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ORIGINAL ARTICLE

Patterns, perceptions, and perceived barriers to physical activity in adult cancer survivors

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Abstract

Purpose Physical activity (PA) during and after cancer treatment is associated with improved cancer- and non-cancer-related outcomes. We assessed for predictors of change in PA levels among cancer survivors.

Methods Adult cancer survivors from a comprehensive cancer center completed a one-time questionnaire retrospectively assessing PA levels before, during, and after cancer treatment along with their perceptions of PA. Multivariable logistic regression models evaluated the association of clinico-demographics variables and perceptions of PA with changes in whether patients were meeting PA guidelines after cancer diagnosis.

Results Among the 1003 patients, 319 (32%) met moderate to vigorous PA (MVPA) guidelines before diagnosis. Among those meeting guidelines before diagnosis, 50% still met guidelines after treatment; 12% not meeting MVPA guidelines initially met them after treatment/at follow-up. Among patients meeting guidelines before diagnosis, better ECOG performance status at follow-up, receiving curative therapy, and spending a longer time on PA initially were each associated with meeting guidelines at follow-up. After controlling for other variables, perceiving that PA improves quality of life (adjusted odds ratio, aOR = 11.09, 95%CI [1.42–86.64], $P = 0.02$) and overall survival (aOR = 8.52, 95%CI [1.12–64.71], $P = 0.04$) was each associated with meeting MVPA guidelines during/after treatment, in patients who did not meet guidelines initially. Only 13% reported receiving

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counseling, which was not associated with PA levels. Common reported barriers to PA included fatigue, lacking motivation, and being too busy.

Conclusions Patient perceptions of PA benefits are strongly associated with improving PA levels after a cancer diagnosis. Clinician counseling should focus on patient education and changing patient perceptions.

Keywords Physical activity · Cancer survivorship · Patient perceptions · Counseling

Introduction

Through advances in both early cancer detection and therapy improvements, cancer patients are now living longer; over 60% of patients are expected to live beyond 5 years after their cancer diagnosis [1, 2]. Thus, cancer care has expanded to include the post-treatment period of survivorship and secondary prevention. Compared to patients without cancer, many cancer survivors have persistent treatment-related side effects such as fatigue, the psychosocial sequelae of being diagnosed with cancer alongside other comorbidities including cardiovascular disease, diabetes, osteoporosis, functional decline, and increased risk of second primary cancers [1, 3].

A key aspect of cancer survivorship focuses on lifestyle behaviors (i.e., smoking cessation, dietary changes, alcohol moderation, and physical activity promotion) [1, 4]. Prior studies have demonstrated that regular physical activity (PA) among cancer survivors can reduce the risk of cancer recurrence, improve survival, help with treatment-related side effects, reduce the development of cardiovascular complications, and improve overall quality of life [4–13]. PA has also been found safe for cancer survivors in both the active treatment and post-treatment phases [11–13]. Optimal PA levels recommended in guidelines of the American Cancer Society and American College of Sports Medicine is 150 min of moderate to vigorous physical activity (MVPA) per week, even during the treatment phase of cancer [14, 15]. In addition, these guidelines also recommend that PA be spread throughout the week and be conducted in addition to one's activities for daily living and that cancer survivors to limit sedentary behaviors.

Prior studies have investigated factors associated with PA among cancer survivors. Younger age, male gender, higher socioeconomic status, more social support, fewer disease-related symptoms, and improved perceptions of PA were each associated with higher levels of PA among cancer survivors [16–20]. Few studies have evaluated factors associated with changes in PA levels in cancer survivors. Of these, the following factors were found to be associated with changes in PA after a cancer diagnosis: age, occupation, education, body mass index (BMI), baseline PA levels, receiving specific cancer therapies (chemotherapy and radiation therapies), and participating in a rehabilitation program [21–26].

Using the health belief model (HBM) framework [27], patients are thought to be willing to adopt healthy behavior changes if (i) there is sufficient motivation, (ii) patients have a perceived threat of health-related sequelae, and (iii) patients believe that health recommendations can prevent or reduce that threat. By applying the HBM to studying PA changes in cancer survivors, we can use a cancer diagnosis as a "teachable moment" to motivate behavior change. To date, patient perceptions of PA and physician counseling on improving PA levels have not been well studied and it is unclear how much patient perceptions play a role and how often physicians are discussing the benefits of PA with patients.

Our study aims were to (i) measure self-reported PA levels both before and after a diagnosis of cancer in a large sample of cancer survivors; (ii) assess the perceptions in cancer survivors of the benefits of PA on three cancer survivorship domains (i.e., 5-year overall survival, quality of life, and fatigue) and perceptions of safety of PA; and (iii) determine if patient perceptions of PA were associated with change in PA level after a cancer diagnosis. We also explored (iv) if cancer patients received any counseling or information from their healthcare providers (family physician, oncologist) on PA and its association with change in PA levels; and (v) perceived barriers to engaging in PA among cancer survivors who were not meeting PA guidelines. These components will be important to inform how best to incorporate PA programs into cancer survivorship programs.

Patients and methods

Patient recruitment and data collection

Cancer survivors across diverse disease sites were recruited from May 2012 to April 2014 at a single tertiary cancer center, the Princess Margaret Cancer Centre, Toronto, Canada, where the study received institutional ethics approval. Patients aged 19 years or greater, with a histologically confirmed diagnosis of either a solid or hematological malignancy of all stages and treatment intents, were included in the study. Cognitive deficits and language barriers that limited patient understanding of the study or consenting process were exclusion criteria.

All consenting patients completed a one-time, self-administered and self-reported questionnaire at an ambulatory oncology clinic visit, which assessed sociodemographic information, PA levels, perceptions of PA, and functional status (as measured by the Eastern Cooperative Oncology Group

(ECOG) performance score and a separate 5-point Likert scale from poor to excellent). Clinicopathological information (including date of diagnosis, stage, treatments received to date, and treatment intent) were obtained from medical chart review.

Given the diversity of cancer subtypes that were included in the study, all forms of systemic therapy were grouped together (chemotherapy, hormonal therapy, targeted agents, and stem cell therapy) and all forms of radiation therapy were grouped together (i.e., external beam, stereotactic beam radiotherapy, radioactive iodine, and brachytherapy). Patients diagnosed with cancer > 10 years prior to the study recruitment date were excluded from further analyses.

Physical activity level and patient perception assessments

Patients retrospectively reported their PA levels at 1 year before their cancer diagnosis (baseline), during treatment, and at follow-up using an adapted validated tool which assesses for and groups types of PA based on their intensity level [28]. Cancer patients were dichotomized based on whether they met regular PA level recommendations of at least 150 min of MVPA per week at each time point [14].

We did not find any previously validated instruments to assess patient perceptions of PA on patient survivorship outcomes. Hence, patient perceptions of the effect of PA on their own health in the three survivorship domains (quality of life, fatigue, and overall survival) were assessed using a 7-point Likert scale (1, makes much worse; 4, no effect; 7, makes much better).

After a mid-study protocol amendment, roughly half of patients also completed additional questions about perceived barriers to PA. These questions included whether or not they felt PA was safe during cancer treatment, what perceived barriers they had regarding being or becoming physically active, and the number of minutes of PA per week that they felt were the recommended PA guidelines [16, 29, 30]. Patients could select as many options as applicable to them from a list of barriers or provide free-text answers, which were then grouped by theme.

Patients were divided into two subgroups based on their baseline physical levels 1 year before diagnosis: those who met MVPA guidelines and those who did not. Within each subgroup, patients were further divided into those who continued to meet MVPA guidelines at follow-up and those who did not, which took into account transient reduction in levels expected during active cancer therapy. As one aim was to assess for factors influencing changes in PA levels after a cancer diagnosis and patients may limit their PA levels during active therapy due to treatment side effects, only patients who were beyond active treatment (i.e., those reporting not undergoing regular intravenous chemotherapy or radiation therapy and were not peri-operative) were included in that particular analysis.

Statistical analysis

Statistical analyses were completed using SAS 9.4 and R (http://CRAN.R-project.org). Descriptive statistics were provided, and comparisons were conducted using Fisher's exact test, Pearson's chi-square test, or Kruskal–Wallis test, where appropriate.

Univariable logistic regression models were applied to evaluate the effects of each primary predictor variable and covariates (sociodemographics, clinicopathological variables) for each PA level subgroup as described above. Multivariable logistic regression models were then applied to construct baseline models using backward selection algorithms of all covariates that showed a trend of association with change in PA level ($P < 0.10$). Each primary predictor variable, namely each perception variable and counseling variable, was then added to each model and its significance evaluated.

Results

Baseline patient characteristics and demographics

Of 2523 patients approached, 1747 were eligible and 1003 were ultimately recruited and completed the study questionnaire (effective response rate, 57%; Fig. 1). For baseline characteristics (Table 1), almost half were female, with a mean age of 54 years; the majority were married, were English-speaking, had completed at least some form of post-secondary education, worked white-collar jobs, and were relatively asymptomatic from their malignancy. Most patients had localized disease and received surgery and systemic therapy. Our study population represented a broad range of tumor subtypes including breast (16%), gastrointestinal (13%), genitourinary (10%), gynecologic (12%), head and neck (11%), hematologic (19%), lung (6%), and other (11%) cancers.

Physical activity at baseline

Of 1003, 318 (32%) met MVPA guidelines at baseline. When compared to those not meeting MVPA guidelines at baseline, those who met guidelines were more likely to be younger, employed, Caucasian, have completed some post-secondary education, and have better ECOG performance status, and were also more likely to perceive that PA can improve their own quality of life, fatigue, and overall survival (Table 1). There were also slight differences in the eventual treatments that patients received between the groups meeting and not meeting guidelines at baseline, with those meeting guidelines more likely to receive systemic therapy but less likely to receive radiation. The distribution of baseline minutes of PA per week for patients meeting and not meeting guidelines is shown in Fig. 2a, b.

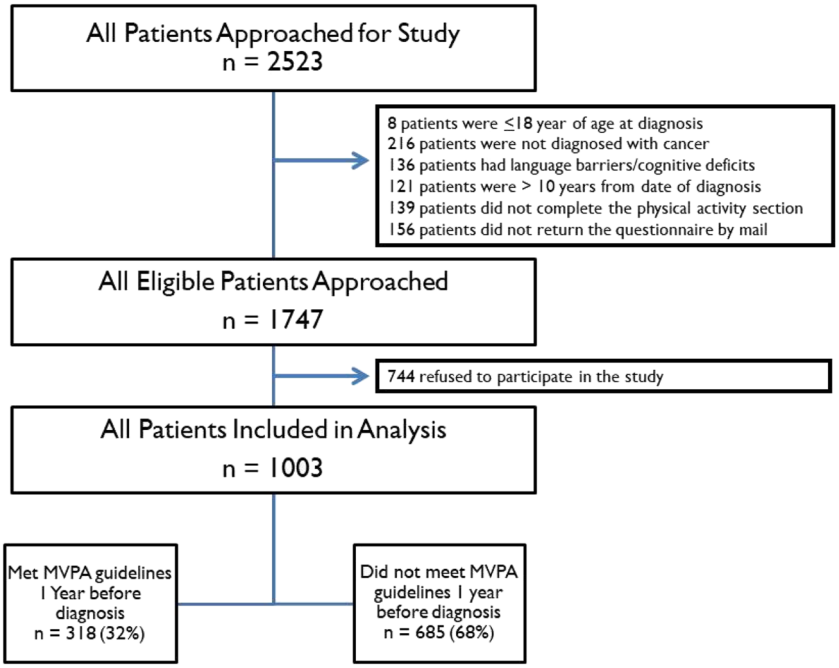

Fig. 1 CONSORT diagram

Changes in physical activity levels

Among patients who met guidelines at diagnosis ($n = 319$), 25% (80/319) of patients reported still meeting guidelines during treatment, and 50% (129/259) met guidelines at follow-up. Among patients who were not meeting MVPA guidelines at baseline ($n = 685$), 3% (22/685) reported improving their PA level to meet MVPA guidelines during treatment, and 8% (57/579) reported meeting guidelines at follow-up. Patients were excluded from the follow-up count if they were still undergoing active treatment. Overall, for those not meeting MVPA guidelines at baseline, only 12% (69/579) improved to meeting MVPA guidelines at any time point after their cancer diagnosis. Figure 2c, d shows the distribution in the absolute change in the minutes of PA stratified by meeting/not meeting MVPA guidelines.

Univariable and multivariable analysis results of significant covariates associated with change in PA level stratified by meeting/not meeting MVPA guidelines at baseline are shown in Supplementary Tables 1 and 2, respectively. For patients who met MVPA guidelines at baseline, patients with better ECOG performance status at follow-up (aOR = 5.56), those who were treated for cure (aOR = 5.00), and those who reporting exercising longer at baseline (aOR = 1.004 per minute) were more likely to keep meeting guidelines after cancer treatment. Among patients not meeting MVPA guidelines at baseline, those completing post-secondary studies (aOR = 2.34), or who had better self-rated health (aOR = 3.52) were more likely to improve to meet guidelines during their cancer care, while those who were older (aOR = 0.97 per year) and who spoke English at home (aOR = 0.39) were less likely to meet guidelines during follow-up.

Association between patient perceptions and physician counseling and changes in physical activity level

Table 2 summarizes the results of our primary predictor variables (patient perceptions and receiving counseling) on change in PA levels after diagnosis. Among all patients, about 90% perceived that PA improves quality of life and 5-year overall survival while 76% perceived that PA improves fatigue. Only 13% of patients recalled receiving counseling from their physicians. Among patients meeting MVPA guidelines at baseline, none of the primary predictors were associated with maintenance of PA after diagnosis, ($P > 0.05$). For patients not meeting MVPA guidelines before diagnosis, perceiving that PA improves quality of life (aOR = 11.09) and overall survival (aOR = 8.52) was individually associated with increased PA (to meet guidelines) after diagnosis. In addition, patients who perceived that PA is always safe were more likely (aOR = 2.57) to increase their PA levels to meet guidelines after diagnosis.

Cancer patient-perceived barriers towards physical activity

Supplementary Table 3 lists the common barriers our patients reported facing which prevented them from undergoing regular PA. Among all patients in general ($n = 489$) and those who were not currently meeting MVPA guidelines ($n = 299$), the top three reported barriers were

Table 1 Summary of sociodemographic, clinicopathological, and primary predictor (perception) variables among all patients, and stratified by whether patients were are meeting MVPA guidelines 1 year prior to diagnosis. All values represent percentages of patients except for age, minutes of MVPA, and follow-up time where the mean and range in brackets are given. *P* values represent comparisons of variables across the two baseline groups using Fisher's exact test or Pearson's chi-squared tests (for discrete variables) and Wilcoxon rank-sum test for continuous variables. *ECOG PS* Eastern Cooperative Oncology Group Performance Status, *MD* doctor, *MVPA* moderate to vigorous physical activity

Variable	Subgroup	All patients ($n = 1003$)	Meeting MVPA guidelines at baseline (1 year prior to diagnosis)		*P* value
			Yes ($n = 318$)	No ($n = 685$)	
Sociodemographic variables					
Age at diagnosis, years	Median (range)	55 (19–97)	51 (19–85)	57 (20–97)	< 0.001
Gender	Male (%)	47	48	46	0.59
Language spoken at home	English (%)	91	92	90	0.20
Employment status	Employed/full-time student (%)	40	46	37	0.01
Employment type	White collar (%)	73	77	72	0.11
Ethnicity	Caucasian (%)	82	88	78	< 0.001
Marital status	Married/common law (%)	72	69	73	0.17
Education	Any university, college, or professional education (%)	63	74	57	< 0.001
Household annual income	Greater than $100,000 (%)	39	47	35	0.001
Minutes of MVPA per week at baseline	Median (range)	30 (0–1200)	255 (150–1200)	0 (0–140)	< 0.001
Follow-up time in months	Median (range)	23 (0–120)	21 (0.4–120)	24 (0–120)	0.25
Self-rated health at follow-up	Very good/excellent (%)	36	44	32	< 0.001
ECOG PS at follow-up	0 (%)	46	52	44	0.009
Clinicopathological variables					
Disease stage at time of assessment	Localized (%)	70	67	71	0.45
	Hematologic (%)	19	20	19	
	Metastatic (%)	11	13	11	
Treatment intent at diagnosis	Curative (%)	94	92	94	0.34
Treatment intent at assessment	Curative (%)	84	85	84	0.93
Surgery at any time for cancer	Received (%)	60	61	60	0.78
Radiation at any time for cancer	Received (%)	45	39	48	0.005
Systemic therapy at any time for cancer	Received (%)	65	69	63	0.05
Patient perception of physical activity level variables					
Perceived impact on safety	Always safe (%)	58	65	55	0.11
	Usually safe (%)	29	26	30	
	Never/rarely safe (%)	0	0	1	
	Do not know (%)	13	9	15	
Perceived impact on quality of life	Improves (%)	91	98	87	< 0.001
Perceived impact on survival	Improves (%)	89	95	85	< 0.001
Perceived impact on fatigue	Improves (%)	76	84	72	< 0.001
Patient recall of counseling					
Received information from MD	Yes (%)	13	13	13	1.000

(1) feeling too tired, (2) not having enough motivation, and (3) being too busy. Another potential barrier may be patient perceptions on what are the true recommended exercise guidelines. The distribution of responses to perceived recommended minutes of moderate to vigorous PA per week is shown in Fig. 2e. The median number of minutes estimated by patients was 120 (range 3–510). Figure 2f shows the distribution of the difference between the actual number of minutes of exercise performed by cancer patients and their perceived number of minutes recommended per week (where negative values are cases whereby the patient perceived the recommendation to be higher than the time they themselves actually exercised). In general, patients tended to exercise at MVPA levels about 50 min per week less than what they perceived as the recommended guidelines.

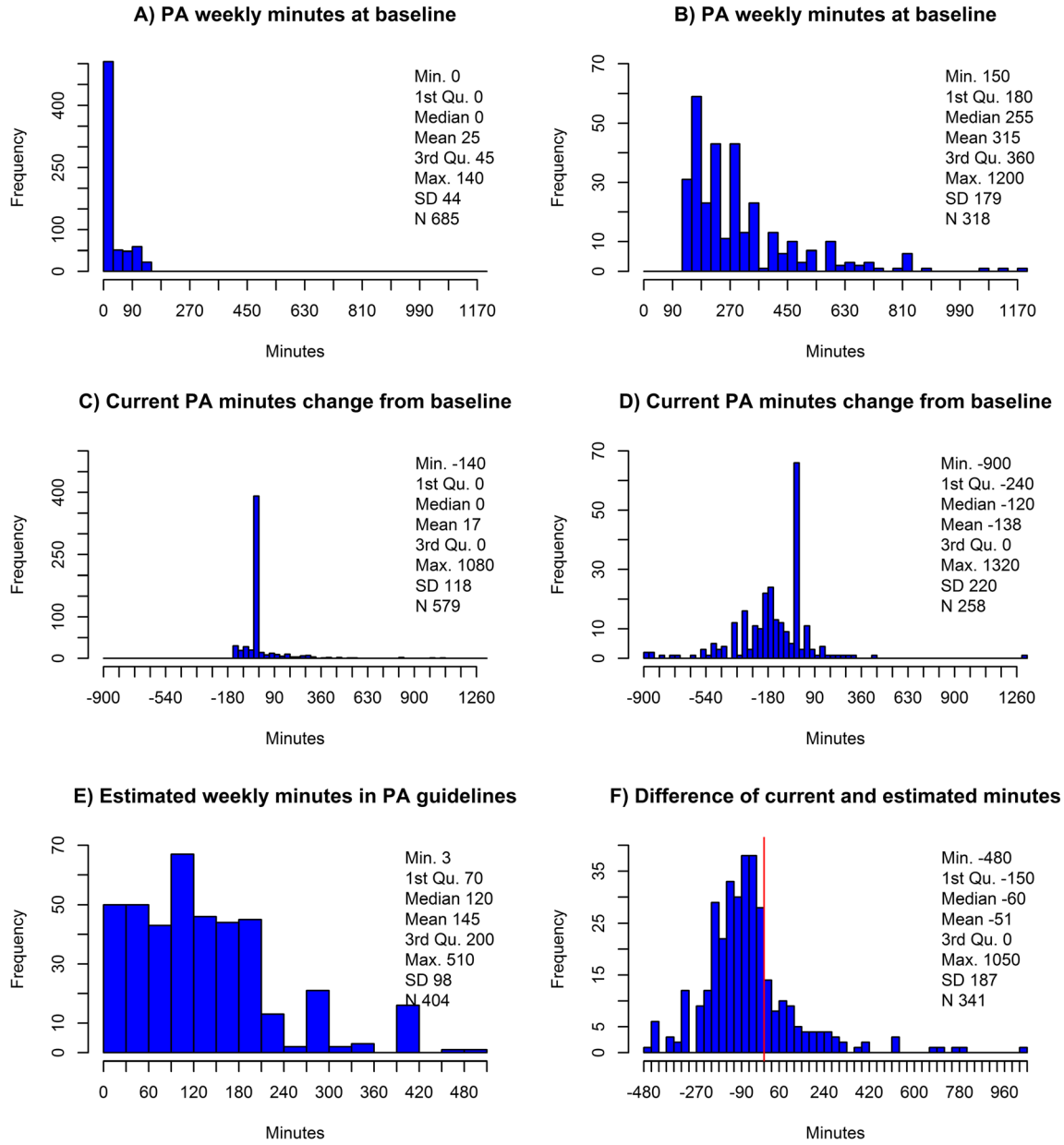

Fig. 2 Distributions of patient-reported minutes of moderate to vigorous physical activity (MVPA) per week for various questions. The distributed baseline MVPA minutes for patients: **a** not meeting MVPA guidelines at diagnosis and **b** meeting MVPA guidelines at diagnosis. The change in minutes of MVPA per week between baseline and follow-up for **c** patients not meeting MVPA guidelines at baseline and **d** patients meeting MVPA guidelines at baseline, whereby negative values in the figures represent a reduction of the minutes of physical activity per week from baseline. The distribution of patient responses to their perceived guideline requirements for the minutes of recommended physical activity per week for cancer survivors (**e**) and difference between patient's perceived recommendation and actual minutes of physical activity per week they are currently performing; the red vertical line represents equivalence between perceived recommendation and actual minutes of physical activity (**f**). Negative values in the panel **f** represent values where patient's actual level of physical activity performed was less than their perceived minutes recommended per week. *Max* maximum, *Min* minimum, *MVPA* moderate to vigorous physical activity, *N* number, *Qu* quartile, *SD* standard deviation

Discussion

Engaging in PA after a cancer diagnosis is associated with both improved quality of life and mortality among cancer survivors [7, 14]. We demonstrate that among patients not meeting MVPA guidelines prior to diagnosis, perceiving that PA improves quality and quantity of life was strongly associated with improving PA levels (to meet guidelines) after diagnosis. Among those meeting guidelines at diagnosis, patients who exercised more minutes at baseline, those undergoing curative treatments, and those who reported better ECOG performance status at follow-up were each associated with maintaining PA at follow-up. Regardless, patients rarely recalled receiving PA counseling from healthcare providers. The most common

Table 2 Summary of univariate and multivariate association analysis results of primary predictor variables with (a) continuing to meet MVPA guidelines from diagnosis to follow-up among patients who were meeting MVPA guidelines at baseline (top) and (b) increased PA levels resulting in MVPA guidelines being met either during treatment or at follow-up among patients who were below MVPA guidelines at baseline (bottom). Multivariate logistic regression models were adjusted for significantly associated multivariate covariates in Supplementary Tables 1 and 2 respectively. *aOR* adjusted odds ratio, *CI* confidence interval, *MVPA* moderate to vigorous physical activity, *OR* odds ratio

Perception or counseling variable	Comparison	Univariable analysis		Multivariable analysis	
		OR (95% CI)	*P* value	aOR (95% CI)	*P* value
Patients meeting MVPA guidelines at baseline 1 year prior to diagnosis					
Safety	Always vs never/rarely/usually/do not know	1.24 (0.59–2.61)	0.57	1.08 (0.48–2.40)	0.86
Quality of life	Improves vs no effect/worsens	3.10 (0.32–30.2)	0.33	2.74 (0.24–31.3)	0.42
Overall survival	Improves vs no effect/worsens	1.51 (0.47–4.89)	0.49	0.98 (0.27–3.51)	0.98
Fatigue	Improves vs no effect/worsens	1.22 (0.62–2.42)	0.56	0.94 (0.43–2.05)	0.87
Received information	Not received vs received	1.25 (0.32–4.90)	0.75	1.95 (0.45–8.54)	0.37
Patients not meeting MVPA guidelines at baseline 1 year prior to diagnosis					
Safety	Always vs never/rarely/usually/do not know	2.58 (1.15–5.78)	0.02	2.57 (1.02–6.49)	0.05
Quality of life	Improves vs no effect/worsens	11.96 (1.64–87.4)	0.01	11.09 (1.42–86.6)	0.02
Overall survival	Improves vs no effect/worsens	12.08 (1.65–88.3)	0.01	8.52 (1.12–64.7)	0.04
Fatigue	Improves vs no effect/worsens	1.21 (0.67–2.21)	0.53	1.00 (0.51–1.94)	0.99
Received information	Not received vs received	0.85 (0.24–3.01)	0.80	0.50 (0.10–2.36)	0.38

barriers to participating in PA by cancer survivors were feeling tired, lack of motivation, or time. Taken together, these results suggest that routine PA counseling should be integrated into cancer care, with patients being educated about the benefits of PA and being provided with practical exercise plans.

To date, studies evaluating factors associated with PA level among cancer survivors have focused on different isolated time points (diagnosis, after treatment, or during long-term follow-up), with the majority limited to breast and colorectal cancer survivors (and a few in other sites) [4, 29, 31, 32]. Multiple prior studies have evaluated factors associated with PA levels and changes in PA levels among cancer patients [17, 18, 20–26, 29, 33]. In comparison to existing studies, our study not only evaluated absolute changes in PA levels, but additionally compared levels to specific guideline recommendations and evaluated the impact of patient perceptions and counseling on behavior change.

The application of health behavior theories helps suggest solutions: using the HBM, cancer patients are motivated by their cancer diagnosis and can perceive a lack of PA as potentially harmful to their quality of life or overall survival [27]. Through proper counseling and education, we hypothesize that patients may adjust their behavior to improve their PA levels. Similarly, using the theory of reasoned action, cancer patients may improve their PA levels in response to them perceiving it to improve their quality of life/survival [34].

Maintaining good levels of PA after diagnosis was associated with being treated for cure, greater PA level (in min/week) prior to diagnosis, and better current ECOG performance status; each of which has predictive with future exercise levels in cancer and/or non-cancer populations [17, 29, 35–39]. Although being treated for cure may provide greater motivation than being palliated, there are multiple benefits of PA among those receiving palliative care [38, 39].

The peri-diagnosis window is a potential "teachable moment" for many lifestyle factors [3, 40], though there are always concerns about patients being overwhelmed during the initial diagnostic, staging, and early treatment phases. Our data suggests that this teachable moment is not fully taken advantage of, given that half of active patients are no longer active later, while only 12% of inactive patients become active as a cancer survivor. Although important factors include incorrect patient perceptions and/or lack of counseling [3, 41], other pragmatic factors include cancer symptoms and treatment toxicities [4, 42, 43]. Education tools should explain how even some toxicities (e.g., fatigue, arthralgia, and bone loss) may improve with PA and also educate patients that PA is safe during and after active cancer treatment [4, 11, 12, 37, 44–46].

Multiple barriers affecting the integration of a standard PA program into routine cancer care include cancer and treatment-related side effects (i.e., neuropathy, lymphedema, ostomies, fatigue) and lack of rehabilitation physiatrists, kinesiologists, or physiotherapists with cancer specialization [4]. Despite about half of clinicians agreeing with the benefits of PA in cancer patients, most are reluctant to take additional clinic time to discuss this and other lifestyle matters with their patients [4, 43, 47]; thus, PA screening in clinic is uncommon [48]. We thus identify the need to develop validated rapid screening and brief interventions (e.g., short but effective

home-based exercise programs) teachable quickly in the ambulatory setting. The outpatient waiting room can be a fertile ground for testing such interventions [48].

There are limitations to our study. As this study is a one-time questionnaire, our data is subject to recall bias and biases of social desirability, which may lead patients to report their lifestyle behavior more favorably toward investigators. We tried to limit recall bias by limiting follow-up to 10 years post-diagnosis. Furthermore, most patients had short follow-up times with a median of 23 months; longer follow-up is required to determine if the changes in PA levels observed are persistent. Longitudinal collection of this data in future studies, including assessing patient perceptions at both baseline and follow-up, would help provide useful information for further studies. Our assessment of patient perceptions was exploratory in nature in this study and used single-item measures to assess perceptions in each domain of cancer survivorship; validation of their psychometric properties is warranted in future studies. Although many perceptions towards survivorship outcomes could be assessed, given the exploratory nature of the study, we chose to focus on these three outcomes which represent different areas of survivorship. Furthermore, there was significant heterogeneity in our cancer patient population as we included patients of multiple disease sites, stages, treatment types, and treatment intents. Some of these factors (i.e., stage of disease, metastatic sites, and possibility of lymphedema from breast cancer surgery) can influence whether patients participate in PA and how much PA they engage in. However, this heterogeneity has its own advantage given the strength of the associations identified in this population. Future validation of findings in specific tumor disease sites is warranted and may help to identify further unique needs and barriers to undergoing PA for each disease site. This, in turn, may help with development of specialized PA programs for each unique tumor site [15].

In summary, many patients who initially met MVPA guidelines reduced their PA levels after diagnosis, while patients who were not initially meeting MVPA guidelines rarely improved their activity level to meeting guidelines at follow-up. Patients perceiving PA to be beneficial and safe were more likely to improve to meeting MVPA guidelines if they were not initially meeting guidelines. Perceptions could potentially be altered through improved counseling; our data suggests that currently, very few patients recalled receiving counseling from their physicians. Examining strategies to integrate PA programs and counseling into routine cancer care should be a priority.

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Compliance with ethical standards

The institutional (University Health Network) research ethics board approved the study. Informed consent was obtained from all individual participants included in the study.

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

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