

Patients' views of physical activity whilst living with and beyond head and neck cancer

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Abstract

Exercise is an important component of recovery following cancer. Head and neck cancer (HNC) patients typically report low levels of engagement in exercise initiatives. The aim of this study was to give insight as to HNC patients' reflections on how and why they would be interested in participating in an exercise programme. A stratified sample of 51 patients based on age, gender and initial interest in an exercise programme was selected from 430 postal survey respondents. Twenty-five took part in a semi-structured telephone interview.

There was responder bias with females, younger patients, those already participating in or interested in an exercise programme being over represented. The responders in this study highlighted issues related to physical activity levels, perceived ability to meet physical activity guidelines for cancer survivors, perceived exercise benefits, perceived exercise barriers, and advice to others diagnosed with cancer. The findings support the premise of personalised interventions tailored towards the specific needs of the patient, supported by patient peers to emphasise the benefits and help motivate patients to take part. In order to promote engagement in exercise there needs to be collaborative, culturally sensitive and individualised approaches, in order to address the specific barriers experienced by HNC patients.

Introduction

There are considerable potential benefits for patients who exercise as a component of their recovery following their cancer diagnosis¹. Although there is research specific to head and neck cancer (HNC)², and improvements in outcomes such as functional capacity and quality of life³, many patients do not avail themselves of this type of activity or intervention. Activity and recreation can be a problem for a significant minority of patients following HNC⁴. In this previous study the main influencing factors were site (oropharynx), advanced stage, radiotherapy and chemotherapy, composite flap, gastrostomy tube, and coexisting conditions. There are many possible barriers to exercise and these typically are physical, emotional, social, fatigue, perception of lack of perceived benefit, previous smoking and alcohol lifestyle, limited exercise participation, comorbidity, older age group, lower educational attainment and socio-economic strata⁵. With so many factors to be considered, HNC patients could be thought of as a distinct group than other cancer or chronic disease conditions within the context of designing and implementing exercise programmes⁶.

It is imperative to have HNC patients views on exercise to allow a better understanding of how an exercise programme might be individualised and what factors might help motivate patients to take part. The aim of this study was to give more detail from the semi-structured telephone interviews that took place subsequent to the postal survey⁵. The intention is to give additional insight as to how and why HNC patients would be interested in participating in an exercise programme.

Patient and Methods

A 2016 survey of a patient cohort treated for primary squamous cell HNC between 2010 and 2014 has been published⁵. A stratified random sample was selected from survey respondents willing to participate in a follow-up thirty-minute telephone survey about exercise as part of a recovery programme for HNC. Selection was based on age (<50, 51-64, ≥65), gender and interest in an exercise programme for HNC patients (Yes, Maybe, No). Patients selected from each of the 18 subgroups were contacted late in 2016 with semi-structured interviews (Table 1) carried out over a four-month timeframe. All resulting interviews were recorded and transcribed verbatim and responses were summarised using content analysis by one of the authors (AWM) regarding physical activity levels, perceived ability to meet physical activity guidelines for cancer survivors, perceived exercise benefits and barriers and any advice about physical activity for others diagnosed with cancer.

Patient characteristics identified for the initial survey were used to compare those selected for the semi-structured interview with those not selected, and for those selected to compare those having interview data with those without data. These characteristics included Index of Multiple Deprivation (IMD 2015) scores, derived from patient postcodes using publicly available data to provide a relative measure of deprivation at small area levels across England. Also included was the Godin Leisure Time Exercise Questionnaire⁷ that measures Intensity of leisure time exercise per week and the Exercise Preferences Questionnaire⁸ measuring how able patients felt about participating in an exercise programme (yes, maybe, no). Also, the University of Washington QOL questionnaire (UW-QOLv4)⁹ contains 12 single question domains with between 3 and 5 response options scaled evenly from 0 (worst) to 100 (best). UW-QOL domains are presented within two subscale scores, physical function and social-emotional function¹⁰ each an average of 6 domain scores. The UW-QOLv4 also contains a question about overall QOL in which patients are asked to consider not only physical and mental health, but also other factors, such as family, friends, spirituality or personal leisure activities important to their enjoyment of life.

The study was approved by the North West – Liverpool Central Research Ethics Committee reference 15/NW/0902.

Results

The initial survey sample comprised 1021 eligible patients, with 430 (42%) responders, and half (215) of these responders were willing to be contacted for a telephone interview. A stratified sample of 51 patients was selected based on age, gender and initial interest in an exercise programme and 25 of these were interviewed; 3 of the audio recordings were not transcribed because of speech impediments and subsequent poor recording quality. Of the other 26 patients who initially expressed an interest and gave a contact phone number they failed to answer the call on two occasions and were not pursued further. Table 2 indicates that 12% of the initial survey responders were selected for interview with noticeably higher selection rates for females and younger patients reflecting the stratification process for selecting the interview sample. Table 2 also indicates an overall interview transcription rate of 43% (22/51) in those selected for interview, with higher rates observed for middle-aged patients and for patients treated with surgery. Rates were also higher for those more interested in participating in an exercise programme, for those more able to participate, and

for those already involved in moderate or strenuous exercise at the time of the initial survey. Rates were notably lower in patients with less than good overall quality of life and with the worst physical and social-emotional functioning. A tabulated summary of the cohort is given in Table 3. Patients' responses were grouped into the following five themes; physical activity levels, perceived ability to meet physical activity guidelines for cancer survivors, perceived exercise benefits, perceived exercise barriers, and advice to others diagnosed with cancer.

Physical activity levels

Four (18%) of the 22 participants were currently completely sedentary. Fourteen (78%) of the 18 physically active cited walking as 'exercise' they currently engaged in, and for 7 of these walking was the only exercise performed. Only 7 (32%) of the 22 engaged in any other type of aerobic activities such as swimming, volleyball, squash, fitness classes, line dancing, and trampolining. Only 3 (14%) currently did any type of resistance training and none performed flexibility exercises. Four (18%) specifically stated that their current physical activity was the same or similar to what they did before their cancer diagnosis, whereas none were doing more. Four (18%) stated they were physically incapable of doing more physical activity than they were currently doing, including two who were currently sedentary. Two perceived no physical restrictions to how much exercise they could perform.

Perceived ability to meet physical activity guidelines for cancer survivors

From their responses, 18 (82%) of the 22 felt physically able to fully meet the American College of Sports Medicine physical activity guidelines for cancer survivors. Only one felt unable to meet any of the guidelines for either cardiorespiratory, resistance, or flexibility exercise due to arthritis. For one participant, only flexibility exercise was within perceived capabilities. Another felt able to do a little resistance exercise and not cardiorespiratory exercise while another was unable to do cardiorespiratory exercise due to a bad knee, dry throat and feeling of choking and pain in the neck resulting from surgery.

Perceived exercise benefits

The most frequently perceived benefit was psychological, with eleven stating either that exercise makes you feel better, less depressed, improves mental well-being, or improves attitude. Two specifically mentioned endorphins when referring to the perceived psychological benefits of exercise. Eight stated exercise has health benefits, but generally were not specific as to what these were, although two specifically mentioned weight loss and

one mentioned an observed reduction in blood pressure. Four cited keeping fit as a perceived benefit and three participants cited the social aspect of exercise as being beneficial. Three stated that exercise was important to prevent cancer recurrence. Three stated that exercise helps regain yourself, reconnect with your body, and feel normal again. One participant stated that exercise keeps you occupied, and another stated it keeps you going.

Perceived exercise barriers

Four of the 22 participants stated they did not perceive any barriers that would prevent them from exercising in the future, with one of these perceiving being fitter now than ever before. Four stated head, neck, shoulder, arm pain or dysfunction as the most important reason for not being able to exercise. For three, fatigue was one of the most important perceived barriers. Three cited dry mouth or throat as an important barrier, with one of these experiencing a choking feeling after a few minutes of exercise and the need to always carry water. Another stated that having a dry mouth during exercise was uncomfortable, making it difficult to speak, and that the dry weather was particularly problematic in exacerbating dry mouth symptoms. Three participants stated that generally feeling unwell was a potential barrier, while only two perceived lack of time as a barrier. Other barriers each cited by one person were arthritis, dyspnoea, a back problem, swelling in a foot that was previously fractured, depression, laziness, and old age.

Advice to others diagnosed with cancer

The most common advice, from eleven participants, was generally to just do some exercise, such as “get on with it” and “go for it”. Six recommended that people should individualise the exercise to their own capabilities and to do what they feel is good for them. Six specifically recommended people should do what they can, listen to their body, and cautioned about overdoing it. Three recommendations were either do as much exercise as they could or referred to a dose-response relationship between the amount of exercise and accrued benefits. Two participants advised that exercise makes you feel good about yourself, or makes you feel better when accomplished. One participant advised that if it feels better it’s got to be good for you. Another recommended exercising in social groups, whereas another advised to do anything that makes you feel better or normal. Finally, one participant advised cancer survivors to have someone accompany them during exercise if not keen to do it on their own.

Discussion

The benefits of moderate-to-vigorous intensity exercise for cancer survivors have been established¹¹. Unfortunately, uptake in exercise following HNC is generally very disappointing. There is a distinct paucity of published feedback from HNC patients themselves that can be used to help inform the initiatives intended to improve participation. Peer reflections give a distinctive insight that can potentially help focus the topic from the patient's perspective. This study, although contributing to the debate, is limited by the small sample. The responder bias in those approached for interview (higher participation in middle-aged patients, those having had surgery, those already participating in or interested in an exercise programme, those generally with better quality of life and function) serves to highlight that given other priorities and lifestyle behaviours, it is hard to engage in a meaningful way, many HNC patients in respect to exercise, even those who in the initial survey said they would be willing to participate in such an interview study. In line with other studies, patients who are hardest to reach in terms of exercise intervention, are underrepresented. Another limitation in this current study is that formal qualitative methodology was not used and evidence was gathered from a structured telephone survey. It was hoped that by using this approach a more representative and diverse sample could have been acquired.

The HNC cohort in the present study generally engaged in low levels of physical activity, with half of the participants being either completely sedentary or only engaging in walking. These low levels of physical activity in HNC survivors have previously been reported in North America¹² where only 14% of participants were meeting the current physical activity guidelines for cardiorespiratory and resistance exercise for cancer survivors despite 82% of participants stating they felt physically able to do so^{13,14}. Few participants, 14%, engaged in resistance exercise. Furthermore, the current NCCN guidelines state cancer survivors should stretch major muscle groups at least 2 days per week¹⁴, however, no participants in the present study stated they engaged in any flexibility exercise. Not engaging in resistance and flexibility exercise is an important issue when considering the established additional benefits of engaging in these types of exercise beyond those associated with cardiorespiratory exercise^{15,16}. A notable application of resistance and flexibility exercise particularly pertinent to HNC survivors is correcting the long-term neck and shoulder dysfunction sometimes observed in this group¹⁷. Our previous study⁵ found that 49% of participants interested in participating in an exercise programme would like to do flexibility exercises, 26% weight

machines, 21% free weights, and 18% resistance bands. Why HNC survivors do not typically perform these types of exercise is currently not known and is an area for future research. It might be due to a lack of perceived benefit, confidence and competence. There needs to be patient education on the expected benefits and how to perform exercises effectively and safely.

Around one-third of participants stated there were health benefits from engaging in exercise but did not specify what those health benefits were. The most frequently cited perceived benefits were psychology-related, such as reduced depression and the release of endorphins. Other specific established benefits from engaging in exercise such as improving health-related quality of life, reducing fatigue symptoms, preventing or managing lymphoedema, improving physical function, improving sleep quality, reducing treatment-related toxicities, and preventing or managing comorbidities^{13,18,19} were not cited by any of the participants. Scientific evidence supports the role of exercise in improving survival in cancer patients²⁰ and it is particularly notable that no participants cited this as a benefit. This indicates much more needs to be done on educating HNC patients on the expected benefits of the different types of exercise to help encourage uptake and adherence. A more fundamental issue is the need for more education and training for healthcare professionals so they have a better awareness of the benefits and safety of exercise for cancer survivors so this information can be conveyed to their patients¹¹. Exercise can be part of prescription both in primary and secondary care, however consideration needs to be given to the specific issues experienced by HNC patients. Eighty-two percent of participants perceived at least one barrier to them engaging in exercise, with the most common barriers being specific to HNC or its treatment. The observed high prevalence of exercise barriers specific to HNC and its treatment is consistent with previous research²¹ and highlights the importance of engaging professionals with expertise in HNC when designing and delivering exercise programmes for these patients. The most common advice on exercise that participants would give to others diagnosed with HNC was to simply do some. However, 27% of participants specifically cautioned about the need for people to exercise within their own capabilities, listen to their body, not overdo it, and do what feels better for you or makes you feel normal. This is consistent with contemporary approaches to exercise oncology in that exercise prescription should be individualised to each patient's needs and capabilities, rather than a 'one size fits all' approach, and should be flexible to actively respond to changes in symptoms and other circumstances that may act as barriers to exercise²². In order to promote engagement in

exercise there needs to be collaborative, flexible, culturally sensitive and individualised approaches. These need to address the specific barriers experienced by HNC patients. Further research is required to establish how best to embed personalised exercise programmes into the care of HNC patients. The personalisation should be conducted within the framework of current physical activity guidelines for cancer survivors^{13, 23} and adhere to established exercise training principles²⁴. Authors are encouraged to comprehensively communicate exercise programmes using the exercise reporting guidelines²⁵ to ensure exercise programmes can be properly evaluated and replicated if desired. An increasingly high priority research area is comparison of remote delivery of exercise programmes compared to more traditional approaches involving group supervised exercise sessions. These different approaches should be compared for feasibility, acceptability, efficacy, and cost. In the interim, all healthcare professionals as a team, have a role to be supportive and where possible motivate and facilitate exercise as part of recovery.

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Declaration of Competing interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Table 1: The structured interview schedule

1. Describe what physical activity you do currently.
2. Describe what physical activity you have done in the past [*identify to what extent the patient has been physically active during his/her lifespan*].
3. What is the maximum amount of physically activity you think you could physically manage per week [*prompt on frequency, intensity, duration, type, including resistance & flexibility exercise*]?
4. Describe what physical activity, if any, you intend to do in the future.
5. Can you explain what you perceive as the most important reason or reasons that might prevent you from participating in regular physical activity in the future?
6. As a cancer patient, what do you perceive as the most important benefits, if any, of participating in regular physical activity?
7. If you were advising a close friend or relative who has cancer about participating in physical activity, what would you tell them?
8. Are you willing to visit the hospital to undertake an exercise test that will be used to assess your fitness and to try identify likely causes of any fatigue and intolerance to physical activity that are common in cancer patients? [*describe Cardiopulmonary exercise test - CPET*].

Table 2: Responders, selection for interview and interview transcription data

		Responders selected for interview		With interview transcript data	
	ALL PATIENTS	12%	51/430	43%	22/51
Gender	Male	9%	30/317	43%	13/30
	Female	19%	21/113	43%	9/21
Age	<50	63%	10/16	30%	3/10
	50-64	12%	21/175	63%	13/21
	≥65	8%	20/239	30%	6/20
Site	Oral	9%	11/122	64%	7/11
	Laryngeal	12%	10/86	30%	3/10
	Pharyngeal	13%	22/176	50%	11/22
	Other	17%	8/46	13%	1/8
Clinical T	Early (0-2)	13%	40/308	40%	16/40
	Later (3-4)	9%	10/113	50%	5/10
	Tx	11%	1/9	100%	1/1
Clinical N	Positive	12%	20/164	55%	11/20
	Negative	12%	31/259	35%	11/31
Treatment	Surgery only	15%	27/175	41%	11/27
	Surgery with CT/RT	10%	15/143	60%	9/15
	CT/RT without surgery	8%	9/112	22%	2/9
FreeFlap	Yes	7%	5/72	60%	3/5
	No	15%	37/241	46%	17/37
IMD quintile	1 Worst	13%	15/117	47%	7/15
	2	11%	6/57	33%	2/6
	3	13%	7/54	43%	3/7
	4	18%	13/71	46%	6/13
	5 Best	10%	9/89	33%	3/9
Do you think you would be able to participate in an exercise programme for head and neck cancer patients?	Yes	16%	28/180	54%	15/28
	Maybe	13%	17/132	35%	6/17
	No	6%	6/109	17%	1/6
Would you be interested in participating in an exercise programme for patients with head and neck cancer	Yes	17%	21/124	52%	11/21
	Maybe	13%	18/143	39%	7/18
	No	8%	12/152	33%	4/12
GODIN status times per week mutually exclusive groups	Strenuous ≥1 a week	24%	12/51	58%	7/12
	At most, moderate ≥1 per week	11%	8/76	63%	5/8
	At most, mild ≥1 per week	8%	11/144	36%	4/11
	No exercise for more than 15 minutes per week	12%	18/146	33%	6/18
UWQOL Physical function subscale score	<60	11%	10/92	20%	2/10
	60-79	10%	13/127	69%	9/13
	80-100	13%	28/210	39%	11/28
UWQOL Social-emotional subscale score	<60	12%	9/78	11%	1/9
	80-100	14%	34/235	47%	16/34
Overall QOL (UWQOL)	Less than good	11%	11/101	9%	1/11
	Good	10%	11/107	55%	6/11
	V good / Outstanding	13%	29/220	52%	15/29

Table 3 Summaries of exercise interview transcripts, alongside case-mix from initial survey

	Sex	Age	Site	Stage	TX	EX1	EX2	Comorbidity	Summary of exercise transcript
1	M	70	O	T4N0	No S	YES	YES	Type 2 diabetes Rheumatoid arthritis	I go walk every day as I live alone - might just go walk round the shops, round the market. I get easily tired. Before I was taken ill I used to go to the gym about three or four times a week. I would consider exercise sessions but feel tired. Exercise gives strength to fight cancer off and stop you getting depressed about things.
2	F	58	P	T3N2	S+	YES	YES		I go swimming (40 lengths) and dog walking daily (two hours). I go swimming three times a week. Exercise pretty much the same as before HNC. Could do more but time consuming. I don't do extreme sports/physical/gym. Could manage exercise session. I intended to try a yoga class or a Pilates. Exercise: keeping yourself active, healthy, aids recuperation.
3	M	37	OTH	T1N0	S	YES	YES		I do an office job. Volleyball once a week and squash, 10,000 steps a day (2-mile walk). I feel that I could do exercise session but active already. Benefit of exercise -stay healthy and hopefully it never comes back.
4	F	42	O	T1N0	S	YES	YES	Alopecia	I do pole dancing. My pole is once a week and it's an hour. But I do cleaning jobs and doing my nurse training so I see that as sort of like exercise. Alopecia makes me self-conscious but doesn't prevent me exercising. I used to go to gym probably two or three times a week before cancer. I feel that I could manage exercise session but main barrier is time. Exercise to keep fitness levels up and the social aspect.
4	M	52	P	T2N2	S+	YES	YES		I drive for a living and I don't do an awful lot of exercise. No exercise at all. Not walking. I used to do gym cycling, running, jogging, two or three times a week and I started again after my treatment, but then I came across some issues and I stopped. I think I could do some gentle exercise again for a couple of hours a week. Probably the fast walking, I've got a bad knee, so I'm waiting for a knee replacement. The difficulty I have with the cancer is because of a lack of saliva, within a couple of minutes of starting to exercise, my throat dries up and it feels like I'm going to choke. Also, severe pains in the head neck. I feel that I could try to manage exercise session. Exercise: I think you've got to be active no matter what and even though I've had the treatment. Waistline.
6	M	37	O	T1N0	S	YES	YES	Colonic stoma low body mass index Avascular necrosis in my knee	I've been having a few health problems this year that are unrelated to the cancer treatment. So, at the moment I'm in quite bad shape because I'm not really doing anything. I am off work (computer screen not physical) because of sickness. I have no energy. Before cancer I was riding it probably was for at least half an hour five days a week. Could manage a reduced exercise session. But you feel lousy when you're having cancer treatment -I wouldn't push it at all. Exercise: psychological benefit.
7	F	64	O	T4N1	S+	YES	YES	Hypertension	I do local gym four days a week, seven classes - Zumba, a step class, trampoline, [sling], weightlifting (kettles/ bar weights). 45 minutes plus five times a week. I am doing exercise since cancer as before was an infant teacher. As a teacher with 30 six-year olds, I was shattered. Classes motivate- could not do by self at home. I felt low after the initial diagnosis and operations. Exercises make me feel more positive.
8	F	63	P	T1N0	S	YES	YES		I walk a few miles a day. I do house work. Not much past physical activity. I feels that I could manage exercise session – an hour in the gym twice a week. Exercise keeps you a bit healthier and you lose weight – better than lazing around.
9	M	61	P	TXN1	S+	YES	YES	Hypothyroidism Atrial fibrillation	I play golf six times a month. I am a member of a gym, but at the moment I'm doing some restoration work, I was building and plastering. Before cancer I was swimming. I could not manage exercise session -build up to it. I have an underactive thyroid, which caused me to have a slight stroke and then an irregular heartbeat and prolapse of disc in my back. Could manage exercise session build up to it. Exercise: It just makes you feel normal again. It just makes you feel like you haven't gone that far past being well that you can't do it. It's good for your mental wellbeing.
10	M	63	L	T2N2	S	YES	YES		I work full time doing a desk job. I exercise similar post-cancer. I've got an allotment. I do a lot of digging and that, physical. Big garden at home too. A couple of hours each day every day. Walking a lot. No gym work. I feel that I could

									do exercise session but active already. Cancer has been a positive in terms of weight loss and lower blood pressure. Fitter since cancer.
11	M	62	P	T1N1	S+	YES	M		I go to the gym about five days a week, I do treadmill, cross-trainer, a few weights and swim. I also play golf a couple of times a week if I can, depending on the weather, and I go fishing. Very similar exercise pattern before cancer as after. Used to have a physical job. No problem in managing a reduced exercise session. Exercise: it keeps your body fit, it helps you out with friends, there to support and help you. It also keeps a positive attitude.
12	M	56	P	T1N0	S	YES	M		I work in retail so physical – walking/lifting. I walk, I go out three or four times a week for a few miles. Exercise would be fairly similar as before cancer. I feel that I could manage exercise session. Could start cycling again as has lost weight since cancer. Benefit of exercise - keeping it away and not coming back.
13	M	70	L	T1N0	S	YES	M	Hypertension Atrial fibrillation	I take the dog for a walk every morning (20 minutes), exercise bike (between 10 and 15 kilometres a day). I wasn't that active before cancer - I was very heavy and I in fact I've lost 18 stone. I don't enjoy exercise I do it because I know it's good for me. Could manage exercise session. Exercise: I do it begrudgingly. But when I've done it, I feel fantastic. It makes you feel better when it's accomplished.
14	F	55	O	T1N0	S	YES	NO		I used to do a lot of exercise before cancer and continue to do so -boot camp. Three hours intense exercise per week, muscle strengthening, flexibility. Rest of exercise in a week is activity like walking. I could do exercise session but active already. Exercise to prevent cancer returning, meeting others, having fun.
15	M	69	P	T3N2	S+	YES	NO		Exercise I've done that for years, it's just something I'm used to doing/ like. Used to be in the army. I have a routine: work bench, do a few abdominal exercises, some weights every other day. Fast walking, I've done actually 40 miles from Monday up until yesterday, Friday. My bike I never do less than 20 miles two or three times a week. I've got a rowing machine that I use on average once a week. I play golf. Slight problem with shoulder and dry mouth. Exercise benefits: The mental aspects and keeping yourself fit.
16	F	71	O	T1N2	S+	M	YES	Atrial fibrillation Chronic kidney disease stage 4 Gout	I do no exercise now but in past swimming, cycling (we go out about once a month for half an hour), walking - swimming about three times a week. I can't physically manage it at the moment. I find that very tiring / I get breathless. Does not feel could manage exercise session. Would like to get back to cycling and swimming (I find that the swimming pools are too cold. When I get cold I get a lot of pain in my jaw and my neck and my shoulders). Exercise is very important.
17	M	69	L	T1N0	S	M	M	Arthritis (neck + spine), Chronic lower back pain Sciatic nerve pain	I walk probably four to 10 miles a week - It's two miles to our local supermarket. We'd walk there for lunch and walk back again. Also caravanning, fishing. Retired I worked in a timber yard - works director. Same pre and post cancer. Not an 'exercise' person. Arthritis so exercise limited. Exercise benefit of your health overall.
18	F	54	P	T2N0	S+	M	M		The only thing I do is walk. I walk every day about three or four miles. Never more exercise in past. Because when I'm at work I'm a cashier (part-time), so I walk round the store. I wouldn't do running - I haven't got around to doing that yet. Feels could manage exercise session. My main problem is the dry mouth. Exercise to keep you going basically and keep you fit. I've just lost my husband through cancer.
19	M	59	P	T3N2	No S	M	M		My focus at moment is to get back to New Zealand with his wife, not exercise. I walk a lot, and I do walk a great deal because we tend to just walk everywhere and not do much else. A couple of miles a day. Used to have a physical job making concrete things and stuff – never a lover of the gym. Feels could manage exercise session. Exercise to prevent depression, exercise is good for you
20	F	62	O	T2N0	S	M	M		I am not physical activity. I used to walk a lot and, well, find it difficult now. Since I've had the operation, I've lost a lot of weight and I'm not as strong as I was. Could manage 20 minutes a week. Before cancer used to regular swimming, tennis and a lot of walking. Could not manage exercise session. Exercise: well you've got to keep yourself active haven't you
21	M	57	P	T2N2	S	M	NO		I do no exercise apart from work. I do a bit of walking. I work for the National Grid, it can be a lot of manual handling work and up and down ladders, stuff like that. I played golf (fair weather /weekends) and used to go to the gym (two

									or three times a week). At moment if I do start doing anything strenuous I can't produce enough saliva. That stops me because I'm continually having to stop to drink. I think the only thing I do at the moment is walking. I'll walk two or three miles, into the town centre, or I will walk into work. Exercise- It's just a general health benefit, physically and mentally cancer or non-cancer. Something is better than nothing.
22	F	78	P	T2N2	S+	NO	NO	A heart bypass 1 year before my cancer	I am retired, elderly, recent widow and very active and continues post cancer – social exercise. I do something each day including 4 mile walk and badminton once a week. I continue to exercise with the heart support group at the local hospital. Activity to keep in touch with others.

Age: Age at initial survey

Tumour site: Oral (O), Laryngeal (L), pharyngeal (P), Other (OTH)

TX (Treatment group): S (surgery alone), S+ (surgery with adjuvant CT/RT), no S (CT/RT, no surgery)

EX1: able to participate in an exercise programme for head and neck cancer patients (YES, NO, Maybe)

EX2: interested in participating in an exercise programme for patients with head and neck cancer (YES, NO, Maybe)