





BMJ Open 'You're kind of left to your own devices': a qualitative focus group study of patients with breast, prostate or blood cancer at a hospital in the South West of England, exploring their engagement with exercise and physical activity during cancer treatment and in the months following standard care

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ABSTRACT

Objectives The aim of this study was to explore the experiences of patients with breast, prostate or blood cancer, regarding their (1) engagement with exercise and physical activity during treatment and in the months following standard care, and (2) the meanings attached to these lifestyle behaviours.

Design A qualitative study using focus groups. The groups were audio recorded, transcribed and analysed using Framework analysis.

Setting A hospital-based cancer treatment centre in the South-West of England.

Participants Eighteen people who had either completed treatment or were currently on maintenance therapy for breast, prostate or blood cancer (non-Hodgkin lymphoma or Hodgkin lymphoma).

Results Participants reported treatment limiting their ability to engage in exercise and physical activity. However, participants were aware of the physiological, emotional and social benefits of exercise and expressed a desire to maintain a physically active lifestyle before, during and after treatment. They noted a lack of concrete guidance and appropriate exercise classes for people with cancer and felt poorly informed about the type, intensity, duration and frequency of exercise they should be undertaking. As such, participants reported making decisions on their own, relying on their intuition and listening to their bodies to gauge whether they were doing enough exercise (or not).

Conclusions Participants were aware of the benefits of a physically active lifestyle during and following cancer treatment, but were not familiar with exercise and physical activity guidelines for people living with and beyond cancer. There is a need for healthcare professionals, academics and policy makers to determine how exercise and physical activity can be supported in clinical settings

Strengths and limitations of this study

- This is a novel qualitative study exploring 'real life' issues experienced by people diagnosed with breast, prostate or blood cancer in engaging with exercise and physical activity before, during and after treatment.
- Data were rigorously analysed by researchers using Framework analysis.
- Participants were recruited from a single hospital site in a specific geographical location.
- There is a risk of sample selection bias because those who opted into the study were likely to be more interested in the topic and motivated to engage in physical activity.

in realistic and meaningful ways accommodating individual patient circumstances.

INTRODUCTION

Worldwide, around 17 million people are diagnosed with cancer each year,¹ with approximately 367 000 new cases in the UK.² Breast, prostate and blood cancers are three commonly diagnosed cancers in the UK, collectively accounting for around one-third of all new cases, 15%, 13% and 6%, respectively.³ Standard care for each form of cancer varies, impacting patients differently, and many people treated for cancer experience poor physical function, psychological distress and reduced quality of

life.^{4,5} Evidence shows that exercise and physical activity (Physical activity refers to any form of bodily movement involving skeletal muscle contraction that results in energy expenditure. Examples of common types of physical activity are: walking, running, dancing, swimming, yoga, and gardening. Exercise is a sub-category of physical activity that is planned, structured, repetitive and purposeful)) is safe following a cancer diagnosis—and at any stage of disease or treatment—and generates many benefits.⁶ Regular exercise and physical activity improve fatigue, depression, anxiety, self-esteem and quality of life and can reduce the risk of recurrence and improve cancer survival.^{7,8}

National and international guidelines recommend that people at any stage of the cancer survivorship continuum engage in regular exercise and/or physical activity.^{8–15} Most recommendations align with those for healthy adults, such as undertaking 150 min of moderate-intensity (or 75 min of vigorous intensities) exercise or physical activity each week combined with resistance exercise using major muscle groups, two times weekly. Recent guidelines from the American College of Sports Medicine advocate more specific structured exercise prescriptions. Overall, the minimum effective ‘dose’ for cancer survivors is 30 min of moderate-intensity aerobic exercise at least 3 days each week for at least 8–12 weeks, combined with resistance exercise on at least 2 days each week. The UK’s Recovery Care Package offers a holistic self-management regimen for people with cancer that comprises physical activity and healthy lifestyle advice.^{16,17}

It is well documented that patients tend to become inactive after a cancer diagnosis¹⁸ and have difficulties engaging in exercise or physical activity after treatment.^{19,20} In the UK, one-third of cancer survivors have reported being physically inactive,²¹ and less than 25% of cancer survivors met physical activity recommendations.²² The challenges faced by patients and the reasons for limited engagement in exercise or physical activity are not well defined. Improving this understanding is critical for producing evidence-based recommendations for supporting an active lifestyle. Meta-analyses of qualitative studies involving patients with breast cancer²³ and prostate cancer²⁴ have identified perceived barriers and facilitators of physical activity during and after treatment. Barriers include fatigue, pain, time or work and caring commitments²³ and incontinence among men with prostate cancer.²⁴ By contrast, well-coordinated cancer teams, social/peer support, tailored coaching and perceived improvements in emotional well-being and self-esteem are commonly reported enablers.^{23,24}

To date, research has predominately focused on common cancers such as breast and prostate cancer. Few studies report on other tumour groups, including blood cancers such as lymphoma. Compared with patients with breast and prostate cancer, patients with lymphoma have different standard care, undergoing an intense treatment schedule, which can comprise periods as an inpatient in isolation.^{25–27} Few qualitative studies differentiate between

tumour groups and the treatment intent (ie, curative or palliative).

This study sought to gain insight into the experience patients have with exercise and physical activity within the complexity of their everyday life. Importantly, our study was outside a research intervention setting in which participants might have the opportunity to participate in an exercise programme and the immediate benefits of social support from peers and healthcare professionals. Exploring ‘real life’ issues affecting engagement with an active lifestyle could inform the design and implementation of future theory-based interventions to promote exercise or physical activity among patients undergoing treatment and beyond.

METHODS

Design

We conducted a qualitative focus group study to understand how people treated for different types of cancer (breast, prostate or blood cancers) engaged with exercise and physical activity since diagnosis. Focus groups gave participants the opportunity to hear each other’s experiences and clarify their viewpoints, particularly if others had contrasting experiences. This study employed a social constructivist approach and the theoretical framework of interactionism, which recognises how individuals make meaning of their experiences through social interactions.²⁸

Participants

Eligible participants (outpatients aged 18 years and over who had been treated for a recurrence or metastasis of breast cancer, prostate cancer, non-Hodgkin lymphoma or Hodgkin lymphoma) were invited to take part. Potential participants who were deemed physically and psychologically able to participate by their oncologist or haematologist received a verbal explanation of the study at a consultation or cancer support meeting. Participants were receiving treatment or regularly attending follow-up appointments and were provided with an information sheet and telephoned by a member of the research team. Written informed consent was obtained.

Patient and public involvement

No patients involved.

Focus groups

Four focus groups were conducted between February and July 2018 at a UK hospital facilitated by the authors with expertise in qualitative research (GW) and exercise physiology (FFB and JET).²⁹ They involved women and men only in the breast cancer and prostate cancer groups, respectively; and a mix of men and women in blood cancer groups. We are mindful of how our academic backgrounds and family histories of cancer may have shaped data collection and analysis. We engaged in team reflexivity to better understand our perspectives.

Box 1 Topic guide—questions for discussion (Although the topic guide was intended to stimulate conversation about lifestyle in general, almost all statements made by participants focused on exercise and physical activity)

- ▶ How has your lifestyle changed since being treated for cancer in relation to physical activity, diet, smoking and drinking alcohol?
- ▶ Given your recent experience of illness, do you feel differently about engaging with these lifestyle behaviours?
- ▶ If/when you do manage to make 'healthy' lifestyle adjustments, do you feel differently about yourself and your diagnosis?

Authors collecting and analysing data did not have clinical involvement with participants. A topic guide explored participants' physical activity engagement since diagnosis (box 1). Groups were digitally recorded, transcribed verbatim and anonymised with pseudonyms.

Analysis

Data were analysed using a five-step process of framework analysis, a matrix-based method of analysis.³⁰ It enables issues to be considered inductively and deductively, while maintaining flexibility for data saturation. In step 1, *familiarisation*, SKS read the transcripts to identify themes. In step 2, *developing a thematic framework*, SKS developed an initial coding framework and refined it with GW and JET. In step 3, *indexing*, SKS and GW separately coded the transcripts. Discrepancies in coding were discussed and a final framework was developed. In step 4, *charting*, SKS summarised the data using the final coding framework within a set of charts. Each participant (case) was assigned a row in the matrix, and each subtheme a separate column. Data were summarised and quotes were extracted. In step 5, *mapping and interpretation*, SKS, GW and JET identified patterns in the data. The analysis compared and contrasted responses in terms of sex, diagnosis (and treatment type), treatment intent (curative or palliative), grade of lymphoma (high vs low).

RESULTS

Sample characteristics

A total of 18 participants took part (table 1). Most were women (n=11) and aged between 32–80 years (mean age: 60.5). Four participants were being treated for breast cancer, five prostate cancer, eight non-Hodgkin's lymphoma (five high-grade, three low-grade) and one for Hodgkin lymphoma.

Themes

Five themes were generated and conceptualised using statements made during the groups, presented in headings below.

'Treatment knocks you for six'

Across the groups, participants talked about the profound impact treatment had on their capacity to engage in exercise or physical activity. Fatigue was the most talked about

Table 1 Sample characteristics (n=18)

Variable	N
Age (mean, range)	60.5 years (32–80)
Age at diagnosis (mean, range)	55.7 years (30–79)
Sex	
Female	11
Male	7
Ethnicity	
White	18
Diagnosis	
Prostate cancer	5
Non-Hodgkin lymphoma (low grade)	5
Non-Hodgkin lymphoma (high grade)	3
Breast cancer	4
Hodgkin lymphoma	1
Treatment phase	
Active monitoring*	14
Treatment†	4
Treatment received‡	
Antibody therapy	11
Chemotherapy	10
Radiotherapy	5
Surgery	3
Follow-up appointments only	1
Treatment intent	
Curative	12
Palliative >12 months expected survival	6

*Active monitoring: not receiving treatment but regularly attending follow-up appointments.

†Treatment: currently receiving treatment.

‡12 participants were receiving (or had received) more than one treatment.

symptom of disease/treatment and was reported to make any kind of physical activity unmanageable.

After the treatment obviously that [exercise] dropped off down a cliff edge. I just couldn't do it whatsoever after a couple of weeks of treatment. I was quite lethargic; everything was hard to do (Kevin, prostate cancer).

I feel like I'm dying because I've got no energy left. For me, even eating a meal absorbs all my energy (Claire, breast cancer).

Most participants felt that their physical activity behaviours changed dramatically since treatment, and they were unable to engage in the same activities as before diagnosis.

Physical activity has been a major burden from me. I used to go to the gym and go out for four miles walks. I can't do any of that (Trevor, prostate cancer).

The debilitating nature of fatigue seemed to disrupt the physical activities that participants were able to engage in. This meant they had to renegotiate how they engaged

in exercise and physical activity within their new physical capabilities and incorporate illness and pain within their self-identity. Participants described swapping more strenuous, structured exercise—such as gym sessions—for incidental, lower intensity activities, such as walking, cycling, yoga at home, gardening and looking after grandchildren.

Achy joints and muscle wasting due to chemotherapy were reported as other consequences of treatment impacting their ability to be active. Some participants described how resuming exercise after treatment had been compounded by comorbid health conditions, including back pain, and in one case, multiple sclerosis.

Many talked about the physical and psychosocial benefits of being active, with some appearing to have a heightened awareness of the benefits. This awareness prompted them to change their mind set and prioritise exercise.

I actually increased my physical activity beforehand, so I made sure I actually upped my activity beforehand. I went into treatment feeling on top of the world (Kevin, prostate cancer).

'You're kind of left to your own devices'

Most participants described receiving very little or no advice on exercise and physical activity from healthcare professionals before, during or after their treatment. Some participants mentioned initiating discussions about an active lifestyle during consultations, and having to make decisions about exercise and physical activity on their own, independent of clinical care.

I used to bring that up all the time [exercise], with [consultant]. Every week I brought it up. You are kind of just left to guide your way through your own recovery (Claire, breast cancer).

Several participants perceived a lack of information about exercise and physical activity for people with cancer and described limited access to services (eg, physiotherapy, nutrition). Participants felt poorly informed about how much and what types of physical activity they should be doing, and whether it was safe.

You don't get much help or support with what physical activity or diet we should have after cancer. I think it's very hard to see a nutritionist within the NHS, there's not any kind of exercise prescription for cancer patients. There's not much protocol or guidelines for cancer patients, so you're kind of left to your own devices (Lena, Non-Hodgkin Lymphoma, low grade).

Participants wanted more advice about lifestyle, but acknowledged the difficulties faced by healthcare professionals over providing advice, due to heterogeneity of disease/treatment and how a 'one size fits all' approach was unrealistic.

Facilitator: Do you think there was enough information from the doctors [about exercise]?

Trevor: I don't think there was, but I do accept that when you start interfering with hormone imbalance and a very complex mechanism that is your body, and varies between one person to another, so you can't go by the book. (Trevor, prostate cancer).

Participants discussed the importance of 'listening to your body' and pacing themselves to prevent overexertion or exacerbating fatigue. In the absence of guidelines and advice, participants recognised their awareness of, and ability to interpret bodily sensations enabled them to engage in exercise in a way they considered safe and appropriate. Listening to their bodies in this way appeared to be part of a process through which participants regained trust in their bodies after diagnosis.

I'll do what I want to do and if it catches up with me, I have to rest, that's what I do. I try to pace as best I can (Cornelia, non-Hodgkin lymphoma, low grade).

A few participants mentioned using step counts with smart watches or activity trackers as a tangible way to monitor progress.

I'm doing the 10,000 Steps every day in March for Cancer Research UK (Stephanie, breast cancer).

(Although some participants were aware of the common goal of achieving 10,000 steps per day, others were not, as indicated by this statement) steps every week (Robert, Hodgkin lymphoma).

You kind of say where are you going to up your 1000

'There's not many groups or activities just for cancer patients'

Several participants with blood or breast cancer described feeling self-conscious of changes in their appearance (eg, hair loss, body shape). Changes in their outward appearance affected their sense of identity and they were fearful of judgement from others. For example, a female participant with blood cancer shared her concerns about exercising while wearing a wig and how vigorous exercise classes were not suitable.

And when you're in a gym, and people on the machines doing them and you're plugging away. I felt so silly (Lorraine, Non-Hodgkin Lymphoma, low grade).

There's not many [exercise] options. They don't give you many because sometimes if you lost your hair and you're feeling uncomfortable with your body. You don't want to go to classes to be infected by people because treatment has changed your appearance, you might feel self-conscious about your body (Stephanie, breast cancer).

Engaging in exercise or physical activity seemed to be a negotiation of risk for some participants living with blood cancer; weighing up the potential benefits and risks of engaging in physical activity with a weakened immune system. For example, some were cognisant of the risk of developing infections in swimming pools and gyms.

Because it's a game you play, the risk during your treatment cycle. Do I do this, because I might get an infection and

then I'll be in hospital to deal with it (Robert, Hodgkin lymphoma).

One participant also expressed frustration at having a Hickman line inserted for treatment as it restricted her ability to exercise.

I've always been a swimmer. I swim five times a week. And when you've a got PICC line, a Hickman line, you can't do these things (Cornelia, Non-Hodgkin Lymphoma, low grade).

Participants expressed the need for more tailored exercise, with instructors who understood their capabilities and the opportunity to meet others in a similar situation.

If you had someone that was able to put on an exercise group that understood the kind of things to these people would be going through. They could definitely tailor it a lot differently to the type of exercise groups that is normally run, which is just hell for leather (Robert, Hodgkin lymphoma).

'The exercise I'm doing, I'm watching it change my body and I feel stronger and more confident with it'

Participants perceived exercise as beneficial for health, but in different ways along the cancer journey. Some participants with breast or prostate cancer considered exercise as a way of *preparing for treatment or surgery* and emphasised the importance of building strength. Some had tried new forms of exercise to prepare for treatment.

I thought I need to start doing more before I get into this because any treatment you want to go into as fit as you possibly can. In those months waiting, I actually put up more activity. I went into treatment feeling on top of the world (Kevin, prostate cancer).

And, again when I got the diagnosis, I decided to do the breast reconstruction. Ten hour op, I've got to get fit for that (Andrea, breast cancer).

Some viewed exercise as *complementing treatment*, although struggled to keep active during treatment. One participant with blood cancer expressed her regret that she had not persevered.

I would always say to people to try and keep that physical activity if you can up while you're having the treatment. It made a huge impact to my life afterwards. So, if I was starting again now, I would do things totally differently (Lorraine, Non-Hodgkin Lymphoma, low grade).

Although most participants discussed their limited capacity to remain active, they were motivated to be active to *support and manage their recovery*. A few participants with breast cancer perceived physical activity as *lowering the risk of cancer recurrence*. One participant expressed her shock when her cancer came back despite doing exercise. However, not all participants viewed exercise as beneficial. One participant receiving palliative treatment, perceived *exercise as futile* when her prognosis was poor.

I did join the gym, I just don't want to go there. It's at a stage of thinking, what's the point, because I'm dying (Claire, breast cancer).

'This is me going back to what I want to be living'

Physical activity seemed to play a part in helping participants renegotiate their sense of sense and re-establish normalcy in their lives after disruption by cancer. Engaging in exercise or physical activity represented a way for participants to return to their 'normal' selves, although for some this meant a 'new normal'. Being physically active seemed to provide a benchmark for recovery and a tangible way to gauge progress.

I do feel like I've achieved something getting myself back to a more normal piece again (Robert, Hodgkin lymphoma).

Participants often compared their physical capabilities before and after diagnosis and set themselves goals over a fixed period. Others emphasised the importance of being physically active over a long period (eg, 5 years) to prevent cancer from returning. It provided a sense of control over their illness and their bodies, which they felt had been taken away. Some participants expressed their frustration if they were unable to reach their goals.

I just had to make five years. I'll do the gym, I'll do the exercise and after five years life's going to be great again. (Claire, breast cancer)

It's really difficult as well cos I'm six months post and so I'm still a long way off reaching my normality again (Robert, Hodgkin lymphoma).

Female participants spoke about reclaiming their bodies after treatment and increasing their self-worth. Being diagnosed with cancer made participants aware of the fragility of life and how important it was to not take life for granted and to 'seize life' with a sense of purpose.

Seizing life. Feeling more positive about what time I've got, whether that is going to be curtailed—I'm really open to, if I get a future diagnosis—I know that that's very possible (Stephanie, breast cancer).

DISCUSSION

This study showed that most participants were aware of the benefits of exercise and physical activity and expressed a desire to lead an active lifestyle. However, opportunities to be active were often constrained by physical limitations, particularly fatigue. Participants noted a lack of professional guidance or appropriate exercise classes for people with cancer, and felt poorly informed about the type, intensity, duration and frequency of exercise or physical activity they should undertake. Participants reported relying on their own intuition and listening to their bodies to identify whether they were doing enough or not.



The notion of ‘listening to your body’ has been observed in other health contexts, where individuals use this approach to take responsibility for their health, guided by bodily messages.^{31–33} The idea of listening to your body is used by some people as an alternative to relying on scientific or medical advice. The current study suggests that participants used this approach to gauge whether they were engaging in exercise appropriately, in the absence of guidance. Additionally, people often describe feeling let down and betrayed by their body after a cancer diagnosis.^{34 35} Listening to your body could represent a way in which people reclaim trust between their sense of self and their body.

Consistent with previous research, the overpowering nature of fatigue influenced participants’ ability to be active irrespective of their cancer type. This is not surprising given that up to 90% of patients report fatigue and around one-third of cancer survivors continue to experience fatigue after treatment.³⁶ Although exercise and physical activity have the potential to mitigate the effects of fatigue,⁸ participants did not explicitly talk about this. Patient information could be provided about the role of exercise and physical activity for managing fatigue.^{37 38} Previous work suggests that patients suffering from fatigue can engage in physical activity with support from healthcare professionals.³⁷

Participants aspired to be physically active to improve their physical functioning and quality of life. This finding aligns with a growing movement, ‘Exercise is Medicine’, a global initiative emphasising that an active lifestyle is integral to the prevention, treatment and management of chronic conditions.³⁹ In cancer, this movement has gained momentum with individualised exercise prescription.^{8 40} Our data also indicate that the ‘exercise is restitution’ discourse influenced participants, motivating them to engage in exercise with the hope of returning to a precancer life.⁴¹ Cancer survivors’ motivations to engage in exercise are often driven by a desire to recreate a sense of structure, control and normality⁴² and through fears that the cancer may return.⁴³

Our study highlights the role of exercise and physical activity in preparing for treatment, known as prehabilitation.^{44 45} Prehabilitation is a strategy, whereby the rehabilitation process starts before cancer treatment or surgery—but after diagnosis—with a focus on improving physical and psychological well-being.^{46 47} Although there are UK campaigns promoting prehabilitation for people with cancer,⁴⁴ participants did not refer to these. This suggests more needs to be done to increase the reach of these campaigns.

Several limitations are noted. Participants were recruited from a single hospital site in a specific geographical location. There is risk of selection bias with those opting into the study more likely to be more interested in the topic. No data were collected on socioeconomic status and the sample included only participants who identified ethnically as white. Our sample limits the transferability of findings to different socioeconomic and ethnic groups.

Given the large differences in physical activity or inactivity between socioeconomic and ethnic groups in non-clinical settings,^{48–50} future research is needed among lower socioeconomic and ethnic minority populations undergoing cancer treatment.^{51 52}

Implications for practice

This study has implications for how exercise and physical activity can be incorporated into routine cancer care. In line with previous studies, participants wanted information, but felt they had to initiate discussion.^{53 54} Consultations present a window of opportunity for healthcare professionals to make the most of the ‘teachable moment’ and inspire patients to be more active.^{37 55} A UK survey showed 51% of healthcare professionals involved in cancer care (oncologists, specialist cancer nurses, surgeons, GPs and allied health professionals) were unaware of physical activity guidelines.⁵⁶ There is debate over which member of the cancer care team is best placed to promote exercise and physical activity. Previous work identified oncologists, specialist cancer nurses and GPs as playing a key role.^{57–59} However, it is unrealistic to expect *any* healthcare professional to discuss exercise and physical activity if they do not feel fully informed,⁶⁰ and when—understandably—discussing clinical matters must be prioritised. Other barriers include concerns about patients’ capabilities and fear of jeopardising their relationship with the patient.^{53 56 59–61}

Despite the increasing number of community and national cancer exercise and physical activity initiatives (eg, Macmillan’s Move More programme),^{62 63} participants did not mention them. Wider dissemination of resources is needed.^{60 64–66} More focus is needed to help patients understand the role of exercise and physical activity in cancer care and to empower them to make informed decisions about their lifestyle. Motivational interviewing—a technique designed to encourage individuals to identify personally important goals and actions to gain confidence in changing their behaviour, through reflective listening and discussion—has shown to be effective in increasing physical activity among people living with cancer.⁶⁷ However, care must be taken to avoid feelings of blame or guilt among patients over their current or past lifestyle.⁶⁸ Another approach—that might be considered ‘best practice’, which has been adopted in Australia—is referral (if appropriate and desired) to an accredited exercise physiologist or physiotherapist with experience in cancer care and exercise.^{69 70}

In the present study, participants acknowledged the complexities faced by healthcare professionals when providing advice on exercise and physical activity and how a ‘one size fits all’ approach is unrealistic.^{15 59 71 72} Our work reinforces the idea that exercise and physical activity might not be appropriate for, or desired by, all patients at all times. As Williams *et al*⁴¹ assert, ‘exercise is mostly good and good for most; but not always and not for all’ (p.452).⁴¹ There is a need for academics and healthcare professionals to reflect on how exercise and

physical activity is encouraged within cancer care.⁴¹ Even if becoming more active is desirable, our work emphasises that individual concerns may be diverse and multifaceted. For example, some participants with blood cancer expressed concerns about exercising in swimming pools and gyms due to increased risk of infections. For others, psychosocial issues, such as body image, were a primary concern, when exercising in front of others. Equally, it is important to be cognisant of the practical difficulties patients may face when juggling exercise with work and home life commitments.^{15 59} Messages such as ‘something is better than nothing’ or ‘being as active as current abilities allow’ might be more realistic and meaningful.

Conclusions

Our findings suggest that people with different types of cancer want exercise and physical activity advice from healthcare professionals during cancer care but currently, many do not have these conversations. Academics and healthcare professionals need to reflect on how exercise and physical activity can be encouraged within cancer care, using conversations and recommendations that are tailored sensitively according to individual circumstances of patients.

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