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Barriers to Physical Activity: A Study of Academic and Community Cancer Survivors with Pain

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Abstract

Purpose: Despite the numerous benefits of physical activity (PA) for patients with cancer, many cancer survivors report challenges to participating in PA. The objectives of this study were: 1) to assess barriers to PA, and 2) to examine participant characteristics associated with modifiable barriers to PA among cancer survivors with pain.

Methods: We conducted a cross-sectional survey study at one academic medical center and 11 community hospitals. Participants completed the 12-item Physical Activity Barriers After Cancer (PABAC) instrument (Cronbach's alpha =0.75). Multivariable regression models examined

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participant characteristics associated with PABAC scores with a higher score indicating more barriers to PA.

Results: Among 662 survivors, 67% had moderate or severe pain (rating 4 or greater on a scale of 0 to 10). Seventy-five percent of survivors did not meet the American Cancer Society PA recommendations on average, and these individuals had higher mean PABAC scores (beta coefficient (β)=2.02, 95% Confidence Interval (CI) 0.96 – 3.09, p<0.001). In adjusted analyses, cancer survivors who were non-white (β=1.55, 0.28 – 2.82, p=0.02), treated at a community hospital (β=1.07, 0.09 – 2.05, p=0.03), had surgery (β=1.69, 0.69 – 2.69, p=0.001) or within 12 months of diagnosis (β=1.15, 0.20 – 2.10, p=0.02) reported greater barriers to PA.

Conclusions: The majority of cancer survivors with pain are not adequately participating in PA. Key demographic and clinical characteristics influence survivors' barriers.

Implications for Cancer Survivors: Efforts to overcome specific barriers are needed to promote PA after a cancer diagnosis.

INTRODUCTION

According to 2016 estimates, over 15 million individuals are living with a cancer diagnosis in the United States, and this number is expected to increase to 20 million by 2026 [1]. A cancer survivor is defined as any individual living with cancer, from the time of diagnosis through the remainder of his/her life [2, 3]. Many cancer survivors experience cancer-related side effects, such as pain and fatigue, which can persist years after treatment has ended [4–6]. Some evidence suggests that physical activity (PA) interventions can improve pain and fatigue in cancer survivors [4–7]. Additionally, PA recommendations from the American Cancer Society (ACS) and other professional organizations encourage cancer survivors to avoid inactivity, return to normal daily activities as soon as possible after diagnosis, and engage in at least 150 minutes of moderate or 75 minutes of vigorous aerobic exercise per week including strength training exercises at least 2 days per week [8–10].

Yet the majority of cancer survivors are not meeting these recommended PA guidelines [11–13]. Previous research exploring why cancer survivors are not physically active has identified a variety of barriers to PA, such as cancer treatment-related side effects, pain, fatigue, comorbid medical conditions, time, and motivation [14–19]. However, the existing literature examining barriers to PA is largely limited to survivors with breast, prostate, and colorectal cancers [18]. Additionally, most of the studies have been conducted among survivors enrolled in lifestyle and/or exercise intervention clinical trials at academic settings, which may already be biased towards enrolling participants with a prior interest and engagement in PA. Further, a paucity of research has examined exercise barriers in cancer survivors with pain.

Our group found that women who experience joint pain while on aromatase inhibitors reported decreased PA [20], which led us to focus on investigating barriers to PA among

survivors with diverse cancer types who reported pain and were treated at community and academic clinical settings. The objectives were: 1) to assess barriers to PA, and 2) to examine if demographic and clinical characteristics are associated with modifiable barriers to PA.

METHODS

Study Design and Population

This study analyzed data from a cross-sectional survey administered to cancer survivors treated at the Abramson Cancer Center (ACC) at the University of Pennsylvania in Philadelphia and 11 ACC-affiliated community hospitals in Pennsylvania and New Jersey. Eligible survivors were 18 years of age or older, had a primary cancer diagnosis of any type, reported experiencing nonzero (>0) pain (on a scale of 0 to 10) in the last seven days, were ambulatory (Karnofsky functional score of 60), and understood written English. Between September 2014 and September 2015, 706 survivors were approached by trained research staff to participate in the study. A total of 668 survivors provided written informed consent and were enrolled. The institutional review board of the University of Pennsylvania approved the study protocol and survey.

Primary Outcome - Barriers to Physical Activity

We developed the 12-item Physical Activity Barriers After Cancer scale (PABAC; Table 1) based on reviewing the literature [16] and eliciting input from clinicians (oncologists, pain specialists, etc.) to identify the most common and salient barriers to physical activity among patients with cancer. Next, we conducted interviews with selected patients with cancer who were not part of the current study to pilot test the 12-item scale. Study participants were asked "Many cancer survivors experience challenges to staying physically active. How much do you agree that you experience the following challenges?" and were given a list of 12 barriers to PA based on the current literature [16] and adapted into a 4-point Likert scale format. The responses ranged from "1=strongly disagree", "2=disagree", "3=agree", or "4=strongly agree". The 12 barriers included nausea, fatigue, pain, sadness, treatment side effects, not enough time/too busy, difficulty getting motivated, difficulty remaining disciplined, lack of safe environment to exercise, lack of financial resources to exercise, surgical complications, and my doctor told me not to exercise. To note, study participants were given the response option of an "other" category to write in their own barriers. However, only 49 survivors provided a written response for the "other" category, and these responses overlapped with at least one of the 12 barrier items stated above. Therefore, we chose to not include the "other" barriers category in the 12-item PABAC scale. The internal consistency for the 12-item PABAC scale was adequate (α=0.75). The scores of the 12 barrier items were summed, with possible scores ranging from 12 to 48. Higher scores indicated more barriers to PA.

Exploratory factor analysis was conducted for the 12-item PABAC scale using principal components analysis (PCA) to extract the factors followed by oblique rotation of factors using Oblimin rotation. The number of factors to be retained was determined by 1) Kaiser's criterion of eigenvalues > 1 and 2) inspection of the scree plot. Reliability analysis was used

to calculate Cronbach's alpha to examine the internal consistency for each PABAC subscale. Based on the PCA results, the 12-item PABAC scale split into four factors: Symptoms, Cognitive, Logistical, and Clinical. The Cronbach's alphas for the four barriers subscales, except the Clinical scale, were moderate: 0.71 for the Symptoms scale (5 items), 0.72 for the Cognitive scale (3 items), 0.73 for the Logistical scale (2 items), and 0.52 for the Clinical scale (2 items) (See Online Resource).

Social demographic and clinical factors

Patient-reported demographic data included: date of birth to calculate age at study enrollment, sex, race/ethnicity, relationship status, education, and height and weight to calculate body mass index (BMI). Participants also reported information about their pain (on a scale of 0 to 10) in the last seven days, meeting ACS physical activity recommendations, cancer type, date of cancer diagnosis, treatment status at time of the questionnaire (i.e., completed cancer treatments, currently receiving cancer treatments, or about to start cancer treatments), and type of cancer treatment(s) received (e.g., radiation, surgery, chemotherapy). Cancer stage was obtained, and cancer type was verified from chart abstractions.

Statistical Analysis

Descriptive statistics were calculated as frequencies and percentages. Independent samples t-tests were conducted to examine demographic and clinical characteristics associated with the 12-item PABAC scale and subscales. Standard multiple linear regression models were used to estimate beta coefficients for participant characteristics associated with the 12-item PABAC scale. Explanatory variables associated with the primary outcome at $p<0.05$ in the bivariate analyses were included in the multivariable regression models. Statistical significance for the multivariable regression models was set at $p<0.05$. For sensitivity analyses, one-way between-groups analysis of variance and post-hoc comparisons using the Tukey HSD test were conducted. Statistical analyses were conducted using SPSS (Windows version 24.0, IBM Corporation, Armonk, NY) and Stata (Windows version 12.0, StataCorp LLC, College Station, TX) software.

RESULTS

Characteristics of Study Participants

Of the 668 enrolled participants, six withdrew from the study prior to completing the survey for the following reasons: changed mind (n=4), time constraints (n=1) and health issues (n=1). Among the remaining 662 participants, the mean age was 60.4±11.6 years (range 23–90 years). Sixty-five percent of survivors were female, 81% white, 68% had completed some college or above, and 65% were in a partnered relationship. Sixty-seven percent of participants reported moderate to severe pain (rating 4 or greater on a scale of 0 to 10 in the past seven days). The majority of participants (75%) reported not meeting the ACS PA recommendations of 150 minutes of moderate activity or 75 minutes of vigorous activity per week on average in the past month. Over half of the survivors (52%) were seen in community hospitals. Approximately 53% of survivors had a non-metastatic cancer diagnosis, and 50% were diagnosed at least 12 months ago. For cancer treatment, the

majority received chemotherapy (88%), surgery (53%), and radiation treatment (53%) (Table 2).

Physical Activity Barriers After Cancer

Table 1 displays the percentage of participants who endorsed experiencing each of the 12 barriers in the PABAC measure. The most common barriers reported were fatigue (78%), pain (71%), difficulty getting motivated (67%), and difficulty remaining disciplined (65%).

Participant Characteristics Associated with Physical Activity Barriers After Cancer

Using the combined total score for the 12-item PABAC scale, we found that survivors who reported not meeting ACS PA guidelines reported higher PABAC scores, indicating greater barriers to PA (unadjusted beta coefficient (β)=2.02, $p<0.001$). Additionally, we found key demographic and clinical characteristics significantly associated with greater barriers to PA (Tables 2 and 3). In unadjusted analyses, we found a significant linear relationship between age and PABAC scores, showing that as age increased, PABAC scores decreased (β=−0.04, $p=0.04$). After adjusting for covariates, the association between age and PABAC scores became borderline significant (β=−0.04, $p=0.06$). Higher PABAC scores were reported by non-white survivors compared to whites (β=1.55, $p=0.02$). In terms of clinical characteristics, survivors who were treated at a community hospital (β=1.07, $p=0.03$) and those within 12 months of diagnosis (β=1.15, $p=0.02$) reported higher barrier scores. Additionally, survivors who received surgery as part of their cancer treatment were significantly more likely to report higher PABAC scores (β=1.69, $p=0.001$) (Table 3).

To explore if subgroups of cancer survivors experience certain types of barriers, we examined the association of demographic and clinical factors with mean scores for each PABAC subscale (i.e., symptoms, cognitive, logistical, and clinical) (Table 4). Similar to the overall PABAC scale, as age increased the PABAC symptoms subscale scores decreased (β= −0.04, $p=0.002$). Female survivors experienced higher scores related to symptoms (12.6 vs. 11.8, $p=0.009$) and cognitive barriers (7.7 vs. 7.2, $p=0.002$) compared to males. Non-white survivors experienced higher clinical barriers compared to whites (3.8 vs. 3.3, $p<0.001$). Study participants who did not attend college reported greater logistical (4.0 vs 3.7, $p<0.01$) and clinical (3.6 vs. 3.3, $p<0.01$) barriers compared to those with higher education. Survivors with a more recent cancer diagnosis (≤ 12 months) had higher symptoms barriers scores than those greater than 12 months from diagnosis (12.8 vs. 11.9, $p<0.001$). Survivors who underwent cancer surgery had higher symptoms (12.7 vs. 12.0, $p=0.01$) and clinical (3.6 vs. 3.3, $p<0.01$) barriers mean scores than those who did not have surgery.

To further explore the association between specific cancer types and time since cancer diagnosis with the 12-item PABAC scale scores, we conducted sensitivity analyses. Using eight categories of cancer type (i.e., breast, gastrointestinal, genitourinary, gynecological, head and neck, hematological, lung and other), we found that the mean PABAC scores did not differ significantly by cancer type (data not shown). To examine if a tipping point existed for the association between time since diagnosis and the 12-item PABAC scores, we split time since diagnosis as ≤ 6 months versus > 6 months and found similar findings as those presented in Table 3. Next, using time since diagnosis as three categories (≤ 6 months, 7 to

12 months, and > 12 months), we found that the mean PABAC scores for those   6 months (Mean=27.8, SD = 4.4) was significantly different from those > 12 months (Mean=26.2, SD = 5.3); however, mean PABAC scores for patients who were diagnosed between 7 and 12 months (Mean=26.5, SD = 5.2) did not differ significantly from patients who were   6 months or > 12 months. Based on these results, we used time since diagnosis as   12 months versus > 12 months as shown in Tables 2–4.

DISCUSSION

Despite the benefits of PA [21], many cancer survivors are not meeting the recommended PA guidelines and report significant challenges to staying physically active after their cancer diagnosis [11, 12]. In our study population of cancer survivors with pain, 75% of participants did not meet the recommended PA guidelines and reported higher barriers scores. Additionally, we found that cancer survivors who were younger and those were non-white reported greater barriers to PA. In terms of clinical characteristics, survivors who were treated at a community hospital, underwent surgery for cancer treatment, or were within 12 months of diagnosis had higher barriers scores. We also found that certain subgroups of cancer survivors, such as females and individuals with less education, were more likely to experience specific types of barriers (symptoms, cognitive, logistical, and clinical) to PA.

In our sample of over 600 cancer survivors, 67% reported moderate to severe pain in the past 7 days, and 71% endorsed pain as a barrier to PA. These findings might be explained by the fear-avoidance model of musculoskeletal pain, which posits that individuals with pain will avoid certain behaviors (e.g., physical activity) that they worry may increase their pain [22]. For example, in a population-based study of older adults with chronic pain, Larsson et al (2016) found that low kinesiophobia (fear of movement) at baseline predicted higher physical activity levels at the 12-month follow-up [23]. Despite PA being a recommended intervention for cancer pain [6, 7], survivors with pain may be more prone to exhibit fear-avoidance behaviors towards PA and attribute their pain as a challenge to participating in PA [14–16, 18, 19].

Our study highlights that key demographic characteristics are associated with barriers to PA and that certain subgroups of cancer survivors may be more prone to specific types of barriers to PA than others. In unadjusted analyses, we found that younger survivors reported higher PABAC scores and PABAC symptoms subscale scores than those who were older. These findings may be due to younger survivors undergoing more intensive cancer treatments or it may be that older survivors are less likely to attribute symptoms as barriers to PA. Previous research has shown that younger survivors experience more symptoms of pain, fatigue, and psychological distress and report poorer quality of life than older survivors [24–26]. For younger patients who report pain and fatigue symptoms, clinical care teams should discuss symptom management strategies, such as proactive rehabilitation or physiotherapy interventions, as a way to mitigate these symptoms and help promote PA throughout the patient's cancer treatment trajectory.

In line with previous research [16], we found that survivors with a high school education or less reported greater logistical and clinical PABAC subscale scores compared to those with

higher education. Additionally, we found that patients in community settings were more likely to have higher logistical PABAC subscale scores than those treated at academic settings. Previous research has shown that individuals living in rural areas have lower PA levels than those living in urban environments, which may be due to limitations in the built physical environment (e.g., bike lanes, parks, etc.) and fewer economic resources [27, 28]. With these findings in mind, clinical care teams should work with certain subgroups of survivors to better address their logistical barriers to PA. For example, clinical care teams or fitness specialists may want to consider referring survivors to community-based recreational fitness centers or recommend home-based fitness routines or online exercise classes that are appropriate for cancer survivors [29].

Further, our results show that females experienced significantly higher cognitive and symptom PABAC subscale scores compared to males. Since previous research has shown that women are more likely to be ruminators [30] and are influenced by peer support, health care providers may want to provide female cancer survivors with motivational support and symptom management strategies to help promote PA after cancer. Female cancer survivors may respond better to nurse-led, group-based, or mobile text-based PA interventions than their male counterparts [31]. Additionally, emerging research is showing that wearable PA monitors have potential to serve as a motivational tool and their use has been found to improve PA levels among cancer survivors [31–34]. Clinical care teams may want to encourage sedentary female survivors to use PA monitors as a way to self-monitor and track PA levels throughout the day.

In terms of clinical characteristics, we found that survivors within 12 months of their cancer diagnosis and those who had undergone surgery reported experiencing higher overall PABAC and symptoms PABAC subscale scores. For cancer survivors with more clinical symptoms and comorbidities, clinicians and surgeons may want to prescribe low-to-moderate intensity physical exercises and/or refer patients to cancer rehabilitation/physical therapy specialists during the cancer treatment period [35]. Previous studies have shown that exercise during and after active cancer treatment is beneficial for improving physical function, health-related quality of life, and cancer-related fatigue [8, 21, 36, 37]. Additionally, research has shown cancer survivors who receive an exercise recommendation from their clinician tend to be more physically active [38, 39].

It is important to acknowledge limitations to the study. While we enrolled survivors with diverse cancer types, the 12-item PABAC measure may not fully capture all barriers experienced by survivors with certain tumor types. For example, a barrier to PA not included in the PABAC measure may be lack of knowledge regarding types of PA that are safe to do. Another limitation is that this study did not assess survivors' PA prior to their cancer diagnosis, which has been shown to be a determinant of exercise behavior post-cancer diagnosis [40]. Additionally, although the developed PABAC measure and its 4 unique subscales (symptoms, cognitive, logistical and clinical) exhibited adequate psychometric properties in our sample, future research is needed to further validate this scale in other cancer populations.

Despite its limitations, this study has numerous strengths including a large population of cancer survivors with diverse cancer types and stages treated at both academic and community clinical settings. The 12-item PABAC tool can be administered in clinic settings to aide clinicians in identifying patient's barriers to PA and guiding appropriate exercise prescription based on the patient's self-reported barriers. In contrast, many of the existing patient-reported barriers to PA tools have been designed to be used within the context of exercise clinical trials, focus on specific cancer types, or consist of checklists with yes/no responses [16, 41, 42]. Our study provides insight into barriers to PA experienced by a large cohort of cancer survivors with pain. In summary, we found that specific types of barriers to PA exist and that key participant demographic and clinical characteristics are associated with these barriers to PA. Future PA interventions should be developed for subgroups of cancer survivors and target specific barriers in order to better promote PA after a cancer diagnosis.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Cancer survivors reported Physical Activity Barriers After Cancer scale

Many cancer survivors experience challenges to staying physically active. How much do you agree that you experience the following challenges?	Response (N=662)				
	Strongly Disagree	Disagree	Agree	Strongly Agree	Endorsing[*]
	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
Not enough time/too busy	127 (20.6)	311 (50.3)	152 (24.6)	28 (4.5)	180 (29.1)
Difficulty getting motivated	40 (6.4)	165 (26.4)	346 (55.4)	74 (11.8)	420 (67.2)
Difficulty remaining disciplined	40 (6.4)	177 (28.4)	345 (55.3)	62 (9.9)	407 (65.2)
Lack of safe environment to exercise	185 (30.0)	367 (59.5)	55 (8.9)	10 (1.6)	65 (10.5)
Lack of financial resources to exercise	180 (28.9)	317 (51.0)	106 (17.0)	19 (3.1)	125 (20.1)
Nausea	184 (29.7)	219 (35.3)	177 (28.5)	40 (6.5)	217 (35.0)
Fatigue	50 (8.0)	90 (14.4)	317 (50.8)	167 (26.8)	484 (77.6)
Pain	56 (9.0)	124 (20.0)	323 (52.0)	118 (19.0)	441 (71.0))
Sadness	165 (26.8)	254 (41.3)	162 (26.3)	34 (5.5)	196 (31.8)
Treatment side effects	124 (25.7)	114 (23.6)	173 (35.8)	72 (14.9)	245 (50.7)
Surgical complications	217 (39.1)	220 (39.6)	89 (16.0)	29 (5.2)	118 (21.2)
My doctor told me not to exercise	311 (52.4)	244 (41.1)	25 (4.2)	13 (2.2)	38 (6.4)

[*] Responses of "agree" and "strongly agree" were considered endorsing the statement.

Due to missing data, some variables do not add up to 662.

Table 2.

Participant characteristics by the 12-item Physical Activity Barriers After Cancer (PABAC) scale scores

Characteristic	No. (% of total)	PABAC score Mean (SD)	*p* value
Age, years			**0.04**
Mean ± standard deviation		60.4 ± 11.6	
<60	297 (44.9)	27.3 (4.8)	
60	365 (55.1)	26.3 (5.2)	
Sex			**0.02**
Male	231 (34.9)	26.0 (5.3)	
Female	431 (65.1)	27.2 (4.8)	
Race			**0.04**
White	539 (81.4)	26.6 (5.1)	
Non-White	123 (18.6)	27.9 (4.9)	
Body Mass Index (kg/m^2)			0.08
Normal weight (< 25)	230 (35.0)	26.2 (5.2)	
Overweight/Obese (25)	428 (65.0)	27.1 (5.0)	
Education			**0.03**
High school or less	212 (32.4)	27.7 (4.3)	
Some college or above	442 (67.6)	26.5 (5.3)	
Relationship Status			0.07
Partnered	431 (65.2)	26.5 (5.1)	
Not partnered	230 (34.8)	27.4 (4.9)	
Cancer Type			0.25
Breast	206 (31.2)	27.0 (5.3)	
Thoracic/Lung	98 (14.8)	26.9 (4.6)	
Hematologic	97 (14.7)	25.6 (5.0)	
Other [*]	260 (39.3)	27.1 (5.0)	
Cancer Stage			0.18
Non-metastatic	323 (53.2)	27.1 (5.0)	
Metastatic	284 (46.8)	26.5 (5.0)	
Time since Cancer Diagnosis			**0.02**
12 months	318 (49.6)	27.4 (4.7)	
> 12 months	323 (50.4)	26.2 (5.3)	
Cancer Treatment Status			0.30
Currently receiving treatment	501 (80.0)	27.1 (4.8)	
Completed treatment	111 (17.7)	25.9 (5.7)	
About to start treatment	14 (2.3)	27.1 (5.5)	
Chemotherapy			0.24
Yes	579 (87.5)	26.9 (5.1)	
No	83 (12.5)	26.0 (4.8)	
Radiation			0.31
Yes	352 (53.2)	26.6 (4.6)	

Characteristic	No. (% of total)	PABAC score Mean (SD)	p value
No	310 (46.8)	27.1 (5.5)	
Surgery			**0.001**
Yes	348 (52.6)	27.6 (5.2)	
No	314 (47.4)	25.9 (4.7)	
Hospital Treatment Location			**0.03**
Academic	321 (48.5)	26.2 (5.2)	
Community	341 (51.5)	27.3 (4.9)	
Met physical activity recommendations in the past month			**<0.001**
Yes	160 (25.3)	25.32 (5.9)	
No	473 (74.7)	27.34 (4.6)	

Due to missing data, some variables do not add up to 662.

*Other cancer type includes but is not limited to: gastrointestinal, gynecological, genitourinary, head and neck, sarcoma, and skin.

Table 3.

Linear regression analyses for participant characteristics associated with the 12-item Physical Activity Barriers After Cancer scale scores

Characteristic	Unadjusted β	95% Cl	*p* value	Adjusted β	95% Cl	*p* value
Age, years	−0.043	−0.084 – −0.003	0.036	−0.041	−0.083 – 0.001	0.055
Gender: Females (vs. Males)	1.187	0.188 – 2.186	0.020	0.251	−0.783 – 1.285	0.633
Race: Non-white (vs. White)	1.313	0.053 – 2.573	0.041	1.546	0.275 – 2.818	0.017
Education: Some college or above (vs. High school or less)	1.170	0.133 – 2.208	0.027	0.960	−0.078 – 1.998	0.070
Treatment location: Community (vs. Academic)	1.028	0.083 – 1.974	0.033	1.070	0.092 – 2.047	0.032
Time since cancer diagnosis: 12 months (vs. > 12 months)	1.178	0.224 – 2.131	0.016	1.150	0.196 – 2.104	0.018
Surgery (vs. No surgery)	1.641	0.699 – 2.583	0.001	1.687	0.688 – 2.686	0.001

The final multiple linear regression model was adjusted for all variables shown in the table β beta coefficient, CI confidence interval

Table 4.

Participant characteristics by subscales of the 12-item Physical Activity Barriers After Cancer scale

Characteristic	Symptoms Barriers	Cognitive Barriers	Logistical Barriers	Clinical Barriers
Age, years	↑*	↔	↔	↔
Gender: Females (vs. Males)	↑*	↑*	↔	↔
Race: Non-white (vs. White)	↔	↔	↔	↑*
Education: High school or less (vs. Some college or above)	↔	↔	↑*	↑*
Treatment location: Community (vs. Academic)	↔	↔	↑	↔
Time since cancer diagnosis: 12 months (vs. > 12 months)	↑*	↔	↔	↔
Surgery (vs. No surgery)	↑	↔	↔	↑*

↑ Higher barriers scores ($p < 0.05$);

*$p < 0.01$

↔ No significant differences in scores (p 0.05)