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High prevalence of somatic complaints and psychological problems despite high self-declared quality of life in long-term cancer survivors

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ABSTRACT

Introduction. To assess the quality of life (QoL) of long term cancer survivors and its determinants.

Material and methods. The research covered a group of 272 disease-free cancer survivors (mean OS = 8 years). Methods: 1) Evaluation of somatic and psychological complaints (with the NCCN Clinical Practice Guidelines in Oncology — Survivorship Assessment, NCCN Guidelines®, V.1.2015); 2) Evaluation with numeric rating scales (NRS, 0–10 points): health status life satisfaction; social support and acceptance; 3) Assessment of the quality of life as dependent variable (NRS).

Results. Analysis revealed high prevalence of numerous somatic complaints, assessment of emotional disturbances, cognitive dysfunctions and surprisingly high global QoL (66%), high overall (77%) and present (74%) life satisfaction, good health (55%), strong impact of illness on life (42%), high social acceptance (80%) and satisfying support (62%). QoL correlated significantly (p < 0.05) with most of NRS measured subjective variables especially health status (-0.74), life satisfaction (0.66) and joy of life (0.63).

Conclusions. High Qol despite somatic ailments might reflect high levels of received support, as well as attitudes towards life and illness. Positive correlations between the QoL and other subjective variables imply that those parameters might be equally important determinants of QoL as somatic indices. Specialized care should provide cognitive evaluation and therapy for cancer survivors to a larger extent than before.

Key words: cancer survivors, quality of life, somatic complaints, satisfaction with life

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Introduction

Both duration of survival and survival rates of cancer patients improve dramatically as a result of progress in oncological diagnosis and treatment. However, this co-exists with an increase in cancer incidence rates due to progressive population aging. These phenomena are observed both in Poland and worldwide. Epidemiological studies conducted by the National Cancer Institute demonstrated that the number of cancer survivors in the United States has increased from 3 million in 1971 to 16.9 million in 2019, probably in 2030 22,2 million and

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the proportion of survivors among all cancer patients approximates 66% [1, 2]. Although the survival rate of Polish cancer patients is somewhat lower (ca. 40%), this proportion still corresponds to a large absolute number of survivors. Despite the increase in their number, the quality of life in cancer survivors has been studied relatively rarely, especially in Poland. Previous studies conducted in the United States and some Western European countries demonstrated that although most cancer survivors present with good health and are actively involved in professional and social life, a considerable proportion of them experience somatic and/or psychological problems and cannot fully enjoy normal activities of daily living.

With no doubt, the difficulties experienced by people who had recently completed an anticancer treatment differ considerably from the problems encountered by long-term cancer survivors. This refers to most areas of the quality of life (QoL), especially to the somatic (greater severity of ailments), psychological (higher incidence of depression and anxiety) and cognitive domain.

The aim of this study was to comprehensively analyze various domains of QoL in cancer survivors. This knowledge may be crucial for offering this group with optimal forms of assistance, tailored to their needs.

Published data about the problems experienced by long-term cancer survivors

According to literature, the term 'long-term survivors' typically refers to people diagnosed with cancer at least 6 years (64%) [3]. The vast majority of patients with such long survival suffered from breast, prostate or colorectal cancer. They frequently (50%) report numerous ailments associated with either early or late anticancer therapy. Some of them may be diagnosed with secondary malignancies [4]. The most common among multiple ailments found in this group are sexual disorders, sleep problems, especially trouble falling asleep (30–50%), fatigue (40–50%) and pain (35%). Other frequently reported problems include oedema (breast cancer) and gastrointestinal dysfunction [5–9].

The list of mental problems reported by cancer survivors includes emotional disorders, such as depression (17–20%) and anxiety (9–23%). Particularly alarming is a high incidence of cognitive disorders, such as memory loss, learning difficulties and problems with fast thinking [5–7]. However, it should be stressed that the above-mentioned statistics are based primarily on subjective self-assessment, and according to some authors, the incidence of cognitive disorders is higher among persons who were previ-

ously informed that they may be more prone to such ailments [10].

Psychological response of patients to a disease experienced years earlier and/or to the treatment thereof usually differs from the reaction of people who still undergo or have just finished oncological therapy. Psychological ailments observed in the latter group, e.g. anxiety or depression, may be directly related to the disease and its harmful treatment (e.g. chemotherapy). Such emotional response may persist for some time after the treatment or be evoked by late physical consequences of the disease and anticancer therapy, such as fatigue, pain, sexual dysfunction, disorders of sleep, and/or cognitive impairment [11, 12].

Moreover, it should be remembered that anxiety and depression are also relatively common in the general population and do not necessarily need to be associated with the disease or its treatment.

A well-established consequence of psychological and social distress experienced by cancer survivors is higher (up to 22-fold) frequency of suicidal thoughts/attempts in this group, as well as their lesser involvement in rehabilitation programs and health-oriented behaviors [13].

Available data on the quality of life in long-term cancer survivors are inconclusive [14–16].

Quite frequently, psychological problems experienced by long-term survivors may manifest similarly to post-traumatic stress disorder.

However, aside from the negative consequences of cancer, also some its beneficial effects are increasingly recognized, among them higher self-esteem, a greater appreciation of life, spirituality and internal peace. Harmonized development of these traits is sometimes referred to as post-traumatic growth [17–20].

Studies in this area, although vitally important, turned out to be particularly challenging, due to the lack of appropriate research instruments.

On the other hand, these positive consequences of the disease may indirectly explain why most cancer survivors examined in previous studies evaluated their QoL as good or even very good [21–23]. However, this hypothesis has never been proved directly, since most previous studies involving cancer survivors centered around physical and psychosocial aspects of QoL, and ailments from these domains usually are disproportional to generally good overall QoL estimates.

While a number of previous studies analyzed QoL in cancer patients during the disease and its treatment, only a few authors examined this problem in cancer survivors, especially those with relatively long survival time.

To fill this gap, we have conducted a study in the latter group; aside from routinely determined measures of QoL in physical, psychological and health behavior domain, we also focused on positive aspects of the disease.

Table 1. Demographic and medical characteristics of the study group

	Initially enrolled	Qualified for analysis		
n	320	285		
Sex	Male: 111 (40.8%)	, female: 161 (59.2%)		
Age, mean [years]	men: 64.9 ± 12.6, w	vomen: 63.6 ± 11.1 (ns)		
Place of residence	Countryside, 20.7%; towns up to 100	000, 32.7%; towns above 100 000, 38.9%		
Marital status	n	%		
Married/common law	190	69.8		
Single	13	4.8		
Divorced	25	9.2		
Widowed	36	13.3		
Missing information	8	2.9		
Total	272	100		
Disease-free survival after treatment,	04 . 40	00.56(.)		
mean [years]	men: 8.1 ± 4.9, w	/omen: 8.8 ± 5.6 (ns)		
Cancer location	n	%		
Head/neck	65	23.90		
Melanoma	47	17.28		
Prostate	15	5.51		
Breast	74	27.21		
Gastrointestinal tract	36	13.24		
Genital system	8	2.94		
Other	12	4.41		
Unknown	4	1.47		
Missing information	11	4.04		
Total	272	100		

Objectives

The aim of the study was to analyze QoL and its complex determinants in long-term cancer survivors.

Specifically, the study centered around:

- 1. Subjective assessment of participant:
 - a) global quality of life;
 - b) physical condition and psychological status;
 - c) the attitudes to life;
 - d) the attitudes to support offered by the others.
- 2. Complex analysis included a relationship between global QoL and the following factors:
 - a) sociodemographic characteristics (sex, age, family status);
 - b) physical and psychological status;
 - c) attitudes to life and its values;
 - d) attitudes to support offered by the others.

Material and methods

The study was conducted between January and December 2015 after receiving approval of bioethics com-

mitee. Informed consent was obtained from all individual participants included in the study. Out of 320 disease-free cancer survivors initially enrolled in the study, 285 were qualified for the analysis. General characteristics of the study subjects are listed in Table 1.

The participants were examined with following tools:

- Evaluation of physical and psychological health status according to Survivorship Assessment NCCN Clinical Practice Guidelines in Oncology patient version (NCCN Guidelines®) for cancer survivors, V.1.2015 © 2015 National Comprehensive Cancer Network Inc * The abovementioned guidelines/survey were used with NCCN permission [22].
- 2. Assessment of independent variables (by NRS):
 - a) physical condition;
 - b) psychological status;
 - c) the attitude to life and health;
 - d) impact of disease on participant's life;
 - e) the attitude to support offered by others.
 - f) overall and present satisfaction with life (NRS, 0–10 p.).
- Assessment of global Quality of life (by NRS) dependent variable.
- 4. Statistical analysis.

Table 2. Items 1-9 Survivorship Assessment, NCCN Guidelines (patient version)

Survivorship Assessment, NCCN Guidelines, items 1–9								
Symptoms		Yes		No		Missing		Total
		n	%	n	%	n	%	
Cardiac toxicity	Toxic effect on cardiovascular system, did patient receive previous anthracycline therapy	34	12.50	134	49.26	104	38.23	272
	2. Post-exercise dyspnea or pain	70	25.73	132	48.52	70	25.73	272
	3. Resting dyspnea	51	18.75	154	56.6	67	24.61	272
Anxiety and	4. Loss of interest	55	20.22	150	55.14	67	24.63	272
Depression	5. Depressiveness	60	22.05	148	54.41	64	23.52	272
	6. Worrying	69	25.36	137	50.36	66	24.26	272
Cognitive function	7. Ability to concentrate	74	27.20	142	52.20	56	20.58	272
	8. Remembering many things	113	41.54	107	39.33	50	19.11	272
	9. Slower thinking	121	44.48	102	37.50	49	18.01	272

Table 3. Reported fatigue and its severity (0–10 scale), item 10, 11 and 12 of Survivorship Assessment NCCN Guidelines

Symptoms						Y	⁄es	ı	Vo	Missing		Total
						n	%	n	%	n	%	
Fatigue	10. Cons	tant fatio	jue			86	31.61	135	49.63	51	18.75	272
	11. Fatigue interfering with normal activity				ectivity	92	33.82	125	45.95	55	20.20	272
12. Fatigue level scale 0–10	0	1	2	3	4	5	6	7	8	9	10	Total
n	22	5	12	14	13	59	18	14	16	5	14	272
%	8.08	1.83	4.41	5.14	4.77	21.69	6.61	5.14	5.88	1.83	5.14	100
	Mean fa	tigue sco	ore 4.88 :	± 2.76								

The goal of this study was to analyze the effect exerted by the above-mentioned variables on the global quality of life of the study subjects (Pearson's coefficients of linear correlation).

The statistical analysis was carried out with STA-TISTICA v.12. Statistical significance of intergroup differences was verified with parametric Student t-test for continuous variables or chi-squared test for categorical variables. Power and direction of relationships between pairs of variables were estimated on the basis of Spearman's coefficients of rank correlation and Pearson's coefficients of linear correlation (r). Multivariate analyses were carried out using the Classification and Regression Trees (CART) [23].

Results

Survivorship Assessment NCCN showed that a high percentage of the patients had reported somatic complaints. Anxiety and depression symptoms were present in approximately 20% of cases. At least every third patient noticed decreased cognitive functions — the ability to concentrate (27%), remembering many things (41.5%), slower thinking (44.5%), (Table 2) constant fatigue (32%) and fatigue interfering with normal activity (33.82%, mean fatigue level was within medium range (4.9 points, 0–10 scale, Table 3).

Almost 40% of patients reported the presence of pain, with weak/medium intensity — mean = 3.7 points in NRS Scale (Table 4).

About 30% of patients suffered from decreased satisfaction with sex, difficulty falling asleep (42.6%) (Table 5).

Scores for NCCN items in the study group — results transformed onto a 0–100 scale are displayed in Figure 1. High severity of self-reported cognitive decline is the most prominent result out of this assessment.

Patients reported high quality of life, overall and present life satisfaction and mostly no willingness to change it (all items scored about 7 or more points in 0–10 NRS scale. Health assessment scored relatively high — 6.9/10 points.

Table 4. The pain and its severity, item 13 and 14 of Survivorship Assessment, NCCN Guidelines

Survivorship Assessment, NCCN Guidelines, items 13 and 14 13. Pain Missing Yes No Total % % % n n 108 39.70 103 37.86 61 22.42 100 14. Pain level 0 1 2 3 4 5 6 7 8 9 10 Total scale 0-10 57 5 4 16 11 23 17 4 10 272 n 11 11 % 20.95 1.83 1.47 5.88 4.04 8.45 6.25 4.04 4.04 1.47 3.67 100

Table 5. Items 15-25 Survivorship Assessment, NCCN Guidelines (patient version)

Mean pain score 3.69 ± 3.27

Survivorship Assessment, NCCN Guidelines, items 15–25								
Symptom		Yes			No	Mi	Total	
		n	%	n	%	n	%	
Sexual Function	15. Satisfaction with sexual life	102	37.5	81	29.77	89	32.72	272
	16. Sexual life concerns	58	21.32	126	46.32	88	32.35	272
	17. Sexual life concerns as a source of worries	39	14.33	139	51.10	94	34.55	272
Sleep Disorders	18. Difficulty falling asleep	116	42.64	103	37.86	53	19.48	272
	19. Excessive sleepiness	61	22.42	149	54.77	62	22.79	272
	20. Snoring	85	31.25	128	47.05	59	21.69	272
Healthy Lifestyle	21. Regular physical activity	104	38.23	118	43.38	50	18.38	272
	22. Fruit and vegetable intake	120	44.11	98	36.02	54	19.85	272
	23. Slimming diet	45	16.54	167	61.39	60	22.05	272
Immunizations and	24. Influenza vaccination	43	15.80	180	66.17	49	18.01	272
Infections	25. Any vaccination	44	16.17	181	66.54	47	17.27	272

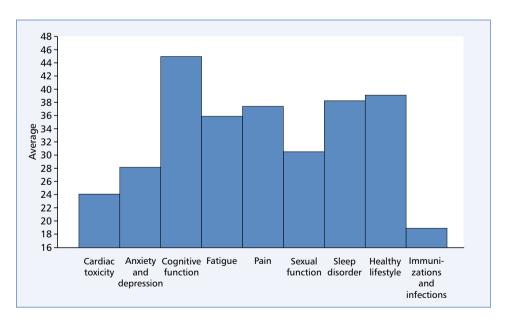


Figure 1. Scores for NCCN items in the study group (the result transformed onto 0–100 scale)

Table 6. Study subi	ects' attitudes to li	ife and health. an	nd life impact of their illness

Variable	Overall life satisfaction		_	ent life faction		npact of ness	I would not change anything in my life		not change assessment anything in my		•	y of Life QoL)
Mean	M =	= 7.79	M =	= 7.73	M =	= 5.32	М	= 6.9	M =	= 6.64	M =	= 7.23
Score range	n	%	n	%	n	%	n	%	n	%	n	%
0–3	11	4.04	19	6.98	90	33.08	42	15.44	18	6.61	13	4.77
4–6	49	18.01	46	16.91	54	19.85	58	21.32	95	34.92	70	25.73
7–10	209	76.83	202	74.26	122	44.85	164	60.29	152	55.88	182	66.91
Missing	3	1.10	5	1.83	6	2.20	8	2.94	7	2.57	7	2.57
Total	272	100	272	100	272	100	272	100	272	100	272	100

Table 7. Study subjects' attitudes to external support and acceptance by others

Variable	Need fo	r support	Receive	d support	Acceptance by others $M = 8.18$		
Mean	M =	5.95	M =	= 7.09			
Score range	n	%	n	%	n	%	
0–3	80	29.41	46	16.91	35	12.86	
4–6	44	16.17	48	17.64	19	6.98	
7–10	140	51.47	171	62.86	209	76.83	
Missing	8	2.94	7	2.57	9	3.30	
Total	272	100	272	100	272	100	

Most of the respondents highly appreciated their life (overall life satisfaction — approximately 77%) and present life satisfaction 74% (Tab. 6).

Approximately 67% of all respondents declared they need support from others (mean = 5.95/10, a great need for support — 51%), and that they receive it (M = 7.09 — highly satisfying support 62%). Mostly they and feel definitely accepted by other people (M = 8.18, 76%) (Tab. 7).

Chi-squared test showed a significant relationship between the items of NCCN Survivorship survey and quality of life in cancer survivors. Higher scores in anxiety and depression fatigue, pain, sleeplessness, depression, problems with concentration and disorders of memory affected negatively overall quality of life (Tab 8).

Spearman correlation of coefficients showed that quality of life correlated most strongly with health assessment (r = -0.74), life satisfaction (0.67), joy of life (0.63), and with "I would not change anything in my life" attitude (0.53) see Table 9.

Multivariate analysis showed predictor importance ranking of data affecting quality of life, overall and present life satisfaction, and no willingness to change anything in life, attitude and self-health assessment scored highest on 0–100 scale.

Discussion

Based on the assessment of psychophysical status in line with the NCCN guidelines, approximately 20% of the study subjects experienced emotional disorders (depressiveness, lack of joy, periodical worries), and 30–40% reported impaired cognitive functions.

These findings seem to be consistent with the results of studies conducted in other countries, especially for emotional factors, and partially also for cognitive ones (reported prevalence of cognitive disorders in European cancer survivors varies considerably, between 19% and 35%) [11, 12]. However, it needs to be emphasized that previous studies were conducted in different settings, and this fact should be considered while comparing their results with our findings.

Our patients reported physical ailments, such as fatigue and pain, more often than cancer survivors from other European countries (fatigue more than 30% vs. 17–26%, pain approximately 40% vs. 31%). The prevalence of sleep disorders among our patients and cancer survivors from other European countries was at a similar, relatively high level, approximately 30 vs. 50% [6]. This is not surprising owing that sleeplessness is also a common ailment in general population, especially among the elderly, and our study group was comprised primarily of older patients.

Table 8. Health status determined in line with the NCCN guidelines. Relationship between the results and quality of life in cancer survivors, *p-values determined with chi-squared test

NCCN item		Y/N		Quality of Life		P*
		Low	Moderate	High		
		(0-3)	(4–6)	(7–10)		
		%	%	%		
Cardiac toxicity	1. Toxic effect on cardiovascular system,	Yes	5.88	20.59	73.53	
	did patient receive previous anthracycline therapy	No	2.27	27.27	70.45	— ns
	Post-exercise dyspnea or pain	Yes	8.70	31.88	59.42	
		No	1.54	25.38	73.08	< 0.05
	3. Resting dyspnea	Yes	4	28	68	
		No	3.95	25.66	70.39	ns
Anxiety and	4. Lack of interest	Yes	7.41	33.33	59.26	
Depression		No	2.01	24.16	73.83	0.05
	5. Depressiveness	Yes	11.67	36.67	51.67	
		No	0.69	22.76	76.55	< 0.00
	6. Worrying	Yes	10.14	33.33	56.52	
		No	0.74	22.96	76.30	< 0.00
Cognitive	7. Ability to concentrate	Yes	5.48	42.47	52.05	
unction		No	2.86	19.29	77.86	< 0.00
	8. Remembering many things	Yes	6.25	32.14	61.61	
		No	0.95	21.90	77.14	< 0.0!
	7. Slower thinking	Yes	5.79	33.88	60.33	
		No	1.01	20.20	78.79	< 0.0
Fatigue	8. Constant fatigue	Yes	9.52	34.52	55.95	
		No	0.75	23.13	76.12	< 0.00
	9. Fatigue interfering with normal activity	Yes	8.89	30	61.11	
	,	No	0.81	24.19	75	< 0.0
Pain	13. Pain	Yes	6.67	31.43	61.90	
	•	No	1.94	23.30	74.76	< 0.1
Sexual Function	14. Satisfaction with sexual life	Yes	0.00	24.75	75.25	
	•	No	7.50	28.75	63.75	< 0.0!
	15. Sexual life concerns	Yes	8.77	24.56	66.67	
	•	No	1.60	28.80	69.60	ns
	16. Sexual life concerns as a source of	Yes	10.26	23.08	66.67	
	worries	No	2.17	26.81	71.01	ns
Sleep Disorder	Difficulty falling asleep	Yes	5.22	39.13	55.65	
	3 3 1	No	1.98	12.87	85.15	< 0.00
	Excessive sleepiness	Yes	6.78	32.20	61.02	
		No	3.40	24.49	72.11	ns
	Snoring	Yes	4.76	29.76	65.48	
		No	3.97	24.60	71.43	ns
Healthy Lifestyle	Regular physical activity	Yes	3.92	25.49	70.59	
, .	-3	No	3.45	29.31	67.24	ns
	Fruit and vegetable intake	Yes	2.52	25.21	72.27	
		No	6.25	30.21	63.54	ns
	Slimming diet	Yes	9.09	25.00	65.91	
		No	3.03	27.27	69.70	ns
mmunizations	Influenza vaccination	Yes	0.00	30.95	69.05	
		No	5.08	25.99	68.93	ns
and Infections						
	Any vaccination	Yes	2.38	28.57	69.05	

To summarize, 30–40% of long-term cancer survivors included in our study reported somatic ailments and cognitive impairment. The frequent occurrence of the latter is particularly alarming and deserves further extensive research.

Approximately 40% of our participants declared undertaking regular physical activity and following a healthy dietary plan including fruits and vegetables. However, only 16% of the study subjects claimed that they have undergone a prophylactic vaccination.

Considering such somatic and psychological status of our participants, the results documenting their life and health attitudes and the impact of illness on their life seems to be quite surprising. Up to 70% of the re-

Table 9. Relationships between quality of life and the attitude to life, health, support and acceptance by other, p-values for Spearman's correlation coefficients

Quality of Life
0.6661 (p < 0.001)
0.5304 (p < 0.0001)
0.6340 (p < 0.001)
-0.7433 (p < 0.001)
-0.2262 (p < 0.002)
-0.1241 (p < 0.092), ns
0.2230 (p < 0.002)
0.2703 (p < 0.001)
0.0120 (p < 0.871), ns
-0.0396 (p < 0.592), ns

spondents declared that they were satisfied with their current life, and approximately 60% assessed their subjective health as good or very good but emphasized that cancer had a very large or at least large impact on their life. Moreover, 90% of the respondents assessed their subjective quality of life as at least good or, even more often, very good (Fig. 2).

These findings are partially inconsistent with the previously mentioned data about the somatic and psychological condition of the study subjects and imply that QoL of them might have been also influenced by other factors than the simple health indices.

Therefore, we investigated the role of support from friends and relatives, as the determinants of QoL in our study subjects. Approximately 80% of the study participants declared receiving support and being accepted by their relatives and friends, and according to more than 70% of the respondents, this type of support was highly desirable.

In light of the relationships mentioned above, we verified what was the impact of participants' health status, determined in line with the NCCN guidelines, on their QoL. Our analysis demonstrated that QoL in long-term cancer survivors was influenced both by their somatic and psychological status. This relationship was observed for some somatic ailments and psychological problems, namely fatigue, pain, sleeplessness, depression, problems with concentration and disorders of memory. These findings do not seem surprising in view of general concept of health-related quality of life.

As mentioned previously, we found an inconsistency between a relatively high prevalence of physical and

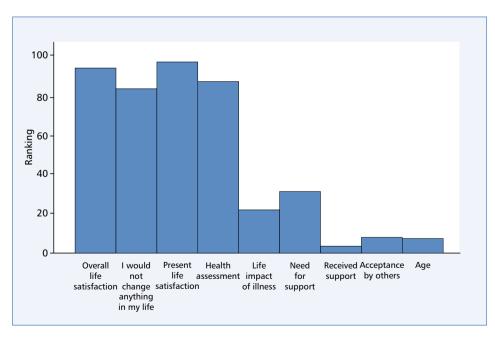


Figure 2. Ranking of predictors importance. Dependent variable: QL. Ranking from 0 (low validity) to 100 (high importance)

psychological ailments and surprisingly high global QoL scores. We assumed that this discrepancy might result from the influence of other than physical and somatic determinants of health; according to literature, these alternative determinants may include a disease-driven change in patients' attitude to life and support from others [19-22]. These changes are sometimes considered as a manifestation of post-traumatic growth. Therefore, we verified if the attitude to life, health and support influenced QoL in long-term cancer survivors. Nearly all these explanatory variables turned out to be significant correlates of QoL in our series. While most of them correlated positively with QoL, the inverse associations were found for the life impact of the illness: the higher was the score for this variable the lower was the QoL of the study subject. Positive correlations between the quality of life and other explanatory variables imply that those parameters might be equally important determinants of QoL as somatic indices. This fact should be considered during planning of comprehensive support for cancer survivors.

Conclusions

To summarize, this study demonstrates that:

- Characteristics of physical and psychological status in Polish cancer survivors were rather similar to those in cancer survivors from other countries.
- Relatively high prevalence of physical ailments and emotional disorders suggests that cancer survivors may require more specialist care than previously supposed.
- Alarmingly high prevalence of cognitive disorders in cancer survivors justifies research on their etiology and possible interventions.
- Considering their general characteristics, cancer survivors presented with surprisingly high global quality of life, life satisfaction and joy of life scores. This might reflect high levels of received support, acceptance, as well as attitudes towards life and illness. However, the latter hypothesis needs to be verified during the course of further research.

Ethical approval

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

Conflict of interest

All authors declare that they have no conflict of interest.

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