Title: Perceived barriers and benefits to physical activity in colorectal cancer patients

Running title: Attitudes to PA in CRC patients

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Abstract

Purpose: There is emerging evidence for the benefits of physical activity (PA] post-diagnosis for colorectal cancer (CRC) survivors. However population studies suggest activity levels in these patients are very low. Understanding perceived barriers and benefits to activity is a crucial step in designing effective interventions. **Methods:** Patients who were between 6 months and 5 years post-diagnosis with non-metastasised disease were identified from five London (UK] hospitals. 495 completed a lifestyle survey that included open-ended questions on their perceived barriers "what things would stop you from doing more physical activity?" and benefits "what do you think you would gain from doing more physical activity?". Patients also recorded their activity levels using the Godin Leisure Time Questionnaire, along with socio-demographic and treatment variables. **Results:** The most commonly reported barriers related to cancer and its treatments (e.g. fatigue). Age and mobility-related comorbidities (e.g. impaired mobility) were also frequently cited. Those who reported age and mobility as barriers, or reported any barrier, were significantly less active even after adjustment for multiple confounders. Most frequently reported benefits were physiological (e.g. improving health and fitness). Cancer related benefits (such as prevention of recurrence) were rarely reported. Those perceiving physiological benefits, or perceiving any benefits were more active in unadjusted models, but associations were not significant in adjusted models. **Conclusions:** We have identified important barriers and facilitators in CRC survivors that will aid in the design of theory-based PA interventions.

Introduction

Colorectal cancer [CRC] is the third most common cancer worldwide [1, 2]. In the UK, 5- and 10- year survival rates are now over 50% [3]. Therefore, there is a need for effective rehabilitation programmes for those living with and beyond CRC, and developing these is now a UK Government strategic priority [4]. There is emerging evidence that regular physical activity reduces recurrence of CRC, CRC-specific and all-cause mortality [5]. Yet, previous data from our research group found around 75% of CRC survivors are insufficiently active [6], suggesting that a diagnosis alone does not act as a teachable moment and intervention is required.

CRC is a disease of ageing, so survivors face a number of barriers affecting mobility that can be observed in general populations of older adults [7]. However, colon and rectal cancer survivors also commonly suffer a number of specific disease and treatment related side-effects that could impair ability to perform in physical activities, including bowel dysfunction, pain, fatigue, altered body imagine, anxiety and depression [7-10]. Indeed, the salient beliefs about exercise are different for CRC survivors than for the general population [11]. There is evidence to support theoretical frameworks underpinning physical activity behaviour in colorectal cancer survivors [11]. Identifying barriers is a key component of most theories, and has been shown to mediate physical activity maintenance in other cancer survivor groups [12]. Therefore, understanding the barriers faced, and benefits perceived, by this unique population is important for intervention development, and health professionals must be aware of perceived barriers and benefits when considering 'prescribing' physical activity for their patients.

However, to date few studies have explored CRC survivors' perceived barriers to physical activity participation, and even fewer have considered perceived benefits. In a longitudinal study Lynch et al. identified disease-specific barriers as most common in a sample of >400 colorectal survivors [13]. However restriction to predefined items could have resulted in exclusion of other potentially

important factors. In 69 participants enrolled on the CAN-HOPE exercise trial, treatment side effects and lack of time were the most common predictors of non-adherence to the intervention [14]. However, those enrolled onto an exercise trial may have been more motivated, so collecting data from larger population-based samples is important. In a recent survey of 600 Canadian CRC survivors, the most commonly cited barriers to sports participation were time, age and agility, although sports participation was low in general [23% of those surveyed participated in sports] [15]. However, in the UK there are a lack of studies examining beliefs about physical activity in CRC patients. Additionally, few studies have examined whether perceived barriers and benefits relate to behaviour.

Therefore the aims of this study were to identify the perceived barriers and benefits to physical activity in colorectal cancer patients and examine whether these related to physical activity behaviour.

Participants and Methods

Data were drawn from a large lifestyle survey of patients with colorectal cancer, recruited from hospitals in London, UK. Participants were considered potentially eligible for inclusion if they had been diagnosed with non-metastasised [M0] disease (given poor prognosis of those with metastasised disease) and were between 6 months and 5 years of diagnosis (to minimise the number still undergoing primary treatment). Consultant oncologists identified potentially eligible patients [n=2203]. These were cross-checked against hospital lists and with GP practices to ensure patients were not deceased, terminally ill, suffering severe cognitive decline, or would be otherwise distressed to receive a questionnaire [n=1006; see **Figure 1**]. The patients received a postal pack containing a letter from the consultant, participant information sheet and the lifestyle

questionnaire. Ethical approval for the study was provided by the UCLH NHS Trust Clinical Research Ethics Committee.

Barriers, benefits and physical activity

Barriers and benefits to increasing physical activity were assessed using two open-response items; "what things would stop you from doing more physical activity?" and "what do you think you would gain from doing more physical activity". These items were developed specifically for this study. Physical activity was assessed using the Godin Leisure Time Exercise Questionnaire (GLEQ) [16]. This measure has demonstrated favourable reliability and validity against objective activity monitoring and measures of fitness [16]. Participants were asked "during a typical 7-day period (a week) how many times on average do you do the following kinds of exercise for more than 15 minutes during your free time?". Participants were asked to report this for strenuous exercise (e.g. running), moderate exercise (e.g. cycling), and mild exercise (e.g. easy walking). In this study physical activity level was dichotomised to those taking part in five or more bouts of moderate/strenuous activity per week *vs*. fewer.

Covariates

Participants were also asked to record their age, sex, marital status and ethnicity. As recommended for studies where a large proportion of participants are likely to be retired, socio-economic status (SES) was indexed using a combination of material circumstances and education (car ownership vs. not, home ownership vs. not, university-level education vs. not) [17]. These items were then summed to generate a score between 0 and 3 (low to high deprivation). Date of diagnosis was obtained from medical records where available and was also self-reported. Participants were also asked to report whether they had any comorbidities (from a pre-defined list), and whether they were still undergoing treatment. They were also asked to record whether their cancer had recurred since initial diagnosis.

Analyses

Content analysis:

Content analysis was used to analyse the survey responses [18]. Given the paucity of research in this area an inductive approach (where themes are drawn from the data) was used. Coding was exclusive (each coding unit could only be coded into one category), ensuring that clearly defined themes were identified and overlap between themes minimised.

Reponses to the open question were entered into SPSS software (v18). Numerical codes were then assigned to segments of text. In some cases respondents provided more than one barrier, and therefore each individual could be assigned several codes. For example, one respondent wrote *'feeling tired/unwell, cold weather, laziness';* in this case four codes were assigned. Codes were then grouped into themes. A second researcher subsequently assigned themes to each coding unit in order to assess inter-rater reliability (Cohen's kappa). Themes were grouped into categories for summary purposes and to provide power for subsequent analyses with physical activity.

Chi square and logistic regression models were carried out to analyse the associations between perceived barriers / benefits and physical activity. The demographics/medical covariates included were age, sex, SES, comorbidities, time since diagnosis, currently receiving treatment, and recurrence. The analyses were run separately for each barrier/benefit category (where the category comprised at least 10% of coding units) and to compare those who reported any barriers/benefit vs. those who reported none. Relationships with the barrier categories of poor condition or fear, and the benefit categories of protection from disease, hobbies/interests, appearance, and getting back to old self were not examined as numbers reporting these barriers were too small. Simple Chi square tests were also run to explore relationships between perceived barriers and an objective measure of that barrier where numbers allowed. This included examining the association between the perceived barrier of age and actual age, the barrier of comorbidities and self-reported

comorbidities, and the perceived barrier of mobility comorbidities and self-reported arthritis. Numbers in other categories were too small for statistical analyses.

Results

Flow of participants is shown in **Figure 1**. 495 (49%) of patients returned the postal questionnaire, of which four were excluded for being incomplete and a further 12 because the patients recorded a cancer other than CRC, leaving a final sample of 479. Since the questionnaire included the consent form, no data were available on non-responders. Participant characteristics are shown in **Table 1**. The mean age of participants was 68 years (range 31-97), 59% were male, >90% were white and the majority (57%) were in the least deprived group. 20% had experienced recurrence and 16% were still receiving treatment. 397 (83%) patients reported at least one barrier. 291 (61%) of patients reported perceiving some benefit to physical activity. Inter-rater reliability was 0.77, $p < 0.001$ for barriers and 0.72, $p < 0.001$ for benefits.

Perceived barriers

The defined themes and categories and how frequently each category occurred are presented in **Table 2**. Fatigue was the most common barrier, reported by 13% of patients. Age and general aches and pains were relatively common (comprising >10% of coding units), along with difficulty breathing / chronic lung comorbidities (10%). Lack of time was the most common general barrier, cited by 8% patients. Associations between perceived barrier categories and physical activity are presented in **Table 3**. Those who reported any barrier were significantly less likely to be active compared to those who reporting no barriers. Those who perceived barriers of ageing and mobility comorbidities were less likely to be active [$p = .012$ and $.031$ respectively]. There were no significant associations for any other individual barriers.

Perceived barrier category were significantly associated with objective assessments in the expected direction. The 'ageing' category was significantly more likely to be perceived as a barrier by older patients (those >65 years were more likely to report ageing barriers than those ≤65 years; $\chi 2$ [1] = 14.71 p <.001), those who had a ≥ 1 comorbidity were significantly more likely to report 'comorbidity' barriers than those who had no comorbidities ($\chi 2$ [1] = 20.80 p <.001), and those with arthritis were significantly more likely to report 'mobility-related comorbidities' than those without ($\chi 2$ [1] = 87.56 p <.001).

Perceived benefits

Perceived benefits are presented in **Table 4.** The most common perceived benefits were 'improving fitness' (cited by 29 % of patients) and improving health was also reported in 18% of cases. Maintaining/ losing weight were also frequently reported (27%), and a number of psychological benefits were reported (but no specific psychological benefit was reported frequently). Only 2% of the sample made any reference to the potential for physical activity to contribute to disease prevention, and more specifically, cancer prevention. Associations between perceived benefits and physical activity are presented in **Table 5**. Although perceiving physiological benefits and perceiving any benefits were significantly related to higher activity in simple analyses (p= 0.002 and 0.019), these were no longer significant in adjusted models. There were no significant associations between any other perceived benefits and reported activity levels.

Discussion

The current study identified a number of potential perceived barriers to and benefits of physical activity in CRC patients. The most commonly reported perceived barriers related to cancer and its treatment (most notably fatigue), ageing and comorbidities. However, only ageing and mobility-specific comorbidities were associated with physical activity behaviour. Patients identified benefits, including changes in health and fitness and weight control, but only a very small proportion

identified that activity might have cancer specific benefits and a large number reported no perceived benefits at all. No reported benefits were associated with activity behaviour. However, activity levels were generally low.

Age was identified as a key perceived barrier to activity in our study. Age was negatively associated with physical activity in this sample, and age-related declines in physical activity are well established [19]. Associations with perceived mobility are perhaps unsurprising; people suffering pain or limitation during movement are probably less likely to be active, but with appropriate support and supervision would likely benefit substantially. Indeed, a lifestyle programme for older cancer survivors revealed that physical activity can slow decline in physical function [20] and there is good evidence in the general population that physical activity can improve health outcomes in older adults [21]. In 600 Canadian colorectal survivors, age and mobility were also among the most frequently cited barriers to sports participation [15]. Therefore age-targeted interventions would be useful.

In our study, disease-specific barriers (particularly fatigue/tiredness) were the most frequently reported. This aligns with the findings of a longitudinal Australian survey of >400 CRC survivors, who cited disease-specific factors as main barriers both at 5 and 12 months post-treatment [13]. In both ours and the Australian sample, fatigue was the most common barrier. In the survey of 600 Canadian CRC survivors, fatigue was also reported as a barrier by 14% of participants (comparable to the 13% observed in the current study). In the Canadian study fatigue also correlated very highly with perceived behavioural control, a key target for Theory of Planned Behaviour interventions [22]. Fatigue was also been cited as a key barrier in breast cancer survivors [12]. The fairly consistent findings for fatigue are important in this context, since there is evidence that physical activity interventions can significantly alleviate cancer-related fatigue (although most trial evidence comes from breast cancer survivors and more trials in CRC are required) [23]. Patients are potentially in a

vicious cycle of becoming less active and extremely fatigued during and after treatment, which then presents as a main barrier to increasing activity levels. Only 7% of patients in our study suggested that physical activity may be beneficial in reducing 'tiredness' or increasing energy levels, so more effort is required in educating patients of the potential benefits of physical activity for reduction in fatigue and supporting them to become more active. Clinical consultations provide an opportune time for benefits to be highlighted.

In our study, there was virtually no awareness that physical activity may be beneficial for any cancer-specific outcome, including recurrence (only 3% reported these as benefits). In contrast, in a recent Canadian study, 41% of those surveyed believed that physical activity may reduce the risk of their cancer returning [22]. In the latter study, participants were given a pre-specified list of potential variables (including reducing risk of recurrence), whereas in our sample open-ended questions were asked. Additionally, the evidence supporting PA for prevention of recurrence has only emerged relatively recently, and there is still need for evidence from randomised controlled trials such as the 'CHALLENGE' trial [24], before provision of this information is likely to be routinely adopted into clinical practice. However, clearly further educational efforts are required to ensure that CRC patients understand that PA may be beneficial in improving post-diagnosis outcomes. In the Canadian study, a similarly large proportion of respondents identified improving health and fitness as the most salient benefit [70% vs 84%] [22].

In the current study, perceiving any barrier was significantly associated with lower reported activity levels, and those who reported age as a perceived barrier had significantly lower activity levels (although other individual barriers were not associated). Few other studies have examined whether barriers and benefits are associated with behaviour. In the aforementioned Australian study, at 5 months post-diagnosis those reporting physical, and social environment, and disease-specific barriers were less likely to be physically active. However at 12 months only disease-specific barriers

were associated [13]. In the Canadian sample, all reported beliefs were significantly correlated with activity levels (although models adjusting for confounders were not presented) [14]. In our study, after adjustment for confounders, perceived benefits did not relate to activity level. It is feasible that the main perceived benefits in our study (e.g. general 'improvements in fitness') were not so intrinsically valuable to the participants at the time (for example if treatment side effects and cancer recurrence were more immediate concerns). This remains to be tested, but future studies could also ask participants to rate the importance of relevant barriers and benefits. It is also feasible that smaller numbers reporting benefits limited the power to detect significant effects.

Overall, there were a number of barriers to physical activity in CRC survivors that could have important implications for clinical practice. It is important that health professional are aware of the barriers their patients face when discussing physical activity with their patients. Additionally, it is feasible that perceived barriers are influencing whether health professionals recommend physical activity to their CRC patients. For example, a recent study from our group found that in a sample of more than 15,000 CRC patients in the UK, only 31% could recall being given any advice or information on physical activity or exercise [25]. Older patients were less likely to recall being given advice (as were those who reported a comorbidity, although differences were very small) [25]. We also demonstrated that very brief physical activity advice during the care pathway may result in significantly higher levels of physical activity in CRC patients [25]. It is feasible that patients worry about whether is safe to be active during and post-treatment, and reassurance from clinicians that is safe to be physically active may be enough to increase activity levels in this generally very sedentary population of patients.

This study had a number of limitations. Overall, only half [49%] responded to the survey, although this is very similarly to other large scale surveys in cancer survivors, such as the UK national CRC Patient Reported Outcome Measures Survey [25]. The majority of respondents were white and from

higher social groups, so findings may not be fully generalisable and more targeted efforts are required to recruit those from lower SES groups. Physical activity was self-reported and future studies should consider objective measures. The physical activity questionnaire used in this study did not provide a measure of the exact amount of time spent in activities and therefore the proportion of survivors meetings the physical activity guidelines could not accurately be determined. In this study, patients who were still undergoing treatment and those who reported that their cancer had returned were included along with those who had finished treatment, adjusting for disease status. However, it is likely that these patients face specific barriers. Numbers were too small in the current study to analyse these separately, therefore future studies with larger samples should identify specific barriers in these groups. However, to our knowledge this is the first study to collect detailed data on both barriers and benefits to physical activity in a relatively large number of CRC survivors from the UK and to examine associations with behaviour. General consistency of findings with Australian and Canadian samples is reassuring and helps in the global effort to design effective interventions for the promotion of physical activity in CRC survivors.

Conclusions

We have identified important barriers and facilitations in CRC survivors that will aid in the design of theory-based PA interventions and shown that barriers relate to activity behaviour. Overall better educational efforts may be required to help CRC understand the now well established benefits of PA.

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Compliance with ethical standards

Ethical approval for the study was provided by the UCLH NHS Trust Clinical Research Ethics Committee and all participants provided informed consent.

Conflict of interest

The authors declare they have no conflict of interest.

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Figure 1: Flow of colorectal cancer patients through the study

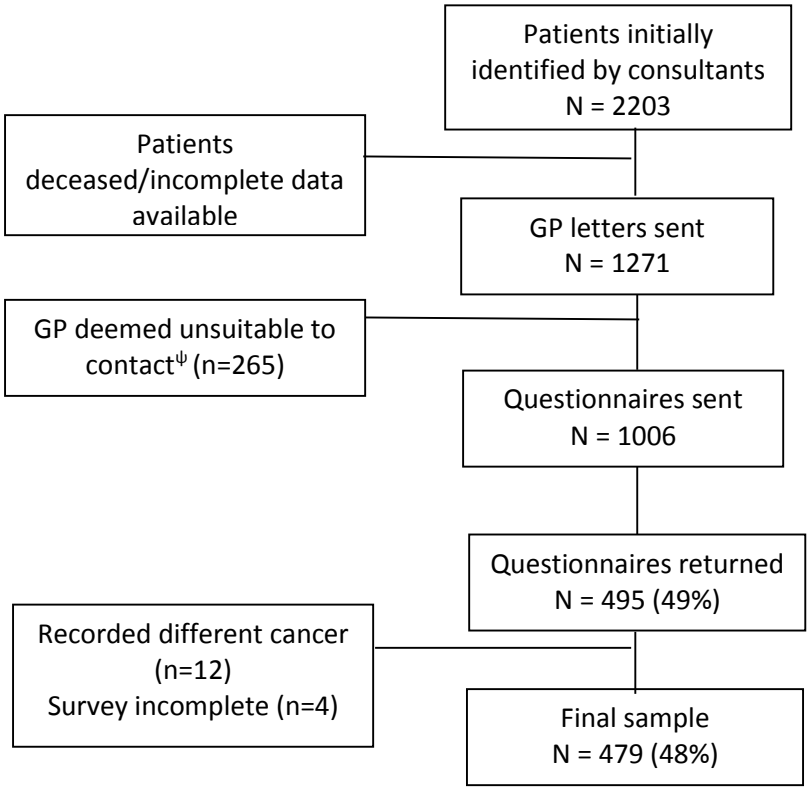

Table 1. Participant characteristics

Characteristics	Men (n=284)	Women (n=194)
Age in years (SD)	66.75 (10.86)	69.37 (11.24)
Missing n=6		
Deprivation: n (%)		
0	153 (57)	74 (41)
1	66 (25)	69 (39)
2	40 (15)	27 (15)
3	8 (3)	9 (50
Missing n=33		
Ethnicity: n (%)		
White	257 (92)	174 (90)
Other	23 (8)	19 (10)
Missing n=6		
Physical activity levels		
≥5 sessions per week	56 (20)	28 (15)
<5 sessions per week	214 (80)	157 (85)
Comorbidities: n (%)		
0	133 (48)	66 (36)
1	85 (31)	70 (39)
More than 1	60 (22)	46 (25)
Missing n=19		
Years since diagnosis (SD)	2.06 (1.45)	2.15 (1.52)
Missing n=0		
Recurrence: n (%)	66 (25)	30 (16)
Missing n=20		
Receiving treatment: n (%)	50 (18)	23 (13)
Missing n=26		

Participants were patients recruited diagnosed with colorectal Cancer and treated in the English National Health Service

Table 2. Perceived barriers to physical activity in colorectal cancer patients

Barriers	N 379	% coding units
Disease / treatment		
Tiredness/fatigue	50	13.2
Colostomy/ileostomy bag	17	4.5
Feeling unwell	15	4.0
Surgery	14	3.7
Hernia	14	3.7
Bowel problems	9	2.4
Cancer treatment	7	1.8
Neuropathy	6	1.6
Nausea	2	0.5
Effects of radiation	2	0.5
Comorbidities		
COPD/breathlessness	36	9.5
Other health problems (e.g. diabetes)	25	6.6
CVD/'heart condition'	11	2.9
Mobility-specific comorbidities		
Arthritis	20	5.3
Lack of mobility	15	4.0
Joint replacement (hip/knee)	6	1.6
Poor balance	2	0.5
Ageing		
General aches and pains	49	12.9
Age	41	10.8
Other commitments		
Work commitments	27	7.1
Family commitments	14	3.7
Social commitments	7	1.8
Fear		
Fear of infection	1	0.3
Fear of falling	1	0.3
Others		
Lack of time	31	8.2
Bad weather	24	6.3
No motivation	22	5.8
Cost	2	0.5
Lack of support	5	1.3
Being overweight	2	0.5
Poor fitness	3	0.8
Inconvenience	1	0.3

COPD= Chronic obstructive pulmonary disease; CVD=cardiovascular disease

Table 3: Association between perceived barriers and physical activity

Barrier	Active (% n)	Chi square	OR (95% CI)
Disease / treatment			
No	49% (162)	χ^2 (1) = .842	1.00 [c]
Yes	44% (46)		.727 (.427 – 1.24)
Comorbidities			
No	50% (187)	χ^2 (1) = 4.31**	1.00 [b]
Yes	36% (21)		.826 (.424 – 1.61)
Mobility-specific comorbidities			
No	51% (200)	χ^2 (1) = 12.25**	**1.00 [b]**
Yes	21% (38)		**.367 (.147 – .914)***
Ageing			
No	52% (182)	χ^2 (1) = 8.99**	**1.00 [a]**
Yes	33% (26)		**.481 (.271 - .853)***
Disease / treatment			
No	49% (162)	χ^2 (1) = .842	1.00 [c]
Yes	44% (46)		.727 (.427 – 1.24)
Other commitments			
No	47% (188)	χ^2 (1) = 1.69	1.00 [c]
Yes	56% (20)		.732 (.312 – 1.72)
Any barrier			
No	62% (54)	χ^2 (1) = 8.45**	**1.00 [c]**
Yes	45% (154)		**.390 (.218 – .698)****

[a] Adjusted sex, socioeconomic status (SES), comorbidities, time since diagnosis, recurrence, current treatment

[b] Adjusted age sex, SES, time since diagnosis, recurrence, current treatment

[c] Adjusted age, sex, SES, comorbidities, time since diagnosis, recurrence, current treatment

'Active' = patients who reported $\geq$5 sessions of activity per week on the Godin Leisure Time Questionnaire

**p<0.005 *<0.0

Table 4. Perceived benefits of physical activity in colorectal cancer survivors

Benefits	N	% coding units
Physical		
Improve fitness	84	28.9
Improve health	53	18.2
Increase strength	26	8.9
More energy / less tiredness	21	7.2
Improves cardiovascular system	13	4.5
Improve mobility	8	2.7
Improves breathing	8	2.7
Ease of activities of daily living	5	1.7
Improves sleep	3	1.0
Improves bowel function	2	0.7
Weight		
Lose weight	68	23.4
Maintain a healthy weight	10	3.4
Social		
Enjoyable	8	2.7
Get out of the house	5	1.7
Socialising	2	0.7
Increase independence	2	0.7
Provides an interest	1	0.3
Psychological		
More alert	6	2.1
Increases confidence	6	2.1
Decrease stress	5	1.7
Relaxation	3	1.0
Peace of mind	2	0.7
Self-satisfaction	2	0.7
Able to cope with more	1	0.3
Reduce risk of depression	1	0.3
Inner strength	1	0.3
New outlook on life	1	0.3
Feel positive	1	0.3
Self-respect	1	0.3
Protection from disease		
Resistance to disease	3	1.0
Increase lifespan	2	0.7
Reduce chance of cancer recurrence	2	0.7
Ward off cancer	1	0.3
Others		
Better figure / appearance	7	2.4
Get back to old self	2	0.7

Table 5: Association between physical activity and perceived benefits

	Active (% n)	Chi square	OR (95% CI) [a]
Physical			
Yes	52% (109)	$\chi^2(1) = 9.52$**	1.00
No	48% (99)		1.21 (.756-1.92)
Weight			
Yes	48% (175)	$\chi^2(1) = .005$	1.00
No	49% (33)		.824 (.449 – 1.51)
Psychological			
Yes	48% (196)	$\chi^2(1) = .000$	1.00
No	48% (12)		.580 (.219 – 1.54)
Any benefit			
Yes	41% (70)	$\chi^2(1) = 5.46$	1.00
No	53% (138)		.921 (.567 – 1.50)

[a] Adjusted age, sex, socioeconomic status, comorbidities, time since diagnosis, recurrence, current treatment'Active' = patients who reported $\geq$5 sessions of activity per week on the Godin Leisure Time Questionnaire **p<0.005