

Exploring cancer survivors' views of health behavior change': "Where do you start, where do you stop with everything?"

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For Peer Review

Exploring cancer survivors' views of health behavior change**Exploring cancer survivors' views of health behavior change': "Where do you start, where do you stop with everything?"**

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Abstract

Objective

Physical activity (PA) and a healthy diet can improve the well-being of cancer survivors. However, cancer survivors often do not engage in these behaviours. This

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3
4 study aimed to explore barriers and facilitators to engaging in these behaviours
5
6 following cancer treatment.
7

8 9 Methods

10
11 During the development of a web-based intervention to enhance health-related
12
13 quality of life in cancer survivors, 32 people who had completed treatment for breast,
14
15 colon or prostate cancer were presented with an intervention for PA and healthy
16
17 eating. In-depth think-aloud and semi-structured interviewing techniques were used
18
19 to elicit perceptions of both behaviours. Data were analysed using thematic analysis.
20
21
22

23 Results

24
25 Some individuals reported implementing positive health behaviour changes to
26
27 maintain health and prevent recurrence, or to help them to move forward after
28
29 cancer. However, others reported feeling abandoned, and many did not report an
30
31 intention to engage in lifestyle changes. Individuals discussed contextual and health-
32
33 related barriers that were specifically linked to their situation as post-treatment
34
35 cancer survivors: individuals described uncertainty about how to implement adaptive
36
37 changes and perceived a lack of support from healthcare providers. Others viewed
38
39 behaviour change as unnecessary or undesirable, with some arguing that non-
40
41 modifiable factors contributed more to their cancer diagnosis than lifestyle-related
42
43 factors.
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47 Conclusions

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50 For many participants in this study, the period that follows treatment for cancer did
51
52 not represent a 'teachable moment'. A variety of complex and heterogeneous factors
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4 appeared to impact motivation, and may limit cancer survivors from engaging with
5
6 diet and PA changes.
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8 9 **Background**

10
11 Survival from cancer in many countries is rising [1]. Despite this, many cancer
12
13 survivors may experience poorer health-related quality of life (HRQoL) following
14
15 cancer treatment. An increase in physical activity (PA) and the consumption of a
16
17 healthy diet can enhance the wellbeing of cancer survivors and reduce risk of cancer
18
19 recurrence [2-5]. The period after cancer treatment has been proposed as a
20
21 teachable moment, which may motivate individuals to adopt risk-reducing healthy
22
23 lifestyle changes [2, 6]. However, only a small proportion of cancer survivors
24
25 implement or maintain lifestyle changes after treatment [3]. It remains unclear why
26
27 some are motivated to make healthy lifestyle changes during and after cancer, while
28
29 others are not [7].
30
31
32

33
34 Common barriers to PA and healthy eating in cancer survivors include a lack of
35
36 motivation or self-efficacy, inadequate knowledge, concerns about pre-existing
37
38 comorbidities, environmental factors such as bad weather, and lack of resources
39
40 such as time or money [8-11]. Many of these issues are barriers to behaviour change
41
42 across diverse health conditions [12-15] and could affect any motivational impact of
43
44 the 'teachable moment' prompted by the completion of cancer treatment. In a study
45
46 about cancer survivors' beliefs about diet quality, responses did not differ based on
47
48 cancer type, age, or gender [16]. Similar findings were reported in a study on
49
50 attitudes towards, knowledge of and seeking of information on PA [17]. While cancer
51
52 survivors share some generic reasons for not engaging with lifestyle changes which
53
54 are found across a variety of health conditions, they are also likely to have unique
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4 physical and emotional reasons specific to their survival or experience of cancer
5
6 which influence engagement with these behaviours.
7

8 Understanding cancer-specific barriers to adopting a healthy lifestyle among cancer
9
10 survivors could help improve the development of targeted interventions for this group
11
12 [18]. During the development phase of a web-based intervention to enhance HRQoL
13
14 in cancer survivors, participants were presented with a website that included
15
16 modules on PA ("*Getting Active*") and healthy eating ("*Eat for Health*"). This
17
18 presented an opportunity to explore potential cancer-specific reasons for engaging
19
20 (or not) in diet and PA changes. We conducted qualitative interviews to explore
21
22 facilitators and barriers to engaging with recommendations for lifestyle behaviour
23
24 change following cancer.
25
26

27 28 **Methods**

29 30 ***Design***

31
32 This study was part of a research programme that aimed to develop a digital
33
34 intervention to support cancer survivors in making behaviour changes in order to
35
36 improve HRQoL [19]. We obtained approval from NHS (Ref no. 191936) and
37
38 University of Southampton ethics committees (Ref no. 17658) prior to data collection.
39
40 The study was reported according to the consolidated criteria for reporting qualitative
41
42 research (COREQ) [20].
43
44
45

46 47 ***Recruitment and procedure***

48
49 We included breast, colon and prostate cancer patients because they are common
50
51 types of cancer with large numbers of survivors [21], and were the target group for
52
53 the intervention being developed.
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4 Participants were recruited primarily through GP practices in Southern England.

5
6 Potential participants identified via searches of GP databases were screened based
7
8 on study inclusion criteria. Individuals who wanted to gain information about making
9
10 healthy behaviour changes or coping with difficult feelings returned a reply slip to
11
12 express interest in participating. The study was also advertised through cancer
13
14 charities (Breast Cancer Care, Prostate Cancer UK, and PCaSO Prostate Cancer
15
16 Network).

17
18
19 Interested participants were screened for eligibility and provided informed consent
20
21 prior to the interview (See Appendix1). Interviews were conducted by trained
22
23 postgraduate students and two qualitative researchers (TaC, LW). Individual
24
25 interviews took place between May 2016 and January 2017 either at the University
26
27 of Southampton or at a location that participants preferred (e.g. their private homes).

28
29
30 We used in-depth qualitative think-aloud interviewing techniques [22]. Using the
31
32 Person-Based Approach [22], we elicited participants' perceptions of the
33
34 intervention, as well as their thoughts about implementing behaviour changes after
35
36 cancer. Semi-structured questions were asked before and after the think-aloud
37
38 section of the interviews. Participants were asked about how they perceived the
39
40 intervention (what they found useful, interesting, or helpful, what they were less keen
41
42 on, and what they would change) and how they felt about PA and healthy eating.

43 44 45 **Analysis**

46
47
48 All interviews were audiotaped and transcribed verbatim. Thematic analysis was
49
50 used to analyse the data [26]. Saturation was considered reached; participants in
51
52 later interviews did not indicate any significant new concerns or barriers to
53
54 engagement with PA or diet. We conducted line-by-line open coding and an initial
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3
4 coding manual was developed by TaC. This coding manual was refined with TeC
5
6 (qualitative researcher with experience in area of cancer survivorship) and updated
7
8 regularly to reflect the ongoing analysis of the data. All of the data were coded, but
9
10 our analysis was specifically focused on identifying patterns within participants'
11
12 accounts related to behaviour change in the specific context of cancer survivorship.

13
14
15 Final codes, and themes were agreed between TeC, AMM (a PA specialist), KB, and
16
17 LY (experienced qualitative researchers and Health Psychologists). Themes were
18
19 clusters of codes that were related to similar aspects of the data. Deviant cases not
20
21 consistent with the overall trend of the data were identified to explore the limits of the
22
23 analysis and to ensure all relevant data were included in the analysis process. The
24
25 findings were discussed with the wider research team (including cancer survivors
26
27 and clinicians with cancer expertise), to ensure clarity of the themes and aid
28
29 interpretation of the findings.
30
31

Results

32
33
34
35
36 Thirty-two participants agreed to participate. Demographic and clinical characteristics
37
38 are reported in Table 1. There were no patterns in the themes in relation to gender,
39
40 age, cancer type, or time since treatment.
41
42

43
44 Many individuals cited non-cancer specific reasons for not engaging in behaviour
45
46 change (see Appendix 3). Participants described the influence that their experience
47
48 of cancer had had on their perceptions of behaviour change. Some of the comments
49
50 reflected the 'teachable moment' after cancer as described previously [3]. Others
51
52 suggested that there may be an opportunity for a 'teachable moment' that is not
53
54 always capitalised on. Individuals discussed barriers and facilitators to change that
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were unique to their status as post-treatment cancer survivors. These themes can be seen in Appendix 4 and are discussed in detail below.

Table 1. Demographic and clinical characteristics of study participants

Age in years	
Mean	68.84
SD	10.76
Range	44-90
Sex	
Male	18
Female	14
Type of Cancer	
Prostate	13 (5 on active surveillance)
Breast	11
Colon	8
Years since treatment¹	
Mean	3.81
SD	2.60
Range	0-9
Education level	
No education	2
Secondary school	9
College/sixth form (post-secondary)	10
Undergraduate	4
Postgraduate	7

¹Excluding five participants on active surveillance

Motivation to change behaviour leads to behaviour change

Some cancer survivors were motivated to change their health behaviours after cancer treatment. Participants described how they had adopted a healthier lifestyle in order to maintain health and prevent cancer recurrence.

“You think about what went wrong with you and to try and keep yourself healthy so it doesn’t happen again, really, isn’t it? That’s the thing. Yeah, just try and look after yourself the best you can.” (Prostate, 6 years post-treatment).

The drive to feel better after treatment helped individuals to persevere with behaviour change despite persistent treatment-related side effects. Others did not want to be

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2
3
4 seen as a victim and felt that adopting a healthy lifestyle helped them to feel better,
5
6 empowered, and able to move on after cancer.
7

8 9 **Motivation, but no behaviour change**

10
11 Most participants recognised that lifestyle changes could be beneficial after cancer.
12
13 However, many described reasons for not changing their behaviour. These are
14
15 outlined in the two sub-themes below.
16
17

18 Absence of support from healthcare professionals (HCPs) after cancer ends

19
20 Despite recognising the potential health benefits of behaviour change, many felt
21
22 motivation was hampered by HCPs failing to understand the experience of cancer
23
24 survivors. Many were uncertain about how to adopt lifestyle changes after cancer,
25
26 describing a perceived lack of advice and support following treatment completion.
27
28

29
30 *“Yes they were helpful when you're there, but that's not usually the time that you're*
31
32 *having any problems, that's just having your particular treatment at that time. When*
33
34 *you have to deal with it by yourself, when you're at home and not at the hospital... I*
35
36 *didn't feel that they were assisting in what you needed once you've left”. - Prostate*
37
38 *cancer, 78, 3 years after treatment*
39
40

41
42 The timing of support right after treatment was considered especially important for
43
44 participants.
45

46
47 *“Nobody ever told me...I had to work that out over time...Whereas if somebody had*
48
49 *given me that list [of healthy foods] at the beginning, that would have been an idea.”*
50

51 (Prostate, active surveillance)
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Participants were concerned about making behaviour changes because they felt that they had figured out what worked best for them and worried about what the impact of these changes might be on their body.

"I've got a fear of changing the diet I eat... if I try a new eating plan, it's going to throw my body out." (Colon, Male, 7 years post-treatment)

A number of participants explored various sources of information to find answers and support regarding lifestyle change. Many were confused by contradictory advice, or information that was difficult to understand.

"you shouldn't eat this, you shouldn't eat that', and there's just too much... out there that conflicts. Where do you start, where do you stop with everything?" (Breast, female, less than a year since treatment)

Occasionally, due to a perceived lack of support from HCPs, participants reported feelings of uncertainty about how to approach lifestyle changes *"I think they give you this treatment and then they send you home and you're just left... you don't know what you can do and what you can't do."* (Prostate, active surveillance)

Recognition of treatment side effects and a need to be realistic about behaviour change

Cancer and treatment side-effects were frequently seen as a barrier to implementing behaviour change.

"I know that exercise will help improve my lifestyle. But how do you exercise when your body won't allow you to?" (Prostate, 2 years post-treatment).

Participants suggested that cancer treatment and medications made it more difficult to make changes. Some noted that cancer had led to muscle-loss that they believed

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would not be regained through exercise. Others spoke about weight-gain due to therapies. This was seen as difficult to change due to ongoing hormonal therapies.

"I do think tamoxifen has a lot to answer for. I can't seem to shift the weight as easy as I used to. So I'd rather take it and be overweight than not take it." (Breast, female, 3 years post-treatment).

Many argued that acceptance of and adaptation to physical limitations due to cancer was a key first step when trying to change behaviour.

"We have got physical limitations and the drugs have caused us joint problems and all the rest of it. And it's about accepting that, and not making a big deal out of it ... just that's how it is." (Breast, <1year post-treatment).

"I think the key thing is realising you can't do you as much as you used to do. I used to go swimming with my kids and now after twenty minutes I'm tired. I'll just sit at the side while you two carry on. Whereas I used to be able to have a couple of hours, quite happily." (Breast, <1year post-treatment)

A number of people felt that post-cancer wellbeing campaigns often failed to include realistic role-models. Many had been exposed to health promoting materials that failed to recognise the impact of cancer and its treatment. Examples of perceived 'high achievers' or 'over-achievers' who had accomplished successful health behaviour change were viewed as intimidating. Participants suggested that this resulted in reduced motivation to engage in behaviour change and that they would prefer interventions that acknowledged the difficulties faced by those after cancer treatment.

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4 *"...you read so many stories of people that have overcome all sorts, but then they've*
5 *gone so much bigger and better than I could ever dream of. I couldn't even have*
6 *done before I had treatment, let alone after. And that is actually quite demotivating"*
7
8

9
10 (Breast, female, 2 years post-treatment).
11

Decision not to change health behaviours after cancer

Rejection of the link between cancer and behaviour

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17 Many felt confident that they had led a healthy lifestyle before cancer, and therefore
18 did not need to change behaviour.
19

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21
22 A number decided not to change their health behaviours, stating that they did not
23 wholly accept the link between health behaviour and cancer. Participants often
24 reported that their health behaviours were not implicated in causing cancer or cancer
25 recurrence.
26
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31
32 *"I think you could eat fruit and veg all day long but it's not going to stop you getting*
33 *cancer..."* (Prostate, active surveillance).
34
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36
37 Some were uncertain or unconvinced that changing their behaviour could have a
38 substantial effect on their health:
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40
41
42 *"Eating foods, healthy, it might make you feel good but you still have cancer. You*
43 *might feel better in yourself but no way are you ever going to get back to normal."*
44

45
46 (Prostate, 6 years post-treatment).
47

48
49 Participants sometimes compared themselves to others and concluded that their
50 behaviour had not led to their cancer. Some described individuals who they
51 perceived as having healthy lifestyles who had nevertheless had cancer or who had
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4 died at a young age. Others cited examples of those with unhealthy behaviours who
5
6 had lived for many years.

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9 *“Now, I smoked for forty-seven years, – they say smoking destroys your heart, meat*
10 *destroys your heart, and lack of exercise destroys your heart. I’ve survived seventy-*
11 *eight years on what I’ve been doing. I was older than my mother and father when*
12 *they died, you know? So, my lifestyle hasn’t been that bad.”* - (Colon, Male, 2 years
13
14
15
16
17 post-treatment)

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19
20 A few participants seemed to find acknowledging a link between behaviour and
21
22 cancer too challenging, as it induced feelings of guilt.

23
24
25 *“I would feel very guilty if I thought that our eating habits had caused me to have*
26 *cancer. I just put it down to a kick in the teeth by life, that's just one of the things that*
27 *happens. It's bad enough having it. My attitude is not ‘Why me?’, but ‘Why not me?’*
28
29
30
31 *But now this is saying ‘It's your fault.’* (Breast, female, 3 years post-treatment).

32
33
34 Other factors people take into account when considering/rejecting behaviour change

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36 Individuals felt it was difficult to change their behaviour due to comorbidities they had
37
38 had prior to the onset of cancer. Some were afraid that making lifestyle changes
39
40 could affect self-management of pre-existing comorbidities.

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44
45 *“It hasn’t been just after the cancer, I’ve always had back and joint problems. I use*
46 *the stair lift because my knees are so painful going up and down the stairs, I did try*
47 *to use it less, but I was frightened of falling.”* - (Breast, female, 3 years post-
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49
50
51 treatment).

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4 *"I think you should, when you've got multiple problems like me, check with the*
5 *doctor. Before you overdo it"* – (Breast, female, 2 years post-treatment).
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9

10 Cancer had led many participants to reappraise their life and priorities. Newfound
11 priorities were not always linked to changing health behaviours. Some felt that they
12 would restrict or limit themselves by focusing too much on lifestyle changes.
13
14 Participants also referred to a newfound awareness that life is short and a need to
15 enjoy it to the fullest. Some explicitly contradicted the view of cancer being a
16 teachable moment for behaviour change, stating that the cancer experience had led
17 to reduced motivation to change behaviour.
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25

26 *"All those years I was watching the weight. When they tell you you've got cancer,*
27 *you think oh for God's sake, to Hell with it all, you know? If I want something I have it*
28 *now."* (Breast, 5 years post-treatment).
29
30
31
32

33 Another participant spoke about prioritising family-time, saying
34

35 *"if it suddenly said oh you've got to go and do three hours running a day, no... that's*
36 *three hours away from my family. They had enough time away from me while I was*
37 *ill..."* (Breast, female, less than 1 year post-treatment).
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43 **Conclusions**

44
45 We have highlighted cancer-specific barriers to lifestyle change that are particular to
46 the experience of post-treatment cancer survivors. We have also extended the
47 existing literature that has often focused on barriers to behaviour change which are
48 generic across conditions but are not unique to the experience of cancer survivors
49 [12-15]. Participants varied greatly in the extent to which they chose to make lifestyle
50 changes after treatment, due to their idiosyncratic needs and the experience of
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4 having cancer. This study offered a novel insight into the decision-making and
5
6 prioritisation that people engage in when asked about changing health behaviours.
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8
9 In keeping with existing literature that proposes that coming to the end of successful
10
11 cancer treatment might represent a 'teachable moment'[6], some people reported
12
13 implementing positive lifestyle changes. Beeken et al [16] noted that behaviour
14
15 change was often motivated by a desire to remain generally healthy rather than to
16
17 prevent recurrence. Survivors reported making or attempting some changes after
18
19 cancer, with diagnosis often serving as an impetus for lifestyle change [16]. In
20
21 contrast, we found that for most individuals, there appeared to be many other issues
22
23 likely to negatively impact on behaviour change, and would have to be addressed to
24
25 make it a teachable moment. Most interviewees could see the benefits of behaviour
26
27 change but described generic (Appendix 3) and cancer-specific barriers that had
28
29 prevented change. As with previous research [8, 9], a lack of confidence and support
30
31 were often cited as reasons for not changing behaviour. Participants also reported
32
33 uncertainty about whether any changes they had made were appropriate or sufficient
34
35 for cancer survivors and did not want to make changes without explicit guidance
36
37 from their HCP. Previous studies have also reported that participants received little
38
39 information from health professionals relating to engaging in PA, with participants
40
41 searching for information via media and websites[17]. Confusion about how to
42
43 implement changes is likely to reduce motivation to make lifestyle changes [23]. It
44
45 appears that (for many) there is the potential for a "teachable moment", but this
46
47 opportunity to promote behaviour change is not always promoted by HCPs in a
48
49 timely and context-specific manner.
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51

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53
54 Another common view was that behaviour change was unnecessary or undesirable.

55
56
57 Many were confident that they had led a sufficiently healthy lifestyle before the onset

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of cancer. Scepticism regarding the influence of behavioural factors in causing cancer could be influenced by a belief that their diet was healthy prior to cancer [24]. Participants in the current study frequently mentioned the role of non-modifiable factors such as family history of cancer or chance. Beliefs that health is controlled by luck or chance are negatively associated with engaging in health-promoting lifestyle [25]. Over-estimation of the influence of non-modifiable factors may be part of a coping strategy to avoid a sense of blame [12]. In our sample, cancer survivors reported they would feel indirectly blamed for their cancer and potentially experience guilt if they were to believe that cancer was possibly “their fault” and attributable to their lifestyle. Perceived overly optimistic expectations of cancer survivors portrayed in the media sometimes led to feelings of stress, or feeling that they should be able to do more. In an intervention setting, this could potentially lead to participants becoming defensive or rejecting the advice given [26].

Behaviour change also appeared impeded by cancer-related side-effects and the influence of the cancer experience on the management of pre-existing comorbidities. Similar findings have been reported elsewhere [17, 27]. Cancer survivors with comorbid diseases often prioritize one chronic condition or symptom over another and many struggle to integrate various self-care strategies into their routine [28]. The current study highlighted that health-related concerns can pose genuine barriers to behaviour change even when cancer survivors are motivated to engage in lifestyle changes. Some of these issues are summarised in Appendix 2 which outlines identified barriers, and suggested actions that HCPs could take to potentially enhance engagement with lifestyle change.

Strengths and Limitations

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4 Participants were presented with a digital intervention for PA ("*Getting Active*") and
5
6 healthy eating ("*Eat for Health*") to elicit perceptions about the websites and about
7
8 both behaviours. The discussions surrounding barriers to behaviour change may
9
10 have been more realistic than if participants had been asked their thoughts on
11
12 hypothetically making behaviour changes, rather than discussing the content
13
14 presented in the intervention.
15

16
17 Individuals who were not interested in behaviour change may have been less likely
18
19 to participate. However, we found that people often took part for altruistic reasons,
20
21 suggesting that the behaviour change aspect of the intervention was not a deterrent.
22
23 The intervention also included a module that focused on stress management, which
24
25 may have attracted some participants (data focussing on perceptions of this module
26
27 is not presented here). As evident in the themes, some participants were not
28
29 interested in behaviour change, providing an insight into this group. Findings from
30
31 large scale quantitative trials are needed to establish the generalisability of the
32
33 findings reported in this paper.
34
35

36
37 When using multiple interviewers, there are likely to be discrepancies between
38
39 styles, potentially leading to variation in information disclosed by the participant.
40

41
42 Efforts were made to reduce this by producing an interview schedule. All interviewers
43
44 took part in a training workshop led by KB to promote consistency.
45

Clinical implications

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47
48
49 Our research has highlighted barriers to behaviour change following treatment for
50
51 cancer that may be important to consider when developing interventions to support
52
53 lifestyle changes in cancer survivors. Our findings highlight a need to acknowledge
54
55 and respect genuine health-related barriers, as well as conflicting priorities of cancer
56
57

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survivors. Overly positive expectations for behaviour change may be rejected as unrealistic and unwanted. It cannot be assumed that cancer will lead to motivation to change; rather than a 'teachable moment', the period after cancer may be better conceptualised as an opportunity to engage in a dialogue about behaviour change priorities, preferences and needs for behaviour change support.

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Conflict of interest

Teresa Corbett, Tara Cheetham, Andre Matthias Müller, Joanna Slodkowska-Barabasz, Laura Wilde, Adele Krusche, Alison Richardson, Claire Foster, Eila Watson, Paul Little, Lucy Yardley, and Kat Bradbury declare that they have no conflict of interest.

Author Contributions

Teresa Corbett and Tara Cheetham should be considered joint first author. All authors made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data.

Kat Bradbury and Lucy Yardley led and supervised the study. Tara Cheetham, Andre Matthias Müller, Joanna Slodkowska-Barabasz, Laura Wilde, and Adele Krusche were involved in the planning of the study and conducted the interviews. Alison Richardson, Claire Foster, Eila Watson, and Paul Little contributed clinical expertise.

Teresa Corbett, Tara Cheetham, Andre Muller, Kat Bradbury, and Lucy Yardley drafted the manuscript. Each of the authors were involved in revising the manuscript critically for important intellectual content. All authors have given final approval of the version to be published.

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Appendices

Appendix 1. Eligibility criteria for participation

Inclusion criteria:	Exclusion criteria
<ol style="list-style-type: none"> 1. Be identifiable from GP case records 2. Not receiving palliative care 3. Have internet access; 4. Have poorer HRQoL: as assessed using the 2 item quality of life subscale of European Organization for Research and Treatment of Cancer) QoL questionnaire C30 instrument (version 3)[20] (EORTC) (i.e. scoring 4 or less out of 7) 5. Have at least one self-reported issue likely to be helped by the intervention, and interested in using web-based support to improve diet or physical activity. 	<ol style="list-style-type: none"> 1. Has not had breast cancer, prostate cancer or colorectal cancer; 2. Have finished primary treatment within the last 3 months or longer than 10 years ago; 3. Currently receiving palliative care; 4. Current serious mental health problem (such as schizophrenia, bipolar disorder, major depressive disorder with or without suicidality, major alcohol or drug problems, obsessive compulsive disorder); 5. No internet access 6. Do not have poor HRQoL: as assessed using the 2 item QoL subscale of EORTC*[20] (i.e. scoring greater than 4 out

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of 7 on average)

For Peer Review

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Appendix 2. Overcoming cancer specific barriers to behaviour change	
Potential barriers to behaviour change	How barriers might be overcome
Feeling blamed or pressurised into making changes after cancer	<ul style="list-style-type: none"> • Avoid discourses which might be viewed as blaming the individual for their cancer (e.g. highlighting link between cancer and behaviour). • Positively framing messages that focus on wellbeing, rather than illness management discourses or risk of disease could enhance health messages. For example the wider benefits of making behavioural changes (such as increased energy, improved mood or memory) could be drawn on. • Facilitate choice of behaviour changes and respect the autonomy of individuals. In some cases individuals may choose not to make changes, or may only want to make changes in a specific area.
Behaviour change in conflict with other priorities after cancer	<ul style="list-style-type: none"> • Interventions could include discussion about cancer survivors' priorities to tailor suggestions to the values of participants as much as possible. • It might be useful to carefully consider enjoyable participation in valued roles and activities as an important feature of cancer survivor's HRQoL. This could be achieved by lessening the focus on "health" and emphasising the social or enjoyment benefits that could be achieved.
Perceived absence of support from HCPs after cancer ends leads to uncertainty about how to adopt lifestyle changes	<ul style="list-style-type: none"> • At discharge, cancer patients could be given brief written information or links to digital resources which provide advice and support for making healthy behaviour changes. It is likely that healthcare practitioners endorsing these resources would persuade patients of their credibility[29, 30]. • Train HCPs in signposting to existing support services after cancer treatment, as well as highlighting how these might complement existing support resources. • Digital interventions or HCPs could discuss concerns that patients have about changing routines after cancer and engaging in healthy behaviours.
Confusion due to contradictory advice or information that is difficult to understand	<ul style="list-style-type: none"> • Clear guidance and information from credible and reputable sources could be provided in an easily accessible format. Interventions may include content designed to challenge misinformation relating to post-cancer care. HCPs recommending such resources, explicitly acknowledging the vast amount of advice out there and noting that this resource is the most sensible approach for the patient would enhance credibility of such

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	<p>guidance.</p> <ul style="list-style-type: none"> • Where possible, individuals could also be encouraged to discuss any confusion about their health and lifestyle changes with a HCP.
<p>Cancer treatment, pre-existing comorbid diseases and medications made it more difficult to make changes</p>	<ul style="list-style-type: none"> • Interventions might be improved by acknowledging genuine health-related barriers that people may face and showing how these can be overcome, or in many cases helped by engaging in health behaviours (e.g. pain, fatigue, depression can be helped by PA). • Carefully designed interventions could be tailored to address age-related or QoL issues. These could acknowledge problems that people may face and providing support to overcome these where possible. • Acceptability may be enhanced by including strategies that may also benefit overlapping symptoms and facilitate self-management of ongoing side effects and pre-existing comorbidities.
<p>Perceived unrealistic expectations about what a cancer survivor should be able to achieve after cancer</p>	<ul style="list-style-type: none"> • Avoid perpetuating unrealistic messages about cancer survivorship by promoting achievable changes that people can build on to accomplish their goals. • Appropriate role models and case studies could be used to avoid promotion of unrealistic messages about cancer survivorship, to acknowledge difficulties with change and model how people overcome such barriers.

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Appendix 3. Non-cancer specific barriers and facilitators for behaviour change cited by participants.

Theme	Code	Explanation of code
Mistrust of experts and advice	Doubt about information from experts and research evidence	Includes discussion of: <ul style="list-style-type: none"> • Contradictions between health guidance and reality • Uncertainty about research evidence • Evidence from 'them' isn't trusted – who are they? • Personal experience that contradicts information from experts • Evidence/guidelines change over time so people lack trust in them <ul style="list-style-type: none"> ○ Research can be biased by researcher's assumptions or aims ○ Guidelines always changing
	Information from the media (websites/newspapers/TV) is trusted	Includes discussion of: <ul style="list-style-type: none"> • Trusted sources of information online or in the media, as well of sources that are not considered useful. • Focuses on media coverage of health behaviour topics such as being more active or what constitutes a healthy diet.
Personal beliefs and knowledge	Personal knowledge of healthy eating and exercise affects beliefs and behaviour	Includes discussion of: <ul style="list-style-type: none"> • Knowledge about the benefits of health behaviour change • Influence of past experience of health behaviour change, comparison to people who haven't had similar past experiences • A wide range of beliefs have been coded relating to specific food types discussed, e.g. alcohol, dairy, fish, meat, processed foods, superfoods, wholegrain foods
	Beliefs about outcomes of behaviour change	Negative outcomes of unhealthy lifestyle <ul style="list-style-type: none"> • Obesity as a consequence of unhealthy eating • Inactivity can lead to obesity and further health problems Positive outcomes of healthy lifestyle <ul style="list-style-type: none"> • Activity can make you feel energised rather than tired • Benefits of healthy eating include living longer and feeling better • Exercise and tiredness as a vicious circle: Not doing enough exercise weakens your body, making it hard to get back into exercising
Perceived need	Already has changed/	<ul style="list-style-type: none"> • Belief that they already have a healthy lifestyle

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to change behaviour (or not)	Could do more	<ul style="list-style-type: none"> • Wants to do more/ Motivated to change
Perceptions of others	Feels they are different to other people	<p>Includes negative perceptions of what it means to 'be healthy' or who can/should change behaviour</p> <ul style="list-style-type: none"> • Likes exercise and thinks maybe other people don't • Negative perception of someone who eats healthily • Inactive people as couch potatoes • Social comparison (e.g. spouse, peers etc.)
	Barriers as false or non-existent	<p>Includes positive perceptions of what it means to 'be healthy' or who can/should change behaviour:</p> <ul style="list-style-type: none"> • Anyone can do more activity: Any barriers given are just excuses • There is a right and wrong state of mind to have
Support to have a healthy lifestyle	Social support as beneficial for health behaviours and lack of support as detrimental to health	<p>Includes discussion of factors that are likely to lead to successful behaviour change including:</p> <ul style="list-style-type: none"> • To make health behaviour changes you need the right information and encouragement. • Positive/supportive influence of other people and support groups <ul style="list-style-type: none"> ◦ More likely to change with other people than on your own • Spousal support and motivation • Electronic tools such as Wii fit programme as motivational support
General barriers to behaviour change	Non cancer-specific barriers to behaviour change	<p>Barriers cited included:</p> <ul style="list-style-type: none"> • Cost: Healthy eating as expensive • Ageing: <ul style="list-style-type: none"> ◦ Behaviour change just for young people (e.g. Vegetarianism) <ul style="list-style-type: none"> ▪ Perception that younger people more likely to change their habits ◦ Age impacts their desire to try new foods ◦ Perception that older people who have disabilities can't be more active • Motivation/ lack of motivation <ul style="list-style-type: none"> ◦ Dislike of healthy eating/exercise ◦ Change as too hard/too much effort • Fear of harm: Worries about pain and harm to self

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		<ul style="list-style-type: none"> • Comorbidities/ other illnesses • Lack of time
Overcoming barriers to behaviour change	Overcoming barriers by using behaviour change techniques	<ul style="list-style-type: none"> • Traffic light system to help participants to make healthier choices (Foods are categorised as green, amber, or red to show users at a glance if a food is has low, medium, or high amounts of fat, saturated fat, sugars and salt, helping them to achieve a better balance). • Recipes give people ideas – overcoming the barrier of not knowing how to eat healthily • Reminders could help people to overcome barriers such as forgetting about their activity goals • Goal setting and monitoring progress are helpful <ul style="list-style-type: none"> • Goals give you something to aim for • Monitoring goals is good as you can track progress and see if you feel better
	Discipline and self-motivation important for behaviour change	<ul style="list-style-type: none"> • Discipline and self-motivation to exercise • Importance of moderation in changing behaviour • The role of habits <ul style="list-style-type: none"> ○ Bad habits are hard to break but having a healthy habit helps keep up healthy behaviour ○ Easy to get into the habit of being inactive but hard to break out of the habit

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Appendix 4. Summary of identified themes		
Theme	Sub-theme	Explanation of code
Motivation to change behaviour reported as leading to behaviour change		This theme addresses cases where people described making changes after cancer and illustrated an understanding of the importance of changing behaviour after/because of having had cancer.
Motivated to change behaviour but do not make behaviour change	Absence of support after cancer ends	This sub-theme refers to reports of people feeling alone after treatment and in need of advice and support. This includes discussions of finding information conflicting and confusing.
	Recognition of treatment side effects and a need to be realistic about behaviour change	This sub-theme describes comments by participants who reported physical limitations, side effects, and emotional consequences that are attributed to cancer and its treatment. This incorporates concerns about behaviour change after cancer specifically, as well as the impact of comorbidities as barriers to attempts to change behaviour.
Decision not to change health behaviours after cancer	Rejection of the link between cancer and behaviour	This theme refers to patients' understandings of what causes cancer and how these perceptions are likely to influence their responses to advice regarding behaviour change.
	Changing behaviour and life after treatment ends	This theme describes comments relating to how participants had reappraised their life and priorities after cancer. The theme includes beliefs about perceived conflicts between recommendations to change and priorities relating to social life and family. The theme also includes references to beliefs about the implications of cancer on what is possible and/or what is a priority.

Exploring cancer survivors' views of health behavior change**Exploring cancer survivors' views of health behavior change': "Where do you start, where do you stop with everything?"**

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Abstract

Objective

Physical activity (PA) and a healthy diet can improve the well-being of cancer survivors. However, cancer survivors often do not engage in these behaviours. This

Exploring cancer survivors' views of health behavior change

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3
4 study aimed to explore barriers and facilitators to engaging in these behaviours
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6 following cancer treatment.
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8 9 Methods

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11 During the development of a web-based intervention to enhance health-related
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13 quality of life in cancer survivors, 32 people who had completed treatment for breast,
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15 colon or prostate cancer were presented with an intervention for PA and healthy
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17 eating. In-depth think-aloud and semi-structured interviewing techniques were used
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19 to elicit perceptions of both behaviours. Data were analysed using thematic analysis.
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23 Results

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25 Some individuals reported implementing positive health behaviour changes to
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27 maintain health and prevent recurrence, or to help them to move forward after
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29 cancer. However, others reported feeling abandoned, and many did not report an
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31 intention to engage in lifestyle changes. Individuals discussed contextual and health-
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33 related barriers that were specifically linked to their situation as post-treatment
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35 cancer survivors: individuals described uncertainty about how to implement adaptive
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37 changes and perceived a lack of support from healthcare providers. Others viewed
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39 behaviour change as unnecessary or undesirable, with some arguing that non-
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41 modifiable factors contributed more to their cancer diagnosis than lifestyle-related
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43 factors.
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47 Conclusions

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50 For many participants **in this study**, the period that follows treatment for cancer did
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52 not represent a 'teachable moment'. A variety of complex and heterogeneous factors
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Exploring cancer survivors' views of health behavior change

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4 appeared to impact motivation, and may limit cancer survivors from engaging with
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6 diet and PA changes.
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8 **Background**

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11 Survival from cancer in many countries is rising [1]. Despite this, many cancer
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13 survivors may experience poorer health-related quality of life (HRQoL) following
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15 cancer treatment. An increase in physical activity (PA) and the consumption of a
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17 healthy diet can enhance the wellbeing of cancer survivors and reduce risk of cancer
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19 recurrence [2-5]. The period after cancer treatment has been proposed as a
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21 teachable moment, which may motivate individuals to adopt risk-reducing healthy
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23 lifestyle changes [2, 6]. However, only a small proportion of cancer survivors
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25 implement or maintain lifestyle changes after treatment [3]. It remains unclear why
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27 some are motivated to make healthy lifestyle changes during and after cancer, while
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29 others are not [7].
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34 Common barriers to PA and healthy eating in cancer survivors include a lack of
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36 motivation or self-efficacy, inadequate knowledge, concerns about pre-existing
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38 comorbidities, environmental factors such as bad weather, and lack of resources
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40 such as time or money [8-11]. Many of these issues are barriers to behaviour change
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42 across diverse health conditions [12-15] and could affect any motivational impact of
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44 the 'teachable moment' prompted by the completion of cancer treatment. In a study
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46 about cancer survivors' beliefs about diet quality, responses did not differ based on
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48 cancer type, age, or gender [16]. Similar findings were reported in a study on
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50 attitudes towards, knowledge of and seeking of information on PA [17]. While cancer
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52 survivors share some generic reasons for not engaging with lifestyle changes which
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54 are found across a variety of health conditions, they are also likely to have unique
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Exploring cancer survivors' views of health behavior change

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4 physical and emotional reasons specific to their survival or experience of cancer
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6 which influence engagement with these behaviours.
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8 Understanding cancer-specific barriers to adopting a healthy lifestyle among cancer
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10 survivors could help improve the development of targeted interventions for this group
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12 [18]. During the development phase of a web-based intervention to enhance HRQoL
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14 in cancer survivors, participants were presented with a website that included
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16 modules on PA ("*Getting Active*") and healthy eating ("*Eat for Health*"). This
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18 presented an opportunity to explore potential cancer-specific reasons for engaging
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20 (or not) in diet and PA changes. We conducted qualitative interviews to explore
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22 facilitators and barriers to engaging with recommendations for lifestyle behaviour
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24 change following cancer.
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27 28 **Methods**

29 30 ***Design***

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32 This study was part of a research programme that aimed to develop a digital
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34 intervention to support cancer survivors in making behaviour changes in order to
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36 improve HRQoL [19]. We obtained approval from NHS (Ref no. 191936) and
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38 University of Southampton ethics committees (Ref no. 17658) prior to data collection.
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40 The study was reported according to the consolidated criteria for reporting qualitative
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42 research (COREQ) [20].
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46 47 ***Recruitment and procedure***

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49 We included breast, colon and prostate cancer patients because they are common
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51 types of cancer with large numbers of survivors [21], and were the target group for
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53 the intervention being developed.
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Exploring cancer survivors' views of health behavior change

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4 Participants were recruited primarily through GP practices in Southern England.
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6 Potential participants identified via searches of GP databases were screened based
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8 on study inclusion criteria. Individuals who wanted to gain information about making
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10 healthy behaviour changes or coping with difficult feelings returned a reply slip to
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12 express interest in participating. The study was also advertised through cancer
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14 charities (Breast Cancer Care, Prostate Cancer UK, and PCaSO Prostate Cancer
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16 Network).

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19 Interested participants were screened for eligibility and provided informed consent
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21 prior to the interview (See Appendix1). Interviews were conducted by trained
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23 postgraduate students and two qualitative researchers (TaC, LW). Individual
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25 interviews took place between May 2016 and January 2017 either at the University
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27 of Southampton or at a location that participants preferred (e.g. their private homes).

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30 We used in-depth qualitative think-aloud interviewing techniques [22]. Using the
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32 Person-Based Approach [22], we elicited participants' perceptions of the
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34 intervention, as well as their thoughts about implementing behaviour changes after
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36 cancer. Semi-structured questions were asked before and after the think-aloud
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38 section of the interviews. Participants were asked about how they perceived the
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40 intervention (what they found useful, interesting, or helpful, what they were less keen
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42 on, and what they would change) and how they felt about PA and healthy eating.

Analysis

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49 All interviews were audiotaped and transcribed verbatim. Thematic analysis was
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51 used to analyse the data [26]. Saturation was considered reached; participants in
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53 later interviews did not indicate any significant new concerns or barriers to
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55 engagement with PA or diet. We conducted line-by-line open coding and an initial
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4 coding manual was developed by TaC. This coding manual was refined with TeC
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6 (qualitative researcher with experience in area of cancer survivorship) and updated
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8 regularly to reflect the ongoing analysis of the data. All of the data were coded, but
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10 our analysis was specifically focused on identifying patterns within participants'
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12 accounts related to behaviour change in the specific context of cancer survivorship.

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15 Final codes, and themes were agreed between TeC, AMM (a PA specialist), KB, and
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17 LY (experienced qualitative researchers and Health Psychologists). Themes were
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19 clusters of codes that were related to similar aspects of the data. Deviant cases not
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21 consistent with the overall trend of the data were identified to explore the limits of the
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23 analysis and to ensure all relevant data were included in the analysis process. The
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25 findings were discussed with the wider research team (including cancer survivors
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27 and clinicians with cancer expertise), to ensure clarity of the themes and aid
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29 interpretation of the findings.
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Results

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36 Thirty-two participants agreed to participate. Demographic and clinical characteristics
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38 are reported in Table 1. There were no patterns in the themes in relation to gender,
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40 age, cancer type, or time since treatment.
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44 Many individuals cited non-cancer specific reasons for not engaging in behaviour
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46 change (see Appendix 3). Participants described the influence that their experience
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48 of cancer had had on their perceptions of behaviour change. Some of the comments
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50 reflected the 'teachable moment' after cancer as described previously [3]. Others
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52 suggested that there may be an opportunity for a 'teachable moment' that is not
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54 always capitalised on. Individuals discussed barriers and facilitators to change that
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Exploring cancer survivors' views of health behavior change

were unique to their status as post-treatment cancer survivors. These themes can be seen in Appendix 4 and are discussed in detail below.

Table 1. Demographic and clinical characteristics of study participants

Age in years	
Mean	68.84
SD	10.76
Range	44-90
Sex	
Male	18
Female	14
Type of Cancer	
Prostate	13 (5 on active surveillance)
Breast	11
Colon	8
Years since treatment¹	
Mean	3.81
SD	2.60
Range	0-9
Education level	
No education	2
Secondary school	9
College/sixth form (post-secondary)	10
Undergraduate	4
Postgraduate	7

¹Excluding five participants on active surveillance

Motivation to change behaviour leads to behaviour change

Some cancer survivors were motivated to change their health behaviours after cancer treatment. Participants described how they had adopted a healthier lifestyle in order to maintain health and prevent cancer recurrence.

“You think about what went wrong with you and to try and keep yourself healthy so it doesn't happen again, really, isn't it? That's the thing. Yeah, just try and look after yourself the best you can.” (Prostate, 6 years post-treatment).

The drive to feel better after treatment helped individuals to persevere with behaviour change despite persistent treatment-related side effects. Others did not want to be

Exploring cancer survivors' views of health behavior change

1
2
3
4 seen as a victim and felt that adopting a healthy lifestyle helped them to feel better,
5
6 empowered, and able to move on after cancer.
7

8 9 **Motivation, but no behaviour change**

10
11 Most participants recognised that lifestyle changes could be beneficial after cancer.
12
13 However, many described reasons for not changing their behaviour. These are
14
15 outlined in the two sub-themes below.
16
17

18 Absence of support from healthcare professionals (HCPs) after cancer ends

19
20 Despite recognising the potential health benefits of behaviour change, many felt
21
22 motivation was hampered by HCPs failing to understand the experience of cancer
23
24 survivors. Many were uncertain about how to adopt lifestyle changes after cancer,
25
26 describing a perceived lack of advice and support following treatment completion.
27
28

29
30 *“Yes they were helpful when you're there, but that's not usually the time that you're*
31
32 *having any problems, that's just having your particular treatment at that time. When*
33
34 *you have to deal with it by yourself, when you're at home and not at the hospital... I*
35
36 *didn't feel that they were assisting in what you needed once you've left”. - Prostate*
37
38 *cancer, 78, 3 years after treatment*
39
40

41
42 The timing of support right after treatment was considered especially important for
43
44 participants.
45

46
47 *“Nobody ever told me...I had to work that out over time...Whereas if somebody had*
48
49 *given me that list [of healthy foods] at the beginning, that would have been an idea.”*
50

51 (Prostate, active surveillance)
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53
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57

Exploring cancer survivors' views of health behavior change

Participants were concerned about making behaviour changes because they felt that they had figured out what worked best for them and worried about what the impact of these changes might be on their body.

"I've got a fear of changing the diet I eat... if I try a new eating plan, it's going to throw my body out." (Colon, Male, 7 years post-treatment)

A number of participants explored various sources of information to find answers and support regarding lifestyle change. Many were confused by contradictory advice, or information that was difficult to understand.

"you shouldn't eat this, you shouldn't eat that', and there's just too much... out there that conflicts. Where do you start, where do you stop with everything?" (Breast, female, less than a year since treatment)

Occasionally, due to a perceived lack of support from HCPs, participants reported feelings of uncertainty about how to approach lifestyle changes *"I think they give you this treatment and then they send you home and you're just left... you don't know what you can do and what you can't do."* (Prostate, active surveillance)

Recognition of treatment side effects and a need to be realistic about behaviour change

Cancer and treatment side-effects were frequently seen as a barrier to implementing behaviour change.

"I know that exercise will help improve my lifestyle. But how do you exercise when your body won't allow you to?" (Prostate, 2 years post-treatment).

Participants suggested that cancer treatment and medications made it more difficult to make changes. Some noted that cancer had led to muscle-loss that they believed

Exploring cancer survivors' views of health behavior change

would not be regained through exercise. Others spoke about weight-gain due to therapies. This was seen as difficult to change due to ongoing hormonal therapies.

"I do think tamoxifen has a lot to answer for. I can't seem to shift the weight as easy as I used to. So I'd rather take it and be overweight than not take it." (Breast, female, 3 years post-treatment).

Many argued that acceptance of and adaptation to physical limitations due to cancer was a key first step when trying to change behaviour.

"We have got physical limitations and the drugs have caused us joint problems and all the rest of it. And it's about accepting that, and not making a big deal out of it ... just that's how it is." (Breast, <1year post-treatment).

"I think the key thing is realising you can't do you as much as you used to do. I used to go swimming with my kids and now after twenty minutes I'm tired. I'll just sit at the side while you two carry on. Whereas I used to be able to have a couple of hours, quite happily." (Breast, <1year post-treatment)

A number of people felt that post-cancer wellbeing campaigns often failed to include realistic role-models. Many had been exposed to health promoting materials that failed to recognise the impact of cancer and its treatment. Examples of perceived 'high achievers' or 'over-achievers' who had accomplished successful health behaviour change were viewed as intimidating. Participants suggested that this resulted in reduced motivation to engage in behaviour change and that they would prefer interventions that acknowledged the difficulties faced by those after cancer treatment.

Exploring cancer survivors' views of health behavior change

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4 *"...you read so many stories of people that have overcome all sorts, but then they've*
5 *gone so much bigger and better than I could ever dream of. I couldn't even have*
6 *done before I had treatment, let alone after. And that is actually quite demotivating"*

7
8
9
10 (Breast, female, 2 years post-treatment).
11

Decision not to change health behaviours after cancer

Rejection of the link between cancer and behaviour

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16
17 Many felt confident that they had led a healthy lifestyle before cancer, and therefore
18 did not need to change behaviour.
19

20
21
22 A number decided not to change their health behaviours, stating that they did not
23 wholly accept the link between health behaviour and cancer. Participants often
24 reported that their health behaviours were not implicated in causing cancer or cancer
25 recurrence.
26
27
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30
31
32 *"I think you could eat fruit and veg all day long but it's not going to stop you getting*
33 *cancer..."* (Prostate, active surveillance).
34
35

36
37 Some were uncertain or unconvinced that changing their behaviour could have a
38 substantial effect on their health:
39

40
41
42 *"Eating foods, healthy, it might make you feel good but you still have cancer. You*
43 *might feel better in yourself but no way are you ever going to get back to normal."*
44

45
46 (Prostate, 6 years post-treatment).
47

48
49 Participants sometimes compared themselves to others and concluded that their
50 behaviour had not led to their cancer. Some described individuals who they
51 perceived as having healthy lifestyles who had nevertheless had cancer or who had
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Exploring cancer survivors' views of health behavior change

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4 died at a young age. Others cited examples of those with unhealthy behaviours who
5
6 had lived for many years.

7
8
9 *“Now, I smoked for forty-seven years, – they say smoking destroys your heart, meat*
10 *destroys your heart, and lack of exercise destroys your heart. I’ve survived seventy-*
11 *eight years on what I’ve been doing. I was older than my mother and father when*
12 *they died, you know? So, my lifestyle hasn’t been that bad.”* - (Colon, Male, 2 years
13
14
15
16
17 post-treatment)

18
19
20 A few participants seemed to find acknowledging a link between behaviour and
21
22 cancer too challenging, as it induced feelings of guilt.

23
24
25 *“I would feel very guilty if I thought that our eating habits had caused me to have*
26 *cancer. I just put it down to a kick in the teeth by life, that's just one of the things that*
27 *happens. It's bad enough having it. My attitude is not ‘Why me?’, but ‘Why not me?’*
28
29
30
31 *But now this is saying ‘It's your fault.’* (Breast, female, 3 years post-treatment).

Other factors people take into account when considering/rejecting behaviour change

32
33
34
35
36 Individuals felt it was difficult to change their behaviour due to comorbidities they had
37
38 had prior to the onset of cancer. Some were afraid that making lifestyle changes
39
40 could affect self-management of pre-existing comorbidities.

41
42
43
44
45 *“It hasn’t been just after the cancer, I’ve always had back and joint problems. I use*
46 *the stair lift because my knees are so painful going up and down the stairs, I did try*
47 *to use it less, but I was frightened of falling.”* - (Breast, female, 3 years post-
48
49
50
51 treatment).

Exploring cancer survivors' views of health behavior change

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4 *"I think you should, when you've got multiple problems like me, check with the*
5 *doctor. Before you overdo it"* – (Breast, female, 2 years post-treatment).
6
7
8
9

10 Cancer had led many participants to reappraise their life and priorities. Newfound
11 priorities were not always linked to changing health behaviours. Some felt that they
12 would restrict or limit themselves by focusing too much on lifestyle changes.
13
14 Participants also referred to a newfound awareness that life is short and a need to
15 enjoy it to the fullest. Some explicitly contradicted the view of cancer being a
16 teachable moment for behaviour change, stating that the cancer experience had led
17 to reduced motivation to change behaviour.
18
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24
25

26 *"All those years I was watching the weight. When they tell you you've got cancer,*
27 *you think oh for God's sake, to Hell with it all, you know? If I want something I have it*
28 *now."* (Breast, 5 years post-treatment).
29
30
31
32

33 Another participant spoke about prioritising family-time, saying
34
35

36 *"if it suddenly said oh you've got to go and do three hours running a day, no... that's*
37 *three hours away from my family. They had enough time away from me while I was*
38 *ill..."* (Breast, female, less than 1 year post-treatment).
39
40
41
42

43 **Conclusions**

44

45 We have highlighted cancer-specific barriers to lifestyle change that are particular to
46 the experience of post-treatment cancer survivors. We have also extended the
47 existing literature that has often focused on barriers to behaviour change which are
48 generic across conditions but are not unique to the experience of cancer survivors
49 [12-15]. Participants varied greatly in the extent to which they chose to make lifestyle
50 changes after treatment, due to their idiosyncratic needs and the experience of
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Exploring cancer survivors' views of health behavior change

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4 having cancer. This study offered a novel insight into the decision-making and
5
6 prioritisation that people engage in when asked about changing health behaviours.
7

8
9 In keeping with existing literature that proposes that coming to the end of successful
10
11 cancer treatment might represent a 'teachable moment'[6], some people reported
12
13 implementing positive lifestyle changes. Beeken et al [16] noted that behaviour
14
15 change was often motivated by a desire to remain generally healthy rather than to
16
17 prevent recurrence. Survivors reported making or attempting some changes after
18
19 cancer, with diagnosis often serving as an impetus for lifestyle change [16]. In
20
21 contrast, we found that for most individuals, there appeared to be many other issues
22
23 likely to negatively impact on behaviour change, and would have to be addressed to
24
25 make it a teachable moment. Most interviewees could see the benefits of behaviour
26
27 change but described generic (Appendix 3) and cancer-specific barriers that had
28
29 prevented change. As with previous research [8, 9], a lack of confidence and support
30
31 were often cited as reasons for not changing behaviour. Participants also reported
32
33 uncertainty about whether any changes they had made were appropriate or sufficient
34
35 for cancer survivors and did not want to make changes without explicit guidance
36
37 from their HCP. Previous studies have also reported that participants received little
38
39 information from health professionals relating to engaging in PA, with participants
40
41 searching for information via media and websites[17]. Confusion about how to
42
43 implement changes is likely to reduce motivation to make lifestyle changes [23]. It
44
45 appears that (for many) there is the potential for a "teachable moment", but this
46
47 opportunity to promote behaviour change is not always promoted by HCPs in a
48
49 timely and context-specific manner.
50
51

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53
54 Another common view was that behaviour change was unnecessary or undesirable.

55
56
57 Many were confident that they had led a sufficiently healthy lifestyle before the onset

Exploring cancer survivors' views of health behavior change

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3
4 of cancer. Scepticism regarding the influence of behavioural factors in causing
5
6 cancer could be influenced by a belief that their diet was healthy prior to cancer [24].
7
8 Participants in the current study frequently mentioned the role of non-modifiable
9
10 factors such as family history of cancer or chance. Beliefs that health is controlled by
11
12 luck or chance are negatively associated with engaging in health-promoting lifestyle
13
14 [25]. Over-estimation of the influence of non-modifiable factors may be part of a
15
16 coping strategy to avoid a sense of blame [12]. In our sample, cancer survivors
17
18 reported they would feel indirectly blamed for their cancer and potentially experience
19
20 guilt if they were to believe that cancer was possibly “their fault” and attributable to
21
22 their lifestyle. Perceived overly optimistic expectations of cancer survivors portrayed
23
24 in the media sometimes led to feelings of stress, or feeling that they should be able
25
26 to do more. In an intervention setting, this could potentially lead to participants
27
28 becoming defensive or rejecting the advice given [26].
29
30
31 Behaviour change also appeared impeded by cancer-related side-effects and the
32
33 influence of the cancer experience on the management of pre-existing comorbidities.
34
35 Similar findings have been reported elsewhere [17, 27]. Cancer survivors with
36
37 comorbid diseases often prioritize one chronic condition or symptom over another
38
39 and many struggle to integrate various self-care strategies into their routine [28].
40
41
42 The current study highlighted that health-related concerns can pose genuine barriers
43
44 to behaviour change even when cancer survivors are motivated to engage in lifestyle
45
46 changes. Some of these issues are summarised in Appendix 2 which outlines
47
48 identified barriers, and suggested actions that HCPs could take to potentially
49
50 enhance engagement with lifestyle change.
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Strengths and Limitations

Exploring cancer survivors' views of health behavior change

Participants were presented with a digital intervention for PA (*Getting Active*) and healthy eating (*Eat for Health*) to elicit perceptions about the websites and about both behaviours. The discussions surrounding barriers to behaviour change may have been more realistic than if participants had been asked their thoughts on hypothetically making behaviour changes, rather than discussing the content presented in the intervention.

Individuals who were not interested in behaviour change may have been less likely to participate. However, we found that people often took part for altruistic reasons, suggesting that the behaviour change aspect of the intervention was not a deterrent. The intervention also included a module that focused on stress management, which may have attracted some participants (data focussing on perceptions of this module is not presented here). As evident in the themes, some participants were not interested in behaviour change, providing an insight into this group. **Findings from large scale quantitative trials are needed to establish the generalisability of the findings reported in this paper.**

When using multiple interviewers, there are likely to be discrepancies between styles, potentially leading to variation in information disclosed by the participant.

Efforts were made to reduce this by producing an interview schedule. All interviewers took part in a training workshop led by KB to promote consistency.

Clinical implications

Our research has highlighted barriers to behaviour change following treatment for cancer that may be important to consider when developing interventions to support lifestyle changes in cancer survivors. Our findings highlight a need to acknowledge and respect genuine health-related barriers, as well as conflicting priorities of cancer

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1 survivors. Overly positive expectations for behaviour change may be rejected as
2
3
4 unrealistic and unwanted. It cannot be assumed that cancer will lead to motivation to
5
6
7 change; rather than a 'teachable moment', the period after cancer may be better
8
9
10 conceptualised as an opportunity to engage in a dialogue about behaviour change
11
12
13 priorities, preferences and needs for behaviour change support.
14

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Exploring cancer survivors' views of health behavior change**Acknowledgments**

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Conflict of interest

Teresa Corbett, Tara Cheetham, Andre Matthias Müller, Joanna Slodkowska-Barabasz, Laura Wilde, Adele Krusche, Alison Richardson, Claire Foster, Eila Watson, Paul Little, Lucy Yardley, and Kat Bradbury declare that they have no conflict of interest.

Author Contributions

Teresa Corbett and Tara Cheetham should be considered joint first author. All authors made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data.

Kat Bradbury and Lucy Yardley led and supervised the study. Tara Cheetham, Andre Matthias Müller, Joanna Slodkowska-Barabasz, Laura Wilde, and Adele Krusche were involved in the planning of the study and conducted the interviews. Alison Richardson, Claire Foster, Eila Watson, and Paul Little contributed clinical expertise.

Teresa Corbett, Tara Cheetham, Andre Muller, Kat Bradbury, and Lucy Yardley drafted the manuscript. Each of the authors were involved in revising the manuscript critically for important intellectual content. All authors have given final approval of the version to be published.

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Appendices

Appendix 1. Eligibility criteria for participation

Inclusion criteria:	Exclusion criteria
<ol style="list-style-type: none"> 1. Be identifiable from GP case records 2. Not receiving palliative care 3. Have internet access; 4. Have poorer HRQoL: as assessed using the 2 item quality of life subscale of European Organization for Research and Treatment of Cancer) QoL questionnaire C30 instrument (version 3)[20] (EORTC) (i.e. scoring 4 or less out of 7) 5. Have at least one self-reported issue likely to be helped by the intervention, and interested in using web-based support to improve diet or physical activity. 	<ol style="list-style-type: none"> 1. Has not had breast cancer, prostate cancer or colorectal cancer; 2. Have finished primary treatment within the last 3 months or longer than 10 years ago; 3. Currently receiving palliative care; 4. Current serious mental health problem (such as schizophrenia, bipolar disorder, major depressive disorder with or without suicidality, major alcohol or drug problems, obsessive compulsive disorder); 5. No internet access 6. Do not have poor HRQoL: as assessed using the 2 item QoL subscale of EORTC*[20] (i.e. scoring greater than 4 out

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of 7 on average)

For Peer Review

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Appendix 2. Overcoming cancer specific barriers to behaviour change	
Potential barriers to behaviour change	How barriers might be overcome
Feeling blamed or pressurised into making changes after cancer	<ul style="list-style-type: none"> • Avoid discourses which might be viewed as blaming the individual for their cancer (e.g. highlighting link between cancer and behaviour). • Positively framing messages that focus on wellbeing, rather than illness management discourses or risk of disease could enhance health messages. For example the wider benefits of making behavioural changes (such as increased energy, improved mood or memory) could be drawn on. • Facilitate choice of behaviour changes and respect the autonomy of individuals. In some cases individuals may choose not to make changes, or may only want to make changes in a specific area.
Behaviour change in conflict with other priorities after cancer	<ul style="list-style-type: none"> • Interventions could include discussion about cancer survivors’ priorities to tailor suggestions to the values of participants as much as possible. • It might be useful to carefully consider enjoyable participation in valued roles and activities as an important feature of cancer survivor’s HRQoL. This could be achieved by lessening the focus on “health” and emphasising the social or enjoyment benefits that could be achieved.
Perceived absence of support from HCPs after cancer ends leads to uncertainty about how to adopt lifestyle changes	<ul style="list-style-type: none"> • At discharge, cancer patients could be given brief written information or links to digital resources which provide advice and support for making healthy behaviour changes. It is likely that healthcare practitioners endorsing these resources would persuade patients of their credibility[29, 30]. • Train HCPs in signposting to existing support services after cancer treatment, as well as highlighting how these might complement existing support resources. • Digital interventions or HCPs could discuss concerns that patients have about changing routines after cancer and engaging in healthy behaviours.
Confusion due to contradictory advice or information that is difficult to understand	<ul style="list-style-type: none"> • Clear guidance and information from credible and reputable sources could be provided in an easily accessible format. Interventions may include content designed to challenge misinformation relating to post-cancer care. HCPs recommending such resources, explicitly acknowledging the vast amount of advice out there and noting that this resource is the most sensible approach for the patient would enhance credibility of such

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	<p>guidance.</p> <ul style="list-style-type: none"> • Where possible, individuals could also be encouraged to discuss any confusion about their health and lifestyle changes with a HCP.
<p>Cancer treatment, pre-existing comorbid diseases and medications made it more difficult to make changes</p>	<ul style="list-style-type: none"> • Interventions might be improved by acknowledging genuine health-related barriers that people may face and showing how these can be overcome, or in many cases helped by engaging in health behaviours (e.g. pain, fatigue, depression can be helped by PA). • Carefully designed interventions could be tailored to address age-related or QoL issues. These could acknowledge problems that people may face and providing support to overcome these where possible. • Acceptability may be enhanced by including strategies that may also benefit overlapping symptoms and facilitate self-management of ongoing side effects and pre-existing comorbidities.
<p>Perceived unrealistic expectations about what a cancer survivor should be able to achieve after cancer</p>	<ul style="list-style-type: none"> • Avoid perpetuating unrealistic messages about cancer survivorship by promoting achievable changes that people can build on to accomplish their goals. • Appropriate role models and case studies could be used to avoid promotion of unrealistic messages about cancer survivorship, to acknowledge difficulties with change and model how people overcome such barriers.

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Appendix 3. Non-cancer specific barriers and facilitators for behaviour change cited by participants.

Theme	Code	Explanation of code
Mistrust of experts and advice	Doubt about information from experts and research evidence	Includes discussion of: <ul style="list-style-type: none"> • Contradictions between health guidance and reality • Uncertainty about research evidence • Evidence from 'them' isn't trusted – who are they? • Personal experience that contradicts information from experts • Evidence/guidelines change over time so people lack trust in them <ul style="list-style-type: none"> ○ Research can be biased by researcher's assumptions or aims ○ Guidelines always changing
	Information from the media (websites/newspapers/TV) is trusted	Includes discussion of: <ul style="list-style-type: none"> • Trusted sources of information online or in the media, as well of sources that are not considered useful. • Focuses on media coverage of health behaviour topics such as being more active or what constitutes a healthy diet.
Personal beliefs and knowledge	Personal knowledge of healthy eating and exercise affects beliefs and behaviour	Includes discussion of: <ul style="list-style-type: none"> • Knowledge about the benefits of health behaviour change • Influence of past experience of health behaviour change, comparison to people who haven't had similar past experiences • A wide range of beliefs have been coded relating to specific food types discussed, e.g. alcohol, dairy, fish, meat, processed foods, superfoods, wholegrain foods
	Beliefs about outcomes of behaviour change	Negative outcomes of unhealthy lifestyle <ul style="list-style-type: none"> • Obesity as a consequence of unhealthy eating • Inactivity can lead to obesity and further health problems Positive outcomes of healthy lifestyle <ul style="list-style-type: none"> • Activity can make you feel energised rather than tired • Benefits of healthy eating include living longer and feeling better • Exercise and tiredness as a vicious circle: Not doing enough exercise weakens your body, making it hard to get back into exercising
Perceived need	Already has changed/	<ul style="list-style-type: none"> • Belief that they already have a healthy lifestyle

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to change behaviour (or not)	Could do more	<ul style="list-style-type: none"> • Wants to do more/ Motivated to change
Perceptions of others	Feels they are different to other people	<p>Includes negative perceptions of what it means to 'be healthy' or who can/should change behaviour</p> <ul style="list-style-type: none"> • Likes exercise and thinks maybe other people don't • Negative perception of someone who eats healthily • Inactive people as couch potatoes • Social comparison (e.g. spouse, peers etc.)
	Barriers as false or non-existent	<p>Includes positive perceptions of what it means to 'be healthy' or who can/should change behaviour:</p> <ul style="list-style-type: none"> • Anyone can do more activity: Any barriers given are just excuses • There is a right and wrong state of mind to have
Support to have a healthy lifestyle	Social support as beneficial for health behaviours and lack of support as detrimental to health	<p>Includes discussion of factors that are likely to lead to successful behaviour change including:</p> <ul style="list-style-type: none"> • To make health behaviour changes you need the right information and encouragement. • Positive/supportive influence of other people and support groups <ul style="list-style-type: none"> ◦ More likely to change with other people than on your own • Spousal support and motivation • Electronic tools such as Wii fit programme as motivational support
General barriers to behaviour change	Non cancer-specific barriers to behaviour change	<p>Barriers cited included:</p> <ul style="list-style-type: none"> • Cost: Healthy eating as expensive • Ageing: <ul style="list-style-type: none"> ◦ Behaviour change just for young people (e.g. Vegetarianism) <ul style="list-style-type: none"> ▪ Perception that younger people more likely to change their habits ◦ Age impacts their desire to try new foods ◦ Perception that older people who have disabilities can't be more active • Motivation/ lack of motivation <ul style="list-style-type: none"> ◦ Dislike of healthy eating/exercise ◦ Change as too hard/too much effort • Fear of harm: Worries about pain and harm to self

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		<ul style="list-style-type: none"> • Comorbidities/ other illnesses • Lack of time
<p>Overcoming barriers to behaviour change</p>	<p>Overcoming barriers by using behaviour change techniques</p>	<ul style="list-style-type: none"> • Traffic light system to help participants to make healthier choices (Foods are categorised as green, amber, or red to show users at a glance if a food is has low, medium, or high amounts of fat, saturated fat, sugars and salt, helping them to achieve a better balance). • Recipes give people ideas – overcoming the barrier of not knowing how to eat healthily • Reminders could help people to overcome barriers such as forgetting about their activity goals • Goal setting and monitoring progress are helpful <ul style="list-style-type: none"> • Goals give you something to aim for • Monitoring goals is good as you can track progress and see if you feel better
	<p>Discipline and self-motivation important for behaviour change</p>	<ul style="list-style-type: none"> • Discipline and self-motivation to exercise • Importance of moderation in changing behaviour • The role of habits <ul style="list-style-type: none"> ○ Bad habits are hard to break but having a healthy habit helps keep up healthy behaviour ○ Easy to get into the habit of being inactive but hard to break out of the habit

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Appendix 4. Summary of identified themes		
Theme	Sub-theme	Explanation of code
Motivation to change behaviour reported as leading to behaviour change		This theme addresses cases where people described making changes after cancer and illustrated an understanding of the importance of changing behaviour after/because of having had cancer.
Motivated to change behaviour but do not make behaviour change	Absence of support after cancer ends	This sub-theme refers to reports of people feeling alone after treatment and in need of advice and support. This includes discussions of finding information conflicting and confusing.
	Recognition of treatment side effects and a need to be realistic about behaviour change	This sub-theme describes comments by participants who reported physical limitations, side effects, and emotional consequences that are attributed to cancer and its treatment. This incorporates concerns about behaviour change after cancer specifically, as well as the impact of comorbidities as barriers to attempts to change behaviour.
Decision not to change health behaviours after cancer	Rejection of the link between cancer and behaviour	This theme refers to patients' understandings of what causes cancer and how these perceptions are likely to influence their responses to advice regarding behaviour change.
	Changing behaviour and life after treatment ends	This theme describes comments relating to how participants had reappraised their life and priorities after cancer. The theme includes beliefs about perceived conflicts between recommendations to change and priorities relating to social life and family. The theme also includes references to beliefs about the implications of cancer on what is possible and/or what is a priority.