmed the positive effects of PA

Most tumour patients completely agreed that PA improved their body awareness (58%) or gave them the feeling that they could do something to better cope with the disease (61%) or feel better (68%). A clear majority was also convinced that PA are not harmful. The duration of the athletic activity has no decisive influence on whether anxiety is affirmed or not. Forty-three percent (of the 840) partly agreed on feeling exhausted by PA. But almost as many (37%) clearly denied this. A clear majority (78%) also clearly disagreed that cancer patients should not be physically active. Two thirds of patients who indicated being physically active at least 5 days per week completely agreed feeling better, having a better physical awareness and feeling that they could make their own contribution. The indication of being only irregularly or very rarely/not at all physically active correlated with the attitude that these positive effects would not apply or that they were unsure whether these effects would apply (p < 0.001, Table 4).

Two hundred eighty-four (37%) of the 761 patients completely agreed that PA could reduce the risk of tumour recurrence. Almost one in two patients who indicated regularly engaging in PA at least five times per week were fully convinced of the reduced risk of recurrence. The duration of the sporting activity had no significant influence on the attitude towards tumour recidivism.

 Table 2
 Physical activities of cancer survivors (multiple choices possible)

		Responses		Percent of the
		Ν	Percent of the activities	cases/patients $(n = 799)$
Туре	of activity			
	Cycling	266	13.3	33.3
	Gardening	230	11.5	28.8
	Walking	226	11.3	28.3
	Speed walking	197	9.8	24.7
	Housework	117	5.8	14.6
	Gymnastics	111	5.5	13.9
	Fitness studio	108	5.4	13.5
	Swimming	107	5.3	13.4
	Hiking	91	4.5	11.4
	Running	73	3.6	9.1
	Machine training	53	2.6	6.6
	Yoga/meditation	52	2.6	6.5
	Dog walking	51	2.5	6.4
	Strength training	41	2.0	5.1
	Jogging	37	1.8	4.6
	Dancing	36	1.8	4.5
	Physical activity at work	31	1.5	3.9
	Water aerobics	29	1.4	3.6
	Team sports	23	1.1	2.9
	Crafts	16	0.8	2.0
	Skiing/snowboarding	14	0.7	1.8
	Climbing stairs	13	0.6	1.6
	Horseback riding	11	0.5	1.4
	Endurance training	8	0.4	1.0
	Golf	6	0.3	0.8
	Aerobics/step aerobics	6	0.3	0.8
	Cleaning the barn	5	0.2	0.6
	Other	49	2.4	6.1
Total		2007	100.0	251.2

Extreme stress as a result of the cancer

On a scale of 1 to 5 (1: extremely burdened; 5: not at all burdened), 904 of the 905 patients indicated the extent to which they felt burdened by the disease and its consequences. A majority of 32% classified themselves as stage 3. Most tumour patients who had received bone protection therapy (women 40%) or who were currently receiving it (27%, women 38%) indicated feeling extremely burdened. The majority of those who felt extremely stressed had received chemotherapy (65%, women 78%), radiation therapy (55%, women 67%) or hormonal therapy (46%, women 55%). Thirty-six percent of men who were currently undergoing chemotherapy reported that they felt extremely stressed. On the other hand, a

group of those who were currently undergoing antibody therapy (10%, men 25%) or a bone protection therapy (20%, men 25%) did not feel any burden. Among the patients who did not feel burdened by their cancer (35%, both men and women) indicated being physically active at least 3 to 5 days per week. On a scale of 1 (minimum) to 10 (maximum), a majority of the respondents were in the middle with a slight tendency to higher scale values when it comes to the assessment of the impairment of life, the control of the disease, the evaluation of the treatment as an aid, the understanding of the illness, concerns about the illness, the severity of the complaints, or the emotional impairment. The result is remarkable with regard to the assessment of the duration of the disease; 43% (of the 884) are convinced that the disease will last forever.

Discussion

In contrast to the rehabilitation phase, only one in two cancer patients participated in an exercise programme during the acute phase, although it has already been proven that the appropriate patient-specific exercises can and should be initiated in the acute phase as long as there are no contraindications [14, 15]. The earlier the patient engages in PA, the sooner physical and mental components are preserved. This is beneficial to rehabilitation. If one assumes that there are only a few contraindications that exclude a movement programme [16], then the percentage of approximately 50% for which no programme has been implemented during the treatment appears to be relatively high. Even if there were circumstances that excluded a PA programme, it is not comprehensible why one in two patients was not informed about how important it is to resume mobility as soon as possible. Similar results were obtained in a patient survey conducted at the University of Frankfurt at the Hessian Clinics and Specialist Practices for Haematology and Internal Oncology in 2011; nearly one in two tumour patients (48%) of the 300 surveyed did not receive any information about PA, although two out of the three respondents said they required information [17]. According to the survey conducted, much more exercise programmes have been carried out during the rehabilitation. But patients were rarely referred to sporting activities in their area. However, a continuation of sporting activities within the rehabilitation chain is necessary to ensure long-term success [18]. If patients received information about specialists, they usually felt well or even very well informed. This could indicate that the healing powers of PA are now seen as an important part of complementary medicine, taking into account the individual wishes and needs of the patient. This survey did not confirm the experience of others, and patients would regard the Internet as a suitable source of information [19].

The relatively high willingness to engage in PA fits the desire of the cancer survivors to be able to improve their

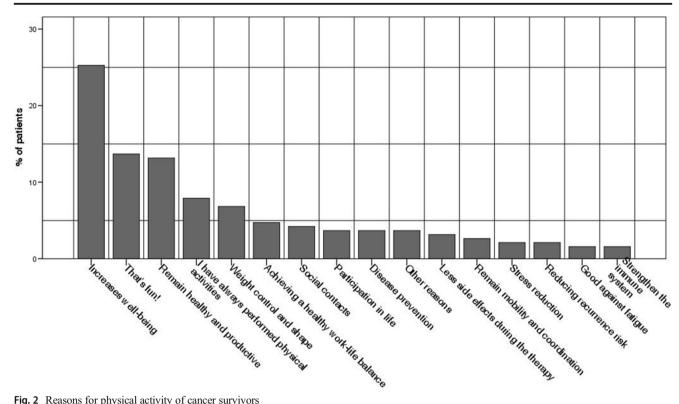


Fig. 2 Reasons for physical activity of cancer survivors

well-being and remain fit and capable. The fun factor seems to be as important as the desired physical effects. The important influence of PA enjoyment on the PA levels of cancer patients has already been determined in another recently published study [20]. Surprisingly, the respondents considered getting to know other patients in the course of common activities to be a less important social aspect. However, this can have a significant influence on psychological outcome parameters and can promote better coping [21].

This survey confirmed the close connection between PA and the positive effects achieved by this self-initiative-not only at the physical level, but also at the psychological level

 Table 3
 Type of physical activity/classification of information
 (information after cancer therapy)

	Information after cancer therapy (n)			
Unsureness about the type of physical activity	Applies completely	61		
	Applies partially	250		
	Applies not at all	432		
	I don't know	84		
Total		827		
Not being able to classify information	Applies completely	43		
	Applies partially	192		
	Applies not at all	494		
	I don't know	87		
Total		816		

(i.e. better self-efficacy, better feeling/better patient empowerment) [22]. For cancer survivors, 2 to 4 h per week (a minimum of three units per week) seems to be a practical investment in order to benefit from such effects. This result (180 min per week on average) is still below (30-40 min per day) the recommendation of the "Cancer and Sport" commission of the German Cancer Society (245 min per week on average) [23, 24]. According to the recommendation of the World Cancer Research Fund/American Institute for Cancer Research (WCRF/AICR) and the American Cancer Society, cancer survivors should engage in at least 150 min of moderate-tovigorous PA per week spread over at least 5 days [10]. When patients rarely or irregularly engage in PA or not at all, this is because of physical deficits as shown by the survey. However, lack of awareness, lack of motivation or unfavourable external factors can also be a hindrance. In literature, there are also reports of various different barriers which are either physical or psychological or result from the personal environment that deter patients from PA. The most frequent are a lack of willpower, a lack of time, or being too busy as well as weakness, lack of self-discipline and "not making exercise a priority" [25, 26]. If patients prefer other activities to physical exercise, they are not really aware of the importance of PA in the context of their cancer therapy and rehabilitation. Especially in view of the fact that many tumour patients see themselves as chronically ill, there are starting points for a worthwhile behavioural change that could improve the course of the disease in the long term.

Table 4 Better body awareness/bett	r cope with the disease	(physical activity)
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Physical activity (*n*)

		Physically active at least 5 days per week	Physically active at least 3 days per week	Physically active at least 1 day per week	Irregularly physically active	Rarely or not at all physically active	Total
Better body awareness	Applies completely	206	179	54	34	9	482
	Applies partially	83	101	56	47	19	306
	Applies not at all	7	6	7	2	8	30
	I don't know	5	9	6	12	11	43
Total		301	295	123	95	47	861
Better cope with the disease	Applies completely	223	186	67	30	5	511
	Applies partially	68	89	39	44	14	254
	Applies not at all	7	11	14	13	15	69
	I don't know	2	8	3	8	12	33
Total		304	299	123	95	46	867

In summary, it should be noted that patients are not adequately informed about the possibilities of PA and that there are still inhibitions outside of physical deficits that could be overcome. Further information and assistance should be provided by all institutions, doctors, specialists and self-help groups involved in the rehabilitation of cancer patients. Future studies may show to which extent an improvement can be achieved.

Limitations

The questionnaire addressed the members of the associations and groups. The results can therefore not be easily transferred to non-members. It should also be considered (at least in part) that patients with a greater affinity to PA tend to answer such questions or assess them more positively because of social desirability. Nevertheless, because of the extensive patient collective, it can be assumed that the survey is reliable enough to be seen as a representative study.

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Compliance with ethical standards According to the rules of the ethics committee at the University Hospital of the Friedrich-Schiller-University at Jena, no ethics vote was necessary.

The study was approved by the local review board of the university of Kiel (registration number: AZ D 447/16).

Conflict of interest The authors declare that they have no conflicts of interest.

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