

Factors influencing people's ability to maintain their activity levels during treatment for soft tissue sarcoma – a qualitative study

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ABSTRACT

Soft tissue sarcoma is a rare connective tissue cancer treated with chemotherapy in the advanced stages. Emerging evidence suggests that physical activity improves symptom management and quality of life for people undergoing chemotherapy for advanced cancer. However, little research reports their perspective. Semi-structured interviews were used within a phenomenological approach to explore factors that affect people's ability to be physically active while undergoing treatment. Six participants were recruited with purposive sampling. Thematic analysis was used to analyse the data. Three themes identified that physical activity was seen as an indicator of a persons' own sense of normality; a feeling of loss and uncertainty for the future had impacts on peoples' ability to be physically active, finally, participants found it challenging to recognise their support needs as their activity levels reduced. Motivation to remain active was individual and numerous barriers affected participants' ability to remain active as their disease advanced, this included a lack of specific guidance whilst undergoing chemotherapy. Participants expressed uncertainty generally in identifying and expressing their support needs as they faced multiple complex issues. Health professionals should be proactive exploring possibilities for physical activity to mitigate the expected physical decline and support symptom management while undergoing palliative chemotherapy.

Key Words: soft tissue sarcoma, physical activity, chemotherapy

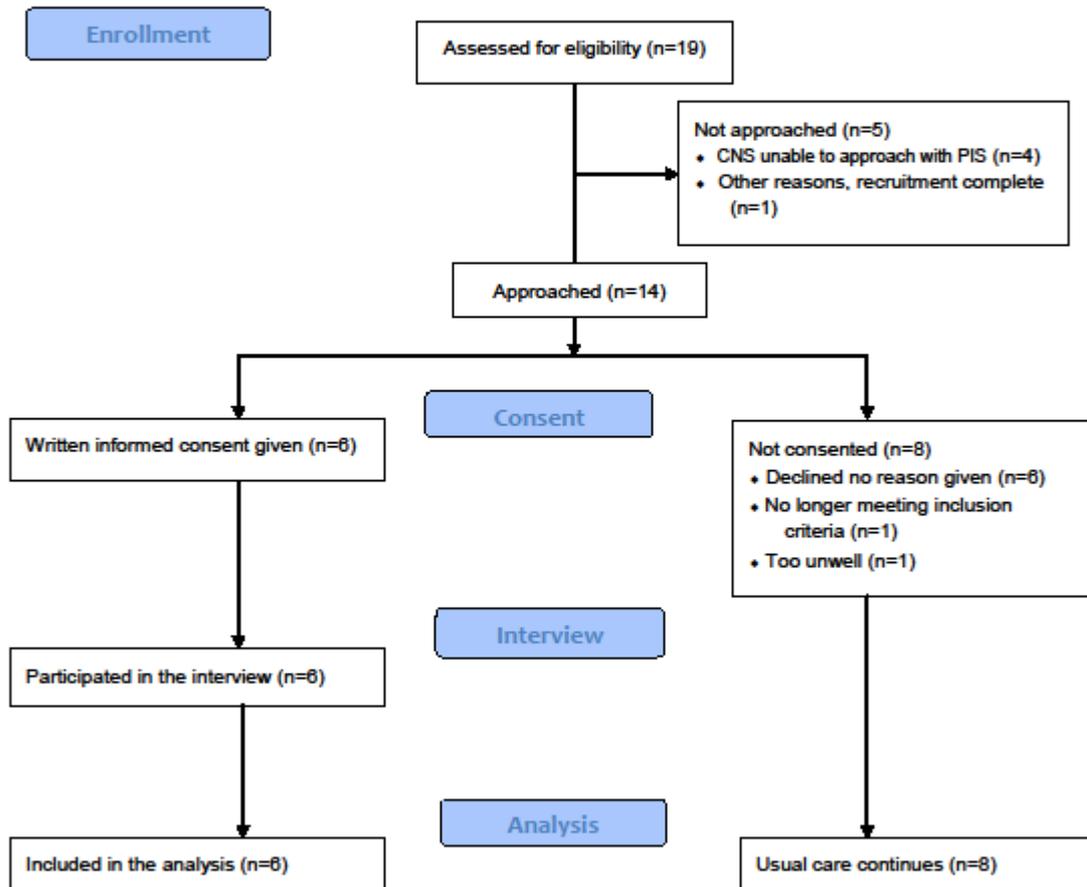
INTRODUCTION

Sarcoma is a collective term for malignancies affecting connective tissue (Kwong, Furtado, and Gerrand, 2014) and there are two broad sub types: soft tissue and bone. With just 3,272 new cases diagnosed in the UK in 2010 (CRUK, 2017), lack of knowledge about soft tissue sarcoma (STS) in the wider population means that diagnosis is often delayed and the disease can be widespread before treatment starts (Schreiber et al, 2006). This has an adverse effect on survival rates (Tobias and Gillis, 2014), with only 45% of people diagnosed in England expected to survive STS for 10 or more years (CRUK, 2017). At the point of diagnosis many people with STS have incurable disease and their only treatment option is chemotherapy with palliative intent, aimed at reducing symptoms and prolonging life (Tobias and Gillis, 2014).

People are often debilitated both from the disease process itself and from the side effects of treatments which may be on-going for the duration of their survival. The symptom burden includes fatigue, weight gain, muscle loss, peripheral neuropathy and cardio-toxicity, as well as functional impairments and pain depending on where the STS is sited (Granda-Cameron, Hanlon, Lynch, and Houldin, 2011). There is a need for rehabilitation and supportive care interventions to help minimise the impact the disease and the treatment side effects have on quality of life and societal participation (NHS England, 2016). All-cause mortality in cancer survivors tends to decrease with increasing amounts of exercise (Lemanne, Cassileth, and Gubili, 2013). Emerging evidence shows that physical activity (PA) is well received, safe and beneficial, helping to improve quality of life, physical performance and minimise the side effects of people treated for advanced cancer (Cheville et al, 2013; Heywood, McCarthy, and Skinner, 2018; Millbury et al, 2015; Quist et al, 2006; Quist et al, 2012;) . Furthermore, Jones et

al (2012) reported functional capacity to be an independent predictor of survival ($p=0.003$) in people with advanced lung cancer with a 13% risk reduction of death associated with each 50m incremental increase in six meter walking test distance achieved. Exercising whilst receiving chemotherapy treatment has recently been shown to help preserve skeletal muscle (Mijwel et al, 2018). There is strong evidence now that increased levels of muscle function and functional exercise capacity are associated with positive disease mediation, however, optimal dosing is as yet unclarified and the research focus is now on factors such as disease specific type, quantity and intensity of exercise prescription (Jones et al, 2012).

Figure 1 CONSORT 2010 Flow Diagram



Despite this, the amount of physical activity people undertake declines as soon as people are diagnosed with cancer, even when people were very active prior to their diagnosis (Blanchard et al, 2003; Irwin et al, 2003). Barriers to remaining active have been identified in people with advanced lung cancer by Cheville et al. (2017) but similar research has not been undertaken with STS. Many people with cancer have rehabilitation needs (Holm et al, 2012), however the diverse range of presentations and the relatively small numbers means there is very little research into STS and any aspect of rehabilitation. In addition, the patient experience regarding physical activity and support needs has not been captured. As a result, supportive interventions for people with STS are currently informed by research based on commoner cancers such as breast and prostate so may not be meeting their specific needs.

The aim of this research was to explore factors which might influence the physical activity people with a STS undertake as they receive palliative chemotherapy, based on their own perspective.

The study was guided by four objectives: 1) Investigate how people with a STS feel their physical activity levels are affected during chemotherapy treatment; 2) Explore factors which might prevent people with a STS from maintaining their usual levels of physical activity during chemotherapy treatment; 3) Discover whether people with a STS are aware of the benefits of remaining physically active during chemotherapy treatment; and 4) Identify any means of support this group of patients would find beneficial in supporting their physical activity goals during chemotherapy treatment

METHOD

Design, Theoretical Framework and Ethics

In order to understand the lived experience of people going through treatment we used an inductive constructionist approach from the phenomenological paradigm. Semi-structured interviews were completed using a topic guide to address the objectives. The study is reported according to COREQ guidance (Tong, Sainsbury, and Craig, 2007). (Blinded) Ethical approvals were received from Scottish Borders REC 14/NS/1016 before data collection started.

Sample Size and Recruitment

Eligible participants were identified from outpatient clinic lists at the oncology centre and were purposively sampled according to the eligibility criteria (Table 1.). A pragmatic approach to sampling was adopted regardless of previous levels of physical activity or co-morbidities to reflect a clinical population. The sample size was pre-selected as six in order to work within available resources for the project at its initiation, and in recognition of the specialist nature of the population (Malterud K, Siersma VD, and Guassora AD, 2016; Varpio et al, 2017).

During recruitment, potential participants were given an information sheet by the Sarcoma Clinical Nurse Specialists when they attended an outpatient appointment. If people gave verbal consent the primary researcher made telephone contact to answer any questions and arrange an interview date to coincide with their second cycle of chemotherapy. For participants' convenience the interviews were completed on a day when they were attending the hospital. Informed, written consent was sought immediately prior to the interview. Participants were free to withdraw consent at any time throughout the study.

Data Collection and Setting

Six face to face interviews were undertaken by SD or RT, lasting between 24 and 54 minutes. The study was conducted between November 2014 and December 2016. Both female interviewers were employed by the Oncology Centre as Physiotherapists and had worked within the Sarcoma Team. SD has a special interest in exercise and cancer rehabilitation and has worked on several initiatives to help promote the awareness of the benefits of remaining physically active amongst people with cancer.

Table 1. Eligibility Criteria

Inclusion criteria	Exclusion and withdrawal criteria
Participants will: 1. have a diagnosis of a soft tissue sarcoma 2. be receiving first line chemotherapy treatment at the Trust's Sarcoma Unit 3. be willing and able to articulate their experience in English	Participants will not: 1. have a performance status >2 indicating they are more symptomatically unwell and therefore unlikely to complete 2 cycles of chemotherapy 2. be under 18 years 3. have had previous chemotherapy for soft tissue sarcoma i.e. be on second or third line treatment as they are more likely to be symptomatic from progressive disease 4. be above the age of 70 as they are more likely to have age related co-morbidities influencing their physical activity levels 5. have been previously treated by the researcher as it might bias their responses to questions related to physical activity

The interviews took place at the Oncology Centre and followed a semi-structured topic guide which was used flexibly to allow for discussion of points important to participants. The topic guide was reviewed by the Chief Executive of Sarcoma UK.

Interviews were audio-recorded and field notes were also taken immediately following the interview. The interviews were transcribed verbatim by the lead researcher for the first three interviews and by an independent transcriber for the final three. Participants were offered the opportunity to review the content of their interview after transcription but none chose to do so.

Table 2. Participant characteristics

	Diagnosis	Metastatic spread	Co-morbidities	Cancer Treatment	PS	Social and Work Status
001 55 years F	Endometrial Sarcoma	Lung, pelvis, bone	none	Surgery Doxorubicin chemotherapy	0	Married, lives with husband Six adult children Housewife
002 69 years M	Inferior vena cava Leiomyosarcoma	Liver and lung	Type 2 Diabetes AF	Gemcitabine and Dacarbazine chemotherapy	1	Married, lives with wife One adult child Retired factory manager
003 60 years F	Abdominal Rhabdomyosarcoma	Liver and lung	none	Doxorubicin chemotherapy	0	Married, lives with husband Two adult children University lecturer and author
004 58 years M	Retroperitoneal Liposarcoma	abdomen pelvis paralumbar intramuscular deposit	HTN DVT/PE Renal stones	resection of retroperitoneal liposarcoma Doxorubicin chemotherapy, 1 cycle	0	Unmarried, cohabiting Company director
005 54 years F	Leiomyosarcoma of the uterus	Lung	none	surgery: TAH, BSO metastatectomy thoracotomy	0	Single Lives alone Cleaner

Doxorubicin chemotherapy,1
cycle

006 Pleomorphic spindle Lung Type 2 diabetes Left adrenalectomy/ 0 Married
53 years cell sarcoma HTN nephrectomy Lives with husband
F Doxorubicin chemotherapy,1 Cleaner
cycle

Key: PS: Performance Status (Oken et al 1982); M; Male; F: female; DVT: Deep vein thrombosis; PE: pulmonary embolus; TAH: total abdominal hysterectomy; BSO: bilateral salpingo-oophrectomy; AF: atrial fibrillation; HTN: hypertension

Table 3. Themes and sub-themes developed from the interview data

Theme	Sub-theme
Physical activity as an indicator of normality	a. Being physically active is part of daily life
	b. Being physically active allows you to fulfil your role
	c. Being physically active is beneficial to physical and mental wellbeing
Implications, loss and uncertainty for the future due to diagnosis and treatment	
The challenge of recognising support needs as physical activity declines	

Data Analysis

A largely inductive approach based on a constructionist perspective was used in the analysis, where the authors derived themes primarily from the data itself rather than from pre-existing theory (Green and Thorogood, 2014; Varpio, 2017). Analysis was conducted after each interview with coding in the transcript margins initially completed by SD who then used flip chart paper to derive the resultant themes. It was felt that data saturation was reached as no new themes were created after the fifth interview. A workshop session was then undertaken with SD, RT and CAS to discuss the themes and review the entire dataset to ensure rigour and reflexivity. The field notes were used at this point to inform the researchers' interpretation of the data. Lastly the themes and supporting quotations were confirmed by GM who is an experienced applied health researcher with qualitative methodologies.

FINDINGS

Three themes were derived from the data:

1. Physical activity as an indicator of normality
2. The implications, loss and uncertainty for the future
3. The challenge of recognising support needs as physical activity declines

Theme 1: Physical activity as an indicator of normality

i. Being physically active is part of daily life

All of the participants reported a strong connection with being active, describing it as *“an important part of life”* and they had all lived active lives prior to their diagnosis.

“I was very active, always always busy, always doing several things at once” (003)

“I like to be active. I was all my life and I don’t want to be stay at home and sit watching television” (005)

And when reflecting on how life has changed, one of the participants stated:

“Yes but as somebody who likes being outside and doing things outside, not being able to do the things I normally would, yeah it’s [the diagnosis] had quite a big impact” (001)

suggesting that being active was an integral part of life rather than something she made herself do.

Despite leading active lives none of the individuals participated in structured exercise such as going to the gym, and did not use the term ‘exercise’ when talking about their former lifestyles. Only one participant enjoyed organised sport, in this case sailing, but was quick to point out that:

“Yeah, I’m not and never have been a regular exerciser as such in terms of you know gym or walking or swimming. But I’ve always been active in terms of I go sailing most weekends” (004)

ii. Being physically active allows you to fulfil your role

The female participants considered being active as critical to their role as mothers.

This motivated them to keep active and maintain a sense of control in order to fulfil this role for as long as possible and protect their family from signs of their illness.

“and also from the point of view of having the children around, you see my children they’re always around and I think well I can’t just be seen to be giving in, I’ve got to be seen to be normal” (003)

Another participant stated:

“you try and put on a brave face and you keep going because of them and then maybe you do a bit too much and you know instead of sort of, um because you don’t want to upset them” (001)

The participants were concerned about the affect their physical limitations might have on their families. The motivation created by this protective maternal instinct to maintain a sense of one’s own normality and remain active is clear:

“when somebody tells you you have cancer, normality flies out of the window, I want to keep things as normal as possible for them, you know, my youngest son is in the last year of his degree and I don’t want this to affect his results, um my other son is working but he has um emotional mental anxiety difficulties and I don’t want to burden him with too much anxiety so it’s important to try and keep as close to normality as possible” (003)

The ability to be physically active also impacted on the participants' roles in the workplace.

Three of the four participants who worked felt they needed to be active in order to do their jobs, commenting:

"I had to be active and I have to still, and have to be in good condition because I'm working as a cleaner at this quite hard, physical work" (005)

"You know I might be on my feet all day long teaching. I mean I always think of my life as literally running from one university to another" (003)

These participants were all very motivated to return to work as soon as possible and their beliefs about physical activity were closely linked to their desire or need to work as they would not be able to perform their role if they lost their fitness as a result of treatment.

More generally, being active also offered the participants a way of affirming their role as a physical being, giving them a sense of capability and in some cases affirming their masculinity. One of the male participants measured his recovery from surgery by being able to drive the rescue boat and pick up capsized sailors. He took pride in his role within the sailing club and acknowledged the physical strength that this required.

iii. Being physically active is beneficial to physical and mental wellbeing

Participants gave many reasons why they felt being active was beneficial for both physical and psychological wellbeing:

“Um well I think certainly for me, being outside is very important. I do tend, I don’t suffer from or call it depression at all but I do feel quite down sometimes, particularly in the winter months but I’ve found for a number of years now if I can get out, in the fresh air or walk outside a bit or do a bit of gardening whatever, it lifts my spirits,” (001)

There was a sense that going outside allowed participants to connect with the outside world and their former ‘well’ self, with one individual stating:

“well it makes you feel more normal, going to the shops or just walking” (003)

The participants also reflected on the emotional benefits of being active:

“It’s the fresh air, it’s the exercise um my wife thinks I’m mad but I enjoy walking alone as well you know you can just sort of walk along and think about anything and just get the brain going a bit sometimes.” (002)

Similarly, another participant described being active as feeling like she had control over her illness:

“Because I just think when you’re more active you cope with things. I don’t want to get to the position where I can’t do this and I can’t do that. And then you kind of go down” (006)

As did another participant in relation to controlling the side effects:

“I think I’m just going to perhaps try a slightly different strategy in the next week or so and maybe just drag myself out for an hour. Sort of walk around, you know round the block a few times or something just to try and not give in to feeling tired and listless all the time” (004)

The participants recognised that keeping active was empowering and demonstrated a belief that giving in to a more sedentary lifestyle would let the disease take hold.

Another participant highlighted the social benefits of being active as sailing underpinned his social life and he enjoyed the sense of challenge and competition. The participants believed activity allowed them to maintain a sense of normal life, reduce their symptoms, increase their energy levels and feel in control.

Theme 2: The implications, loss and uncertainty for the future

Many participants had a prolonged period of uncertainty involving different hospitals and multiple investigations prior to their diagnosis:

“It [the diagnosis] was very uncertain and that was the shock.” (003)

This sense of shock resonated with all the participants, with another describing going into hospital for a routine operation and finding out she had cancer. She stated she had “no idea’ that her symptoms represented a life limiting illness and the suddenness of the diagnosis was traumatic.

Participants were also living with uncertainty surrounding their treatment options and prognosis:

“So at the moment there’s very limited information from previous kind of treatment as to whether this will be successful or not.” (004)

Participants' experience of previous treatment influenced their confidence and expectations. Typically their recovery from surgery went better than they anticipated and they were able to return to normal activities quite quickly; in contrast once they started undergoing chemotherapy they started to feel worse and it started impacting on their ability to be physically active:

"In fact until the start of the chemotherapy three weeks ago I wasn't ill as such you know the kind of slightly odd thing now is it's the chemotherapy is definitely making me feel worse"
(004)

There was a sense that participants felt more unwell after starting chemotherapy and experienced debilitating fatigue:

"You just have no energy, it's not that you want to sleep particularly it's just you feel as though your legs won't get you there you know it's just this feeling that you know that you're not going to make it." (001)

Feeling unwell reduced their physical ability and impacted on their function, for example:

"Um I'm having to accept help with the housework because it's I just you know I mean I'm keeping the basics done um and that would be fine but you know I've got quite a big family and the church are very helpful and they're helping me out I just can't do all the things I would normally do." (001)

Uncertainty around how they might feel after treatment also affected their views on returning to work:

“I don’t know if I will be able to work after more chemo cycles because it was, I went after the first to work but it was very hard. I don’t know how I stood on my feet, but I did it” (005)

“I don’t know how I’ll feel once the chemotherapy ends, I just don’t know I um you know if I carry on feeling like I’m feeling I probably could go back and do some teaching, it would probably be easier

than I think it’s going to be whether I’ll feel the way I used to I’ve no idea I just don’t know” (003)

One of the challenges participants found was managing the variability in their symptoms, “I mean every day is different” as one participant mentioned, which is typical of chemotherapy treatment and makes it difficult for patients to adhere to a routine or confidently plan ahead. This quotation

demonstrates the frustration:

“So some days have been, you know felt pretty good, I’ve been able to do stuff, go out. You know feel fairly normal. I’ve been sailing a couple of times. But then I’d find that I needed a couple of days

where I’d just do very little, sleep a lot. And then the last ten days, well no, seven days I’ve not really felt up to doing very much at all. I’ve felt very tired, quite weak, quite light headed. So, Yeah I’ve done very little in the last week.” (004)

This pattern of enforced inactivity and sedentary behaviour is in contrast to the active picture that the participants painted of themselves prior to their diagnosis. The participants

were only receiving their second of potentially six cycles, however, they already express a sense of fear for how they

may feel by the end and increasing anxiety in their physical capabilities:

“Well I think if the chemo doesn’t work then that’s the inevitability because the tumour’s just growing so quickly, that eventually I think I’ll be bedridden” (004)

They were concerned about the cumulative effect of treatment side effects, but also associated a decline in function with deterioration in their overall health. One participant stated:

“ I think, I think that just the fact that I couldn’t be physically active it would be I don’t know really it’s er it’s the sort of I think it’d too glib to say it would be the beginning of the end sort of thing but it would maybe in my mind be something like that – I feel all the time I can be active and keep going I know I’m trying to fight this thing you know and er if I couldn’t do that, um I think I would be worried.” (002)

This quotation illustrates the perception that reducing activity levels when you are fighting a terminal disease may represent a deterioration in your condition. None of the participants openly talked about the palliative nature of their disease, but they referred to keeping active and doing normal things as being reassuring that they were remaining well. The future and their role in life appeared compromised by decreasing activity levels, reduced confidence and increasing anxiety regarding disease progression.

Theme 3: The challenge of recognising support needs as physical activity declines

The participants reported they had not received much information regarding physical activity whilst receiving chemotherapy. Two participants referred to being given a Macmillan booklet and one mentioned receiving general advice to keep active from the medical team but there was still uncertainty:

“I did ask about exercise and they said it was important, I wasn’t sure whether they meant like um going to the gym or just you know not sitting on the settee all day – I wasn’t quite sure about the level of exercise I should do” (003)

“I’m still really very unsure about what I should or shouldn’t be doing as far as being active” (006)

Although the participants all reported feeling debilitated by the fatigue, they had not been offered specific support to help them manage it, nor had they requested any.

One of the participants reported she felt fatigue was not a serious enough complaint to bring up with her medical team:

“I think partly you’re almost a bit embarrassed to discuss tiredness because it sounds so silly” (001)

She also said she would have found it easier to discuss how the fatigue was affecting her if she had been asked about it directly.

Interestingly, only one of the participants felt they required support to help them with symptoms or to maintain their activity levels, saying advice on how much she could manage would be helpful.

“oh information, any information to help me where I am now as to regards to what I can do or what I should or shouldn't do” (006)

Three participants reported they may need more input from health professionals in the future if things changed. And two participants wondered whether frailer or older patients might need a greater level of support than themselves. Peoples' openness to advice is clearly individual with one of the participants stating:

“No I don't take much notice of all that official guidance” (004)

Whereas another participant said:

“I listen to advice and I act upon it” (006)

DISCUSSION

Much emphasis is now placed on how being active can reduce both disease symptoms and the side effects of cancer treatment, however, the functional benefits of exercise are not as widely discussed but may be of more importance to people with advanced disease than clinicians are aware of (Cheville et al, 2017; Gralla et al, 2014). There are significant barriers preventing cancer patients from maintaining an active lifestyle (Blaney et al, 2010).

Understanding individuals' motivations and practical goals is key to their successful rehabilitation at every stage of the disease. This study provides insight into peoples' attitudes towards physical activity as they receive palliative chemotherapy treatment for STS.

The interviews tell a progressive story of participants leading busy, vital lives before the shock of a terminal diagnosis and treatment toxicity undermines confidence in their physicality. As theme one, 'indicator of normality' demonstrates, all of the participants described how an active lifestyle had been part of their normal social and role functioning prior to their illness. All of the participants were clear about the health and wellbeing benefits of being active. The psychological benefits of activity are well documented (Knapen, Vancampfort, Moriën , and Marchal, 2015) and exercise prescription is now commonplace in the management of mental health conditions. Twenty five percent of people living with a cancer diagnosis have an unmet mental health need (NHS England, 2014) and without any specific advice, the participants described how keeping active helped them all psychologically.

The participants reported that being physically active simply made them feel better and more able to cope. Researchers studying groups of people with other advanced cancers report similar benefits to symptoms, physical function and participation. Adamsen et al. (2012) interviewed patients undertaking chemotherapy treatment for advanced lung cancer and reported an improved sense of emotional wellbeing, strength, physical fitness and vitality despite significant levels of fatigue. This was borne out by adherence levels of 76% to

a structured exercise programme. In addition, a feasibility study by Hoffman et al. (2013), based on seven participants following surgery for lung cancer achieved a 96% rate of reported adherence to a home balance and exercise programme designed to address fatigue. Participants expressed that the programme gave them 'a lot of strength' so that they 'could keep going'. Conversely in our study, participants did not report exercise helped them to cope with fatigue but that this symptom was the biggest barrier to maintaining previous activity levels, highlighting the importance of education around the management of fatigue.

Managing physical health wasn't a commonly reported benefit in this study. However, living with a long-term condition increases the incidence of cancer and this patient group often experiences a complex health picture so, keeping physically active is of proven benefit (Macmillan, 2015). It is significant that this was not raised more commonly as a motivating factor in this study and its omission might indicate that the message of the importance of physical activity for physical health is not reaching people treated for advanced cancer.

Theme one 'physical activity as an indicator of normality', also demonstrated how each individual's approach to activity is highly personalized, based on many factors including their preferences, lifestyle, age, family status and in some cases economic position. Whilst traditionally a standardised exercise programme might have been prescribed, these findings suggest that it is paramount that health professionals adopt an individualised approach and understand the factors which influence people's activity preferences and inherent motivation.

The first theme 'physical activity as an indicator of normality' suggests that appreciating people's roles whether in a family, at work or on a wider social level may provide a useful insight into someone's motivation to remain or return to activity. This individualised approach to maintain participation, is supported by Maddocks and Granger (2017) work using the Goal Attainment Scale in the palliative care setting.

Significantly, none of the participants referred to the term 'exercise'. Despite being very vocal about the benefits of being active, these participants were not active gym attenders, and only one of them participated in organized sport. Using the term activity instead of exercise might prevent health professionals from alienating patients and allow a dialogue about the benefits of activity to occur. The specific dose response to activity levels and the benefits to people with advanced cancer continues to be explored by researchers and is currently unclear in this population (Cheville et al, 2017).

Studies have shown that being active as opposed to completing regular exercise is sufficient to reduce the health risks of a sedentary lifestyle and therefore activity on any level should be encouraged (Ekblom-Bak et al, 2012).

Recognising that motivation to be active comes from enabling a return to function rather than a sporting goal permits rehabilitation professionals to approach conversations with patients in a different way. Asking patients about the functional impairments they are experiencing rather than their symptoms might be more insightful. This is supported by use of the WHO-ICF domains regarding activities and participation, and needs to be addressed arguably more directly than subjective quality of life measures (Bayly, Wilcock, Higginson,

and Maddocks, 2017). These can be used to direct conversations, enhance motivation and work meaningfully towards shared goals (Maddocks and Granger, 2017).

This approach may also allow individuals to recognise that they may benefit from support, as our findings showed that participants were unlikely to declare their functional limitations in medical consultations. During the interviews this group of highly motivated people all freely discussed the limiting effects the sarcoma and treatment had on their ability to remain active but theme three demonstrates they did not recognise they might require support and had not brought these issues up in medical consultations. Perhaps they did not directly link their symptoms to their reduced function; or as suggested by Wagland et al, (2016) patients with advanced cancers might downplay their symptoms fearing a negative impact on further treatment being offered if their performance status seems compromised. In some cases the interview process appeared to be the first time participants had verbalized the impact that the physical restrictions both the disease and the treatment had inflicted; and there was a process of realization as people talked about their experience. Given that patients tend to under-report fatigue (Bayly, Wilcock, Higginson, and Maddocks, 2017) and rely on their own support mechanisms to cope, this poses a challenge to health professionals in a busy clinical setting.

Participants discussed the change in routine as they underwent chemotherapy and their perception that increasing inactivity symbolized their lives moving away from normality towards something unknown. Several barriers to remaining active were mentioned throughout the interviews but the unknown nature of both the illness and the treatment

seemed to be the biggest deterrent and is likely to significantly influence people's ability to commit to acting on advice regarding physical activity.

There were also reports that there had been clear guidance from health care professionals at some parts of the treatment, i.e. following surgery, but guidance seemed less clear during chemotherapy. It is our responsibility to educate, however informing people in a timely, sensitive way is a challenge, and the participants in this study had differing views as to how much information they wanted to know. Activity on any level should be encouraged by all clinicians, even if they are not experts in rehabilitation, since the content of medical consultations is influential for patients and their families (Macmillan 2016).

Strengths and Limitations

The small sample size clearly limits the generalisability of the findings however its main strength is that it is the first exploration of physical activity with this rare population group and the findings are supported by larger studies in other palliative populations. A second potential limitation with this study is that all of the participants had an interest in activity and were physically motivated people. This study does not therefore provide insight into the views or support needs of people who are not leading active lives at the point of treatment.

We attempted to limit the inherent bias of the lead interviewers being experts in the field of physical activity and oncology by using a topic guide approved by the chief executive of the

leading sarcoma charity and ensuring that the participants had not had previous clinical contact with the researchers. However, in the interests of transparency, we acknowledge that despite the robust process adopted for the analysis, the interpretation of the data in any qualitative research is coloured by the researchers' underlying beliefs and experience.

CONCLUSION AND CLINICAL IMPLICATIONS

The clinical and social situations become increasingly complex for people living with advancing disease. In this study the participants' relationships with exercise were described based on their experience as healthy individuals and used to maintain their sense of normality, self and role. Physical activity levels reduced during chemotherapy primarily due to fatigue, uncertainty surrounding the impact of treatment and unclear guidance from health professionals. Participants expressed regret that they were no longer able to perform to the same level and uncertainty about the risk this posed to fulfilling their roles.

This suggests there is a gap in their knowledge of the health benefits gained by continuing to be active as they undergo treatment and the support that might be available to them.

Proactively investigating individual's own goals and utilising their activity habits therapeutically might help clinicians to address some of the uncertainty patients face, manage their symptom burden and promote a more positive hopefulness.

Key Learning Points:

- Be proactive and predictive in assuming physical activity levels will decline
- Initiate conversations about symptoms and their impact on function and role
- From diagnosis onwards, encourage activity and participation, not necessarily “exercise”
- All MDT members must share a consistent approach

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