

This is a repository copy of Attitudes, challenges and needs about diet and physical activity in endometrial cancer survivors: a qualitative study.

White Rose Research Online URL for this paper: http://eprints.whiterose.ac.uk/122776/

Version: Accepted Version

Article:

Koutoukidis, DA, Beeken, RJ orcid.org/0000-0001-8287-9351, Lopes, S et al. (2 more authors) (2017) Attitudes, challenges and needs about diet and physical activity in endometrial cancer survivors: a qualitative study. European Journal of Cancer Care, 26 (6). e12531. ISSN 0961-5423

https://doi.org/10.1111/ecc.12531

© 2016 John Wiley & Sons Ltd. This is the peer reviewed version of the following article: Koutoukidis DA, Beeken RJ, Lopes S, Knobf MT, Lanceley A. Attitudes, challenges and needs about diet and physical activity in endometrial cancer survivors: a qualitative study. Eur J Cancer Care. 2017;26:e12531. https://doi.org/10.1111/ecc.12531, which has been published in final form at https://doi.org/10.1111/ecc.12531. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving. Uploaded in accordance with the publisher's self-archiving policy.

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



Abstract

With rates of endometrial cancer survival increasing, there is growing interest about lifestyle behaviours that could improve quality of life and reduce the risk for chronic diseases. The current study aimed to explore the attitudes, challenges, and needs of endometrial cancer survivors regarding diet and physical activity. Sixteen UK-based endometrial cancer survivors participated in two focus groups (n=5, n=3) or individual telephone interviews (n=8), using a semi-structured interview guide. Data were collectively analysed by two researchers until consensus was reached on a coding structure. Data analysis proceeded until themes were identified. Participants were within five years post cancer treatment with median age and BMI of 57 years and 25.83kg/m², respectively. Three themes were identified: i) defining a healthy lifestyle, ii) factors influencing diet and physical activity, and iii) needing to search for information. Results suggest interventions should incorporate recommendations on managing late-treatment effects, and behaviour change techniques for cognitive, practical, and social barriers to healthy lifestyle changes. Health care professionals are in a vital position to provide or introduce endometrial cancer survivors to in-person behaviour change interventions at the early post-treatment period.

Keywords

Endometrial cancer, survivorship, diet, physical activity, healthy lifestyle, qualitative

Introduction

Cancer survivors comprise a high-risk group for lifestyle-related conditions, such as cardiovascular disease (Weaver et al., 2013). While they often report making health behaviour changes (Demark-Wahnefried et al., 2005), evidence of such changes is limited (Kim et al., 2013, Milliron et al., 2014, Williams et al., 2013b). Compared to survivors of other cancer sites, endometrial and breast cancer survivors have the highest comorbidity burden post-diagnosis (Leach et al., 2014) and gynaecologic (endometrial and ovarian) cancer survivors are less likely to be physically active compared to breast cancer survivors (Weaver et al., 2013). Given that lifestyle advice is scarce in current practice (Jernigan et al., 2013, Nicolaije et al., 2012), there may be a need to support endometrial cancer survivors in making appropriate healthy lifestyle changes.

However, the extent of perceived need for lifestyle advice is unknown in this population. Survivors of other cancer sites have reported a desire for support and evidence-based advice regarding lifestyle changes after cancer treatment such as dietary advice for symptom management, and reduction of fear for food choices after treatment (Anderson et al., 2013, Williams et al., 2013a, Avery et al., 2014). Whether the lifestyle information needs are similar between survivors of endometrial cancer and other cancers may depend on their specific factors influencing diet and physical activity, given the different treatments and

treatment effects across cancer sites. Moreover, these needs are unlikely to be the same for each individual.

Understanding the attitudes of endometrial cancer survivors towards healthy lifestyles could inform the design of behaviour change interventions. Initial randomized clinical trials have indicated the feasibility of such interventions (von Gruenigen et al., 2012). Furthermore, large-scale interventions seem effective in improving physical and psychological parameters in survivors of other cancer sites, but document only low recruitment rates and moderate adherence rates (Adams et al., 2014). Identifying barriers to trial participation is crucial for the design of feasible and cost-effective interventions.

Qualitative research can allow for a wide range of views from the target population and, thus, appropriately inform the design process.

Using a framework can help with the design of lifestyle interventions. The person-based approach to intervention development is a systematic framework of self-management intervention design using qualitative methods (Yardley et al., 2015). This framework may be particularly relevant for this population, given the focus on post-treatment self-management within the vision of the National Cancer Survivorship Initiative (DH, 2010). Therefore, this qualitative study aimed to examine the perceived importance of health behaviours after endometrial cancer treatment, and the factors influencing adherence to a healthy lifestyle

after treatment. It also aimed to explore the information that endometrial cancer survivors obtain after treatment, and their preferred method of information delivery.

Methodology

Participants and recruitment

Endometrial cancer survivors within five years post active treatment were eligible to participate. Using purposive sampling, individuals were approached through non-NHS (National Health Service) support groups, namely the Eve Appeal Gynaecology Cancer Research Fund, the Womb Cancer Support UK, and the Cancer Research UK's Cancer Chat online forum. Additionally, individuals who had participated in a previous study conducted by this research team and who had expressed an interest to participate in future research were contacted. We aimed to obtain a broad range of views but there is limited guidance on the appropriate numbers to use when triangulating focus groups with interviews. Other studies that have combined the two for pragmatic reasons have conducted one small focus group (n=3) and two interviews (Taylor, 2005). Another conducted one large focus group (n=7) and one interview (Rees et al., 2003) while a further study carried out a small focus group (n=3) and eight interviews (Memon et al., 2016). We therefore aimed to follow the general guidance for qualitative studies, which is to continue recruiting until data saturation is reached (Morse, 2000). We aimed for focus groups of at least five participants,

however for pragmatic and ethical reasons, one group went ahead with three attendees because of last-minute dropouts. Approval to conduct the study was granted by the UCL Research Ethics Committee (project 5245/001).

All participants provided written informed consent for publication of individual data.

Prior to focus groups or interviews, participants completed a short questionnaire about their demographics and current lifestyle behaviours (WCRF, 2007, Milton et al., 2011) to inform and enhance interpretation of the data.

Discussion protocol

The discussion topics (Table 1) were developed based on previous pilot studies and the literature, with input from all authors (Morgan and Krueger, 1997). They included open questions regarding the perceived importance of health behaviours after cancer treatment, barriers to and facilitators of adherence to a healthy lifestyle after treatment, and obtained and desired information about a healthy lifestyle. Participants were prompted if required. The topic guide was piloted with two lay subjects for acceptability.

Procedure

Two audio-recorded focus groups (n=5, n=3) took place at University College London between July and September 2014. For pragmatic reasons, participants who were unable to attend were subsequently offered the alternative of a telephone interview. The groups were closed to the participants and the researchers only. DAK and RJB facilitated the 1.5-hour

discussions, acting as moderator and note-taker alternately. Survivors were prompted towards an open discussion about their thoughts and experiences. Telephone audio-recorded interviews (n=8) adhered to the focus group protocol and lasted about 30-45 minutes.

Analysis

Qualitative data from the focus groups and the telephone interviews were transcribed verbatim and checked against the recordings for accuracy by an independent individual. Data were analysed using a previously described six-phase thematic approach (Braun and Clarke, 2006). It aimed to provide a rich description of the data, and to identify themes at an explicit level using a realist approach (Braun and Clarke, 2006). Analysis was carried out in NVivo version 10 (QSR International Pty Ltd, 2014). As data were acquired, DAK repeatedly read the transcripts for essential familiarisation and to generate initial codes. These were discussed with AL, RJB, and TK in an iterative five-cycle process until the final coding tree (Supplementary file 1) was generated following completion of data collection. An independent researcher (SL) coded one random focus group transcript and two interview transcripts under these codes; equal to 43% of the data. The inter-rater reliability was high (mean weighted Kappa: 0.96). Minor differences were resolved by discussion. The size of the coded text chunks was determined to reflect the true meaning of the context of the statement.

DAK coded the rest of the transcripts based on the established coding structure.

Transcripts of both interviews and focus groups were checked against the coding tree for differences. No differences were revealed by collection strategy. Thus, all data were analysed collectively. The data from both interviews and focus groups were mutually informative for the conceptualization of the themes. Code names were collated into potential themes and themes were reviewed and refined to ensure internal homogeneity and external heterogeneity. All themes were checked against the transcripts to ensure that they reflect the majority of participants. Individual experiences were also highlighted. The paper followed standard reporting guidelines (COREQ completed checklist in Supplementary file 2) (Tong et al., 2007).

Results

Participants' characteristics

Of the 34 screened survivors (

Figure 1), 16 participated in the study. Table 2 presents the socio-demographic and self-reported treatment characteristics. The median age was 57.4 years. Most (81.3%) reported their race and ethnicity as White British. About half were married (56.3%) and had a degree or higher degree (53.3%). Four participants (25%) were affected by obesity, half met the recommendations for intake of vegetables and whole grains, about 40% met those for fruits, but only 12.5% reported meeting the physical activity guidelines (Table 3).

Themes

The themes identified were: i) defining a healthy lifestyle; ii) factors influencing diet and physical activity; and iii) needing to search for information. The type of treatment received is shown in each identified quote, with a, b, and c to indicate surgery, chemotherapy, and radiotherapy, respectively.

Defining a healthy lifestyle

Not only did participants believe that healthy eating and physical activity were critical for their overall health, but their definition of a healthy lifestyle also included mental, sexual, and psychological well-being.

I do think a healthy lifestyle has to include your mental health [...] alongside what you eat and your exercise. (FG1_3, 55 years, a & c).

They generally embraced the idea of a sensible diet with moderate amounts of a variety of foods, especially home-cooked. Regarding specific foods, they considered fruits, vegetables, whole grains, fish, and moderate alcohol intake being part of a healthy diet. Only a couple of participants mentioned legumes as specific parts of a healthy diet. In contrast, unhealthy choices included red meat, processed foods, and, sugar. The negative role of excess salt consumption and the ambiguous role of supplements in disease prevention were also mentioned.

Trying not to eat too much in total, trying to eat lots of fruit and vegetables, trying to not eat too much processed food, trying to eat home-cooked food where possible. We have oily fish like salmon once a week (Int_3, 64 years, a & c).

I think we should all, everybody as a whole, should be avoiding processed foods, the likes of McDonald's and that. I'm a firm believer in preparing food from scratch using just fresh products and steering away from pop (FG1_2, 55 years, a & c).

Regarding physical activity, participants generally emphasized the frequency and duration of activities rather than their intensity.

[Healthy lifestyle is] plenty of exercise, plenty of moving around (Int_3, 64 years, a & c).

It ought to be a balance between food intake, probably very low on any animal product, and some exercise. Not necessarily strenuous and not necessarily building up, body building stuff (Int_5, 53 years, a).

Factors influencing diet and physical activity

Some participants reported making changes towards their diet and physical activity after their cancer diagnosis while others did not. The factors influencing diet and physical

activity behaviours were categorized as cognitive, physiological, emotional, social, and practical.

Cognitive factors

Participants generally regarded healthy eating and physical activity as important factors influencing their overall health, and for this reason tried to engage with them.

Surviving cancer empowered participants to make lifestyle changes thought to be healthier like including nuts and organic products in their diet, cutting down sugar, eating breakfast, or being more physically active.

I think healthy eating is important to anybody but especially to me [...]. It is a necessity, not a luxury. And I cannot afford to have [low quality food] — I do not know if this is going to help with cancer or not — but you know in my mind the only thing that I am doing that is in my control is the food. You cannot control much else (Int_5, 53 years, a).

However, some thought that there was little need for change because they believed they were already following a healthy lifestyle.

It [cancer] made no difference whatsoever. I mean, I just do what I have always done (Int_1, 67 years, a & b & c).

Some participants mentioned that physical activity could be helpful in terms of symptom management, like fatigue, constipation, and bladder dysfunction. Overall, physical activity was mentioned as an essential contributing factor to their health and physical functioning.

[Physical activity] keeps everything moving, and it gets the oxygen and the blood flowing around the body (Int_7, 84 years, a & c).

Others maintained unhealthy behaviours as part of their return to normality postcancer.

I am overweight, I hardly exercise - I do very little, I have a sedentary job. [...] What I've done is I've put it out of my mind and that's it. I don't think about, oh I've had the cancer, I can't do this, I can't do that, I must be careful. I've just gone back to my life and carried on as normal (Int_8, 61 years, a).

Participants reported being more conscious about their dietary choices after cancer diagnosis. For example, they described forcing themselves to eat more fruits. They also reported putting in additional effort to be physically active. Survivors believed that knowledge about healthy eating and physical activity can positively shape behaviour.

I am forcing myself to go to [exercise] classes. [...] I have made myself start eating fruit, where I have always really hated fruit (FG1_5, 60 years, a & b & c).

They described successfully implementing a system of behavioural regulation to maintain a healthy lifestyle after cancer treatment on their own.

The main problem was not doing too much [...]. So, I did it in a systematic way. [...] I did what I could. I walked a lot, and then just gradually built up from there (Int_4, 51 years, a).

Two participants reported keeping a food diary after cancer treatment. One did so to identify foods that may cause symptoms and found it both helpful and easy using a mobile phone application. The other participant kept the diary as a helpful self-monitoring weightloss strategy. One participant was also using a pedometer as a weight management strategy.

[Regarding the bowel symptoms] I kept a food diary. I still do keep one. I have kept that over a year and a half, hoping that I might be able to go, 'It's mushrooms.' [...] I found it very useful. But I found it difficult originally to keep it in a notebook. [...] I found a very good app for the food diary [...] and I have started keeping it (FG1_3, 55 years, a & c).

Others found the idea of food and exercise diaries a potentially helpful way of understanding their dietary habits but had not engaged in it. Using small, attainable goals and rewards were deemed potentially helpful strategies for leading a healthy lifestyle.

I suppose it is goal setting. I think if you are living beyond cancer, you want to have something to look forward to, really, planning activities. A bit like a bucket list but smaller goals, not necessarily big things to do; but perhaps smaller things that you can achieve [...].

That's how I deal with it, really (FG1_4, 55 years, a).

I would have to set my own sort of system of rewards, really [to improve my lifestyle] (Int_3, 64 years, a & c).

Physiological factors

Cancer treatment did not influence the lifestyle pattern in some survivors. Others described how treatment effects conflicted with their motivation to lead a healthy lifestyle.

Treatment effects, such as fatigue, neuropathy, dizziness, pain, lymphedema, and bowel symptoms, were common reasons to avoid certain exercises, like crouching or yoga. Some survivors replaced these activities with others that were not influenced by treatment effects.

Before I was diagnosed I was doing four Zumba classes a week. I can't do that... I've got up to two a week. And anytime I try any more, I'm ill (FG1_4, 55 years, a).

Treatment effects also affected dietary choices. Decreased food intake shortly after treatment was attributed to cancer-associated anorexia. Participants referred to specific diet alterations that they had made to avoid bowel symptoms rather than for health reasons.

Treatment effects, like bowel disturbances after radiotherapy, led to avoidance of specific foods, like cheese, fruits, and spicy foods.

Before I had all the treatment, I used to eat lots of fruit and things, but I don't eat fruit now. And brown bread, I don't eat much of that either.

I eat many vegetables at the moment (FG1_1, 57 years, a & b & c).

One survivor mentioned being meticulous about fibre avoidance as a prophylactic measure. The specific symptoms and dietary changes were alternated with no particular pattern across the post treatment trajectory. The specific foods varied widely among individuals who had radiotherapy, with one survivor reporting increased fruit consumption after treatment as part of a healthier lifestyle and another reporting avoidance of fruits due to bowel symptoms.

It comes and goes. So, I might have a month where I can eat a conventional healthy diet and then there will be two or three weeks where I have to eat only what I can eat, and then you just have to work around that (FG1_3, 55 years, a & c).

So it is almost like I am trying to eat healthily and I want to have the brown sandwiches but I know if I have the brown sandwiches... I am already going to the loo so frequently that it is a risk (FG2_2, 33 years, a & b & c).

Emotional factors

Participants reported feeling better when physically active. They preferred gentle exercises, and walking. Some were also keen on group exercises but found gym exercises boring.

[Physical activity] clearly makes you feel better and it clearly keeps everything ticking over (Int_1, 67 years, a & b & c).

They also acknowledged that the emotional experience of cancer had influenced their lifestyle patterns.

Because often people feel sick emotionally after cancer, I certainly did. And it is surprising how often you feel all right during the treatment but it is at the end of it that it is all sorts of emotional problems and so on. I think particularly exercise is difficult to know about. You think it is more difficult and doesn't necessarily cheer you up that much (Int_3, 64 years, a & c).

Practical factors

Participants were keen on engaging in charity events. Some of them participated in physical activity events, like walks and marathons organized by cancer charities. The opportunities offered by the environment (e.g. weather, proper infrastructures, owning a dog) facilitated or posed a barrier to physical activities. Time constraints for physical activity were commonly reported.

I am lucky in that the environment is there; I have a nice run on my doorstep, so I just set off and I run [...]. Time is my main pressure for not..., my main excuse for not walking to work, for instance, or not... I think, oh I'll do that later (Int_4, 51 years, a).

Financial constraints were reported for attending a gym and cost was recognized as a barrier for choosing healthy foods.

Going to the gym does not appeal; apart from that is expensive.

[...] I think one of the barriers was initially restocking [on healthier foods]. You know, throwing, change, and restocking. I have spent quite a lot to be honest (Int_5, 53 years, a).

Social factors

Participants regarded social support from family and friends as critical in every part of their life including diet and physical activity. Some discussed diet and activity issues with

their close family and friends but others did not. Role modelling by friends was seen as a motivation for keeping up a healthy lifestyle. They found participating in physical exercise groups helpful. Motivation from other family members facilitated both everyday physical activity and participation in more structured activities.

My children wanted to do it [a half-marathon]. They said, "Come on, you do it as well". So I said, "Fine, I will" (Int_1, 67 years, a & b & c).

Furthermore, family members encouraged participants to improve their diet quality by both providing them with healthy options and through verbal encouragement.

So, my sister, who looked after me, made me eat fruit for breakfast and healthy things (FG1_5, 60 years, a & b & c).

On the other hand, one participant perceived obesity-related social stigma as a barrier to engagement in healthy lifestyle activities.

People just assume that I eat loads of chocolate, I eat this, I do this and I do that. Or they'll go, 'Why is she in the gym? Why is she dancing like that with the size of her?' And there's part of me going, oh, maybe I can't go, because it's just that stereotypical thing (FG2_2, 33 years, a & b & c).

Needing to search for information

Received advice

These who underwent radiotherapy received dietary advice for bowel symptom management (e.g. fibre elimination) during treatment. None of the participants received unsolicited nutrition and physical activity advice from their health care professionals post-treatment. Participants prompted them for potential advice but many did not receive satisfactory advice. One professional encouraged one of the survivors to drink more green tea. Other professionals were not aware of existing local cancer survivors' groups or just advised survivors to eat healthier.

There was no support and no advice of what to do. Because I went into the menopause as well, so I was kind of like saying, well, what can I do for that? They were like: "Well, I don't know.

You can go to a health food shop." That is basically how they left me. So, I have had to kind of like research that myself (Int_6, 46 years, a).

Information sought

Most participants sought lifestyle information after their cancer diagnosis on the Internet. However, they found it difficult to disentangle and select trustworthy information, given the number of potential sources and their time constraints. Confusing information from

the media included advice on sugar, and dairy products. Cancer charities were regarded as helpful sources.

Unless you actually know where to look and what sites are reliable, it is just a mine of information, it puts all kinds of things in your mind, and you do not know which is the best advice to take. I went to the NHS website, because obviously that is generally a trustworthy site, but it did not really give me much information, it just really outlines the details of endometrial cancer. There was nothing to say where you could go for some support or anything like that (Int_2, 37 years, a).

I found more information on the Macmillan site than I had from anywhere else, I suppose (FG1_3, 55 years, a & c).

Some survivors sought information about healthy lifestyle from other sources, such as personal trainers, naturopaths, health food shops, and friends following raw diets.

And also I have a friend who trained recently as a nutritionist and she asked me to be her guinea pig (laughing). She is a naturopathic person. Anyway, their advice seemed to be extreme but it was virtually to eat no white, no refined carbohydrates (Int_3, 64 years, a & c).

Desired advice, timing, and methods of delivery

Participants also spoke about the advice they would like to have received. They would welcome advice regarding healthy lifestyle, recovery, and symptom management and were keen to participate in a lifestyle program tailored to their post-treatment effects. Others found it unnecessary to participate in such a lifestyle program, particularly if it was focused on diet, as they considered themselves to already have a healthy dietary pattern.

And I would have liked to have been invited or told about if there was such a thing [a lifestyle program], or even told to start one (FG1_5, 60 years, a & b & c).

[Advice about physical activity] How long, how many hours, how many minutes? What would be too much? How often a week? I do not know any of these (Int_5, 53 years, a).

They would prefer to receive healthy lifestyle advice immediately after treatment at their hospital discharge or in their early follow-up appointment. It was also mentioned that they would like to be introduced to a program at diagnosis or during treatment but would be keener to attend after they had finished their treatment.

It would be nice before you go out of the hospital if someone come around, sat down and say: "We have got this booklet, we think it

would be beneficial for you to make the changes" (Int_5, 53 years, a).

Participants were interested in receiving reliable information about healthy lifestyle from their health care professionals or being directed to appropriate services by them. They stressed interpersonal skills, such as patience as core competencies for the person advising them.

GP's probably the initial person that would be able to assess the situation, but I don't think it's necessarily a GP that needs to continue that support with you (FG2_2, 33 years, a & b & c).

Varied views on the preferred mode of delivery for healthy lifestyle advice were expressed. Most participants preferred modes that involved personal contact like group meetings or one-to-one sessions.

It would be a group. It is nice to meet, not to meet and chat necessarily, but to have, you know, other people in the same boat, if you like (Int_5, 53 years, a).

Yes. I think it needs to be a one-to-one, because if they give you a booklet or go on the website, it is so impersonal. If you have a one-to-one then at least you know that someone is concerned and they want to help. It is not so helpful if it is just a paper. I mean, even if

they've got it and they talk to you and then they give it to you, I think that would be the best thing (FG1_1, 57 years, a & b & c).

Geographical distance to such sessions was deemed a significant barrier for attendance. Preference for such a program to focus on well-being rather than cancer was also mentioned.

So I want it to be specific for me, but I do not want it to be about cancer, I just want it to be about going forward – this has happened to you, this is what you've got, maybe, so try this, because when you've got that, you can still do this, and very specific information (FG1_1, 57 years, a & b & c).

Others preferred web-based materials for convenience reasons, or exclusively selfhelp materials.

I would personally like to see it online, I would find that useful. You could just sift through and find what you want. If it was good and fairly detailed advice, I'd be quite happy to look up... it's when I want it (FG1_3, 55 years, a & c).

Discussion

In this study, endometrial cancer survivors perceived a healthy lifestyle to cover all aspects of well-being, including mental and physical health. Participants generally reported

trying to engage in healthy lifestyle behaviours as a means to improve their overall health and for some cancer-specific benefits. Despite this, less than 50% reported adherence to nutrition guidelines and only 12% met physical activity recommendations. Treatment effects were barriers to healthy lifestyle choices. Furthermore, social and practical factors also influenced diet and physical activity behaviours. Participants generally reported inadequate information provision and a need to search on their own for advice and support. Preferences for intervention delivery varied with advice delivered in-person and immediately post-treatment most favoured.

As with other cancer survivor groups (Anderson et al., 2013, Avery et al., 2014), participants valued healthy eating and physical activity for their overall health and well-being. However, these were only part of a broad meaning of healthy lifestyle, indicating the importance of other factors, like mental and sexual well-being. Regarding diet, evidence suggests that cancer survivors (Klassen et al., 2014) have diverse interpretations of healthy eating. In our study, awareness of the components of a healthy diet echoed the evidence (Katz and Meller, 2014), but was only partially reflected when reporting their actual diet, particularly because of low tolerance for high-fibre foods. Similar issues have been described by colorectal cancer survivors (Baravelli et al., 2009). Guidance on managing this side effect might be helpful.

Regarding physical activity, most preferred non-vigorous activities, consistent with previous studies (Hammer et al., 2014, Karvinen et al., 2006). Our results are in line with a review on correlates of physical activity in adults (Bauman et al., 2012), indicating that health status, self-efficacy, prior physical activity, motivation, social support, and action planning – among others – are positively associated with physical activity. These similarities with the general population can inform multi-level intervention development. Specifically, adaptations of existing effective interventions to survivors' particular needs, such as acknowledgement and management of late-treatment effects, may result in well-received and potentially effective interventions in this population.

The behavioural issues, needs, and challenges described above provide insight for the development of lifestyle interventions. The current findings sit well under the intervention planning stage of the person-based approach to intervention development (Yardley et al., 2015). The intervention planning stage of the framework focuses on identifying essential components for the intervention to create the guiding principles for its design. The results suggested that the most highly desirable in-person advice should be initiated by health professionals, delivered immediately post-treatment, and needs to be easy to access geographically. Education and training for health care professionals can decrease various barriers to provision of lifestyle advice, such as their belief that such advice will not affect cancer outcomes, their perception of lack of clear guidelines, and lack of time (Williams et

al., 2015). Local community centres and hospitals could be vital resources if blended with regular personalised contact with survivors. Given the geographical dispersion of cancer survivors, a combination of clinic- and home-based interventions may serve this purpose (Stull et al., 2007).

Additionally, some participants described successfully regulating their behaviour to maintain a healthy lifestyle after cancer treatment. Although research suggests some people experience self-monitoring as demanding and tedious (Burke et al., 2009), survivors found the self-monitoring techniques for diet and physical activity helpful; thus, informing the acceptability of potential interventions. Previous interventions in endometrial cancer survivors have effectively implemented these behaviour change techniques (von Gruenigen et al., 2012). Furthermore, a meta-regression of healthy eating and/or physical activity interventions showed that self-monitoring was the most effective technique for promoting behaviour change (Michie et al., 2009).

As part of the intervention development process, the results have informed the final program design for pilot testing. In the pilot intervention, health care professionals will introduce to eligible post-treatment survivors a group-based program. It will focus on the importance of healthy eating and physical activity for well-being and overall health, and encourage self-monitoring and behavioural goal setting. The intervention will include guidance on management of side effects, such as fatigue and bowel symptoms. It will also

acknowledge the importance of other aspects of lifestyle and provide relevant resources that survivors can refer to. Results will inform its acceptability and feasibility.

The study has both strengths and limitations. It is the first to describe the attitudes of endometrial cancer survivors towards their diet and physical activity in the UK. Being exploratory, large and robust population based surveys may elucidate the complexity of food choice and physical activity (Begg and Woods, 2013, Marteau et al., 2012). The study has a small but comparable sample size with other qualitative studies (Meraviglia and Stuifbergen, 2011). We believe data are saturated, as no new themes were emerging from the last interviews. Last-minute absences from the focus groups meant groups were small, but the decision was made to go ahead with these, for practical reasons and to avoid wasting the time of those who did attend, which could be considered unethical. Through the group interaction, focus groups allow the expression of the extent of participants' experiences and the generation of data and insights that may be undisclosed in interviews (Kingry et al., 1990). Although small, the size of the groups allowed for both group interaction and in-depth discussion, though this may have been greater in a larger group. The in-depth experiences were further reinforced from the Individual interviews. This allowed for a more comprehensive understanding of survivors' attitudes (Lambert and Loiselle, 2008). The convergence of participants' characteristics and main themes across the two qualitative methods strengthened the trustworthiness of the findings. However, timing of the

questionnaire before the qualitative discussions may have also primed them on the topic of interest. Despite the strong link between endometrial cancer and obesity (WCRF, 2007), we aimed to obtain the breadth of attitudes by including participants irrespective of body mass index. However, their high socio-economic status, together with their engagement with charities, technology, and research call for future research to confirm how transferable the results are in endometrial cancer survivors across the UK. On a positive note, the participation of non-white, non-British survivors adds to the data diversity. It would be reasonable to speculate that most participants took part as they were highly interested in diet and physical activity, given their positive attitudes towards healthy lifestyle. Furthermore, research participants tend to be healthier than the population from which they are sampled. Based on their shortcomings in optimally following the cancer prevention guidelines, and the possibility of social-desirability bias in answering the questionnaire, further research can elucidate if the awareness and health behaviour practices in survivors of more deprived socio-economic groups is similar.

Conclusion

In conclusion, health behaviour change interventions in this population need to be tailored to specific treatment effects, and consider cognitive, social, and practical barriers for adoption.

Health care professionals are in a vital position to provide or introduce endometrial cancer survivors to in-person interventions at the opportune early post-treatment period. Such

interventions	are needed w	ithin cance	r survivorship	care plans	to improve	survivors'
outcomes.						

References

- ADAMS, R. N., MOSHER, C. E., BLAIR, C. K., SNYDER, D. C., SLOANE, R. & DEMARK-WAHNEFRIED, W. 2014. Cancer survivors' uptake and adherence in diet and exercise intervention trials: An integrative data analysis. Cancer.
- ANDERSON, A. S., STEELE, R. & COYLE, J. 2013. Lifestyle issues for colorectal cancer survivors--perceived needs, beliefs and opportunities. Support Care Cancer, 21, 35-42.
- AVERY, K. N., DONOVAN, J. L., HORWOOD, J., NEAL, D. E., HAMDY, F. C., PARKER, C., WADE, J. & LANE, A. 2014. The importance of dietary change for men diagnosed with and at risk of prostate cancer: a multi-centre interview study with men, their partners and health professionals. BMC Fam Pract, 15, 81.
- BARAVELLI, C., KRISHNASAMY, M., PEZARO, C., SCHOFIELD, P., LOTFI-JAM, K., ROGERS, M., MILNE, D., ARANDA, S., KING, D., SHAW, B., GROGAN, S. & JEFFORD, M. 2009. The views of bowel cancer survivors and health care professionals regarding survivorship care plans and post treatment follow up. J Cancer Surviv, 3, 99-108.
- BAUMAN, A. E., REIS, R. S., SALLIS, J. F., WELLS, J. C., LOOS, R. J., MARTIN, B. W. & LANCET PHYSICAL ACTIVITY SERIES WORKING, G. 2012. Correlates of physical activity: why are some people physically active and others not? Lancet, 380, 258-71.
- BEGG, D. P. & WOODS, S. C. 2013. The endocrinology of food intake. Nat Rev Endocrinol, 9, 584-97.
- BRAUN, V. & CLARKE, V. 2006. Using thematic analysis in psychology. Qualit Res Psychol, 3, 77-101.
- BURKE, L. E., SWIGART, V., WARZISKI TURK, M., DERRO, N. & EWING, L. J. 2009. Experiences of self-monitoring: successes and struggles during treatment for weight loss. Qual Health Res, 19, 815-28.
- DEMARK-WAHNEFRIED, W., AZIZ, N. M., ROWLAND, J. H. & PINTO, B. M. 2005. Riding the crest of the teachable moment: promoting long-term health after the diagnosis of cancer. J Clin Oncol, 23, 5814-30.
- DH 2010. National Cancer Survivorship Initiative Vision. In: DEPARTMENT OF HEALTH, M. C. S. N. I. (ed.).
- HAMMER, S. M., BROWN, J. C., SEGAL, S., CHU, C. S. & SCHMITZ, K. H. 2014. Cancer-related impairments influence physical activity in uterine cancer survivors. Med Sci Sports Exerc, 46, 2195-201.

- JERNIGAN, A. M., TERGAS, A. I., SATIN, A. J. & FADER, A. N. 2013. Obesity management in gynecologic cancer survivors: provider practices and attitudes. Am J Obstet Gynecol, 208, 408 e1-8.
- KARVINEN, K. H., COURNEYA, K. S., CAMPBELL, K. L., PEARCEY, R. G., DUNDAS, G., CAPSTICK, V. & TONKIN, K. S. 2006. Exercise preferences of endometrial cancer survivors: a population-based study. Cancer Nurs, 29, 259-65.
- KATZ, D. L. & MELLER, S. 2014. Can we say what diet is best for health? Annu Rev Public Health, 35, 83-103.
- KIM, R. B., PHILLIPS, A., HERRICK, K., HELOU, M., RAFIE, C., ANSCHER, M. S., MIKKELSEN, R. B. & NING, Y. 2013. Physical activity and sedentary behavior of cancer survivors and non-cancer individuals: results from a national survey. PLoS One, 8, e57598.
- KINGRY, M. J., TIEDJE, L. B. & FRIEDMAN, L. L. 1990. Focus groups: a research technique for nursing. Nurs Res, 39, 124-5.
- KLASSEN, A. C., SMITH, K. C., BROSBE, M., COA, K. I., HANNUM, S. & CAULFIELD, L. E. 2014. What is a Healthful Diet? Cancer Survivors' Interpretations of Their Own Dietary Recall Data. 142nd Americal Public Health Association Annual Meeting and Exposition. New Orleans, LA.
- LAMBERT, S. D. & LOISELLE, C. G. 2008. Combining individual interviews and focus groups to enhance data richness. J Adv Nurs, 62, 228-37.
- LEACH, C. R., WEAVER, K. E., AZIZ, N. M., ALFANO, C. M., BELLIZZI, K. M., KENT, E. E., FORSYTHE, L. P. & ROWLAND, J. H. 2014. The complex health profile of long-term cancer survivors: prevalence and predictors of comorbid conditions. J Cancer Surviv.
- MARTEAU, T. M., HOLLANDS, G. J. & FLETCHER, P. C. 2012. Changing human behavior to prevent disease: the importance of targeting automatic processes. Science, 337, 1492-5.
- MEMON, A., BARBER, J., RUMSBY, E., PARKER, S., MOHEBATI, L., DE VISSER, R. O., VENABLES, S., FAIRHURST, A., LAWSON, K. & SUNDIN, J. 2016. What factors are important in smoking cessation and relapse in women from deprived communities? A qualitative study in Southeast England. Public Health, 134, 39-45.
- MERAVIGLIA, M. G. & STUIFBERGEN, A. 2011. Health-promoting behaviors of low-income cancer survivors. Clin Nurse Spec, 25, 118-24.
- MICHIE, S., ABRAHAM, C., WHITTINGTON, C., MCATEER, J. & GUPTA, S. 2009. Effective techniques in healthy eating and physical activity interventions: a meta-regression. Health Psychol, 28, 690-701.

- MILLIRON, B. J., VITOLINS, M. Z. & TOOZE, J. A. 2014. Usual dietary intake among female breast cancer survivors is not significantly different from women with no cancer history: results of the National Health and Nutrition Examination Survey, 2003-2006. J Acad Nutr Diet, 114, 932-7.
- MILTON, K., BULL, F. C. & BAUMAN, A. 2011. Reliability and validity testing of a single-item physical activity measure. Br J Sports Med, 45, 203-8.
- MORGAN, D. L. & KRUEGER, R. A. 1997. Focus group kit, SAGE Publications, Inc MORSE, J. M. 2000. Determining Sample Size. Qualitative Health Research, 10, 3-5.
- NICOLAIJE, K. A., HUSSON, O., EZENDAM, N. P., VOS, M. C., KRUITWAGEN, R. F., LYBEERT, M. L. & VAN DE POLL-FRANSE, L. V. 2012. Endometrial cancer survivors are unsatisfied with received information about diagnosis, treatment and follow-up: a study from the population-based PROFILES registry. Patient Educ Couns, 88, 427-35.
- REES, C. E., FORD, J. E. & SHEARD, C. E. 2003. Patient information leaflets for prostate cancer: which leaflets should healthcare professionals recommend? Patient Educ Couns, 49, 263-72.
- STULL, V. B., SNYDER, D. C. & DEMARK-WAHNEFRIED, W. 2007. Lifestyle interventions in cancer survivors: designing programs that meet the needs of this vulnerable and growing population. J Nutr, 137, 243S-248S.
- TAYLOR, B. 2005. The experiences of overseas nurses working in the NHS: results of a qualitative study. Diversity in Health & Social Care, 2.
- TONG, A., SAINSBURY, P. & CRAIG, J. 2007. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care, 19, 349-57.
- VON GRUENIGEN, V., FRASURE, H., KAVANAGH, M. B., JANATA, J., WAGGONER, S., ROSE, P., LERNER, E. & COURNEYA, K. S. 2012. Survivors of uterine cancer empowered by exercise and healthy diet (SUCCEED): a randomized controlled trial. Gynecol Oncol, 125, 699-704.
- WCRF 2007. Food, Nutrition, Physical Activity and the Prevention of Cancer: A Global Perspective. Washington, DC: World Cancer Research Fund / American Institute for Cancer Research.
- WEAVER, K. E., FORAKER, R. E., ALFANO, C. M., ROWLAND, J. H., ARORA, N. K., BELLIZZI, K. M., HAMILTON, A. S., OAKLEY-GIRVAN, I., KEEL, G. & AZIZ, N. M. 2013. Cardiovascular risk factors among long-term survivors of breast, prostate, colorectal, and gynecologic cancers: a gap in survivorship care? J Cancer Surviv, 7, 253-61.

- WILLIAMS, K., BEEKEN, R. J., FISHER, A. & WARDLE, J. 2015. Health professionals' provision of lifestyle advice in the oncology context in the United Kingdom. Eur J Cancer Care (Engl), 24, 522-30.
- WILLIAMS, K., BEEKEN, R. J. & WARDLE, J. 2013a. Health behaviour advice to cancer patients: the perspective of social network members. Br J Cancer, 108, 831-5.
- WILLIAMS, K., STEPTOE, A. & WARDLE, J. 2013b. Is a cancer diagnosis a trigger for health behaviour change? Findings from a prospective, population-based study. Br J Cancer, 108, 2407-12.
- YARDLEY, L., MORRISON, L., BRADBURY, K. & MULLER, I. 2015. The person-based approach to intervention development: application to digital health-related behavior change interventions. J Med Internet Res, 17, e30.

Figure legend

Figure 1: Participant flow diagram

Tables

Table 1: Discussion protocol

Table 2: Socio-demographic and treatment characteristics

Table 3: Lifestyle characteristics

Supplementary files

Supplementary file 1: Coding tree, docx

Supplementary file 2: COREQ Checklist, docx

Acknowledgements

This work was supported by the University College London (UCL) Grand Challenges

Scheme, the St. Bartholomew's Hospital Nurses League, the Department of Women's

Cancer at the UCL EGA Institute for Women's Health, and the NIHR Biomedical Research

Centre at UCL Hospitals, London, United Kingdom. The funders had no role in the study

design, the collection or analysis of data; or the preparation, review, or approval of the

manuscript.

Conflict of interest

None declared