



Article

Experiences of Physical Activity in Mesothelioma: A Qualitative Enquiry

Lorelle Dismore ^{1,*}, Leah Taylor ², Christopher Hurst ^{3,4}, Avinash Aujayeb ², Hannah Poulter ⁵ and Katherine Swainston ⁶

¹ Innovation, Research and Development, Northumbria Healthcare NHS Foundation Trust, North Tyneside Hospital, Rake Lane, North Shields NE29 8NH, UK

² Respiratory Department, Northumbria Healthcare NHS Foundation Trust, North Tyneside Hospital, Rake Lane, North Shields NE29 8NH, UK; leah.taylor@northumbria-healthcare.nhs.uk (L.T.); avinash.aujayeb@northumbria-healthcare.nhs.uk (A.A.)

³ AGE Research Group, Translational and Clinical Research Institute, Faculty of Medical Sciences, Newcastle University, Newcastle NE1 7RU, UK; christopher.hurst@newcastle.ac.uk

⁴ NIHR Newcastle Biomedical Research Centre, Newcastle upon Tyne Hospitals NHS Foundation Trust, Cumbria Northumberland Tyne and Wear NHS Foundation Trust and Faculty of Medical Sciences, Newcastle University, Newcastle upon Tyne NE4 5PL, UK

⁵ School of Social Sciences, Humanities and Law, Teesside University, Middlesbrough TS1 3BX, UK; h.poulter@tees.ac.uk

⁶ School of Psychology, Population Health Sciences Institute, Faculty of Medical Sciences, Newcastle University, Newcastle NE2 4HH, UK; kate.swainston@newcastle.ac.uk

* Correspondence: lorelle.dismore@northumbria-healthcare.nhs.uk

Abstract: Patients with a mesothelioma diagnosis often have relatively sedentary lifestyles and low physical activity. Reducing sedentary behaviour and being more active could be beneficial. A greater understanding of the factors associated with physical activity is needed to inform the development of interventions. Semi-structured interviews with patients with mesothelioma and informal carers were performed and analysed thematically. Three themes were generated: (1) the impact of disease burden and physical and psychological symptoms, (2) the psychosocial consequences and benefits of physical activity and (3) unpredictability and maintaining control. Participants had become increasingly sedentary during diagnosis and while undergoing treatment. Symptoms were key factors contributing to these reductions. Being less active reduced social connectedness and impacted psychological well-being. Some participants had lost confidence in being active and were worried about the potential negative consequences of doing more. Being able to walk was a priority, and they felt hopeful about increasing this in the future, but this depended on optimisation of symptoms. Clear guidance from healthcare professionals was needed to support engagement in physical activity. Declines in physical activity can have meaningful consequences for patients. Optimisation of symptoms is important to devise strategies to support patients with physical activity. Along with encouragement from healthcare professionals.

Keywords: physical activity; mesothelioma; qualitative



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1. Introduction

Malignant pleural mesothelioma (MPM) is a rare cancer associated with exposure to asbestos [1]. There are approximately 2700 new cases diagnosed each year, and the United Kingdom (UK) has the highest incidence in the world, with 2 in 100 people in England surviving their disease for 10 years [2]. Recent advancements in treatments have substantially improved survival [3], but many patients with mesothelioma experience high symptom burden and poor quality of life [QoL] [4,5]. Factors impacting on QoL include poor performance status, disability and loss of independence [6–8]. Optimising physical activity levels and QoL are therefore key goals of supporting patients [7], and

physical activity is recommended for patients with any type of cancer and at all stages of treatment [9].

Maintaining regular physical activity may extend patients survival whilst improving their overall QoL and may have benefits as adjuncts to current best supportive care for patients with mesothelioma [10–13]. Lifestyle interventions have been studied in lung cancer patients [14], but less is known about mesothelioma. A feasibility study is under way to explore how exercise therapy can improve symptom control, fitness and QoL of mesothelioma patients [15]. Key aspects of the cancer and the population being diagnosed with mesothelioma likely influence acceptability of exercise interventions designed to improve QoL. For example, patients with mesothelioma are often older, more sedentary and engage in lower levels of physical activity [7–16], meaning uptake in interventions may be relatively low.

Designing interventions that are acceptable to patients to reduce unwanted outcomes can be a complex process. Research that focuses on patients' and informal carers' experiences could help guide the development of new interventions, treatments and innovations in service delivery that meets the needs of the people receiving them [17]. Caregivers of patients engage in a wide range of practical daily activities and experience their own activity impairments, carer burden and are at increased risk of developing depression [18].

2. Methods

This qualitative study was part of the Health and Lifestyle of Patients with Mesothelioma (Help-Meso) Study [19]. The Help-Meso study aimed to develop an understanding of experiences of physical activity in mesothelioma with views sought from patients with mesothelioma and their informal carers. The insights could support the development of physical activity interventions that may provide meaningful benefits to the patient. Findings related to diet, appetite and nutrition have been previously published [20,21]. This paper reports the findings from the qualitative study that utilised semi-structured interviews to examine experiences and views around physical activity from the perspectives of patients with mesothelioma and their informal carers. The Help-Meso study was granted ethical approval from the Wales Research Ethics Committee 7 (REC 287193) and local National Health Service Research and Development approvals and conforms to the Declaration of Helsinki. The study was funded by Mesothelioma UK.

2.1. Participants and Recruitment

Patients with mesothelioma and their informal carers (e.g., family members, friends) were recruited from a single secondary care mesothelioma specialist service in the National Health Service (NHS) in the United Kingdom. Participants were identified as eligible for participation by the mesothelioma specialist team. Study inclusion criteria included patients ≥ 18 years, diagnosed with mesothelioma and able to provide informed consent. Informal carers were a relative or friend of the patient. The lead author (LD) mailed a participant information sheet and invitation to the participant(s) and contacted them to discuss their participation.

2.2. Interviews

Semi-structured interviews were conducted between September 2022 and August 2023. Nine interviews were conducted within the participants' own homes and three were conducted over the telephone. Interviews lasted between 15 and 60 min. Open-ended questions focused on participants' experiences of physical activity. For example, 'How has mesothelioma impacted on your physical activity?' and 'What do you think the disadvantages of being physically active, and is there anything you are afraid of?' (Appendix A). The interviews were audio-recorded and transcribed verbatim.

2.3. Data Analysis

Data were analysed using Reflexive Thematic Analysis (TA) [22] with the stages outlined by Braun and Clarke [23]. Reflexive TA relies on the subjective skills of the researcher and coding was open and organic, with no use of any coding framework. Themes were the outcome of data coding and iterative theme development [24]. This involved data familiarisation by immersion with the data to understand depth and breadth of the content, by reading and re-reading the data set; initial code generation by organising the data through labelling items into meaningful groups; generating themes by sorting codes into initial themes and identifying meaning of and relationship between initial codes; theme review by identifying coherent patterns and reviewing the entire data set; theme defining and naming with support from relevant quotations. Theme development was discussed at several meetings to refine the specifics of each theme and provide a clear definition and name for each theme. L.D. K.S. and C.H. reviewed and agreed the final themes.

3. Results

In total, 18 participants were consented and interviewed. This included 11 patients with mesothelioma (9 pleural and 2 peritoneal) and 7 informal carers. Patients were aged 56–83 years (mean age 74 years), 10 were male, all the participants were White British, and three lived alone. The informal carers were wives ($n = 5$), son ($n = 1$) and daughter-in-law ($n = 1$). In total twelve interviews were conducted. Of these interviews, 6 patients were interviewed on their own, 5 patients were interviewed with their informal carer(s) and 2 carers participated in 1 interview.

3.1. Thematic Analysis

Thematic analysis generated three themes (1) the impact of disease burden and physical and psychological symptoms, (2) the psychosocial consequences and benefits of physical activity and (3) unpredictability and maintaining control.

3.1.1. Theme 1: The Impact of Disease Burden and Physical and Psychological Symptoms

The burden of mesothelioma and the impact of symptoms influenced physical activity behaviour. This was especially the case during the diagnostic pathway and while undergoing treatment, such as a pleural drain, radiotherapy, and/or chemotherapy. Burdensome symptoms and side-effects from treatment included fatigue, breathlessness, and nausea.

Well, a lot [decline in physical activity] because I get fatigued. Plus, I've been through a whole batch of chemotherapy and the chemotherapy has long-lasting effects. I went through six sessions of chemotherapy when I came home, and the cancer came back, and that [news] affected me really badly. It's been quite a while since I used my stick and that's just dwindled away (HMP 05).

It's not a case of being afraid, it's some of the side effects of treatment are debilitating like nausea and being tired. I still now and again get overcome with tiredness and have to go and lie down for an hour. I would like to go back to doing what I used to do, but I'm not fit enough at the moment. . . it's the treatment and side effects of the treatment. I didn't have all these symptoms before the treatment started (HMP 02).

Participant accounts highlighted frustrations with a decline in their ability to walk and perceptions of becoming increasingly sedentary.

I've got to because I can feel it, I can feel my legs going now, do you know what I mean? I need to get. . . it's just because I've never had a good walk for a few weeks do you know what I mean? Sitting around, lying around (HMP 01).

Adverse physical impacts of declines in physical activity were also notable in other participants narratives. They reflected on changes to their body composition (weight loss and muscle loss), in turn affecting their physical activity behaviour.

I've lost a lot of weight. I was quite a sturdy man, biceps, triceps, deltoids were well developed, and they've wasted away. I look like a scarecrow a bit now; I've lost a lot of weight. I'd lost 4–5 kg in total but last week when I was weighed, I'd put a kg back on, which the doctor thought was a good sign (HMP 02).

Despite these frequently described adverse consequences of treatment on physical activity behaviour, participants who responded well to systemic anti-cancer therapy, noticed positive improvements in their physical activity behaviour. Upon starting treatment, they felt physically able to regain some of their activities.

When I first started the therapy. . . I could have only just walked around the house and sit down and read, since I've had immunotherapy, my activities increased quite a lot. I'm now at the stage where I can walk around the house no problem at all, do light gardening duties. . . (HMP 13).

Individuals were hopeful for the future that they could be more active, but this was driven by response to treatment and optimisation of symptoms.

3.1.2. Theme 2: The Psychosocial Consequences and Benefits of Physical Activity

As physical activity declined for example, walking outdoors, taking part in voluntary and paid work, and playing golf, this meant that opportunities for social engagement and interaction that are inherent with these activities also reduced. Cognitive declines associated with these reductions in physical activity were discussed.

It's a skilful game [golf] which keeps your mind active. You're playing with people you've known for years so its companionship. I'd like to improve it but at the moment I'm taking every day as it comes (HMP 02).

One patient and his wife discussed previously having an active role with their grandson, but changes in treatment impacted on these activities.

I'd like to get out and about a bit more. . . I am a tour guide, but I've not been able to do any tours. . .but just being able to get out and meeting people, is the next step. . .which I haven't been able to do at all. . . people I haven't seen or spoken to in ages (HMP 12).

Play and jump in the swimming pool. . . but I can't see that happening again not with the drain in anyway (HMP 10).

Only one participant performed structured exercise (swimming) prior to diagnosis, eventually becoming unable to do this due to a pleural drain. He reflects in his narrative the adverse physical and psychological impact of no longer being able to exercise. Being able to regain activities and perform structured exercise improved mental health and well-being, enabling patients to regain normality.

I've done it all my life [swimming]. . . it's like a dog out of water it really is, you're addicted to it. . . mentally I'm more relaxed again. . . you go shopping and you're mentally okay (HMP 10).

Reduced physical activity had additional negative psychological consequences. The participants had lost confidence in being active during their treatment as they were uncertain of how to manage mesothelioma-related symptoms.

3.1.3. Theme 3: Unpredictability and Maintaining Control

Participants were concerned about the potential adverse consequences of increased physical activity, including doing too much and the residual impact of this, and many talked about taking things 'day-by-day'. Participants were fearful about making social plans due to not knowing the outcome of treatment. Maintaining functioning role in respective family

units was a motivator in staying physically active for this population. There was a fear of further reductions in physical activity; they felt uncertain with a lack of control around symptoms and disease progression.

I know at some point I'm going to have to have some more [treatment], well I don't know what I'm going to have to have, I'll find out more in the next couple of months (HMP 12).

He does worry about tiring himself out too much because he did that at the beginning and he made himself feel quite unwell for a few days, he thought he was superman and that he'd be able to do this, that and the other, and he knocked himself back. . . I think he's afraid of pushing himself a little bit too much (C13 Wife).

For the informal carer, they too expressed similar concerns and were worried about their relative overdoing it. They felt anxious and for some, this caused conflict within the family unit.

I'm frightened in case it's going to break down the line [pleural drain] if he does too much. . . I'm worried. . . I'm telling him off now 'please don't do that' I'm frightened in case it does more damage. . . he would just carry on as per normal. . . I'm a bit more wary of it. . . but when he's lifting very heavy things that's when I get worried, you get annoyed at me (C03: Wife).

Attitudes towards maintaining physical activity were intertwined with attempts to maintain control over condition deterioration. Some of the participants implemented strategies such as buying a treadmill and walking around the house, and this helped to support their aim of maintaining independence and quality of life. This subgroup of participants felt motivated to be as fit as possible for as long as possible. Attempts to maintain levels of physical activity in the future were driven by motivations to continue engaging within their family unit.

As I'm getting more and more confident that I can walk farther and farther. I can walk quite a good distance now. I can walk a couple of miles now. I like to walk; I like to see (daughter) happy on her bike or her scooter and me wife likes to power walk, so she sets herself away I walk behind her. I walk slowly so exercise doesn't really figure heavily in my life at all (HMP 05).

Participants highlighted that clear guidance accompanied by tailored support from healthcare professionals was needed to support engagement in physical activity within the context of their treatment and symptoms. Intentions to participate in lifestyle interventions were variably spread within the sample. Some were content with their current activity levels and therefore did not want to pursue more, and they felt self-motivated to become more active when able to. Only one participant described how exercise was a priority in his life. For others, being able to walk was a key goal.

4. Discussion

This qualitative study has developed an understanding of the experiences of physical activity in patients with mesothelioma. Optimising physical activity has the potential to be an effective component of patient management and is recommended for patients with any type of cancer.

Three themes were generated from our interviews. The first theme was the impact of disease burden and physical and psychological symptoms. Patients with cancer can experience debilitating symptoms, which may influence attitudes towards, and engagement in, physical activity. It is difficult for older patients with cancer to stay physically active during oncological treatment [25]. Symptoms including pain and fatigue negatively influenced activity participation and fatigue is as an overwhelming feeling [25,26]. Yet, a multidimensional approach recommends controlling the level of fatigue with the use of nonpharmacological modalities, including physical activity [27]. In this current study, fatigue was a commonly reported symptom impacting on activities. Future interventions should promote the benefits of physical activity for controlling fatigue, which may seem

initially counterintuitive for patients [27]. Interventions need to consider treatment side effects, and the psychological symptoms associated with mesothelioma. As well as the environmental and organisational barriers that individuals may experience such as a lack of knowledge and time constraints [28].

The second theme identified the psychosocial consequences of reduced physical activity. The long-term consequences of treatment are poorly addressed, such as neuropathy [29], which have unique effects on capability and opportunity to remain physically active. As mesothelioma progresses, patients become less physically active, limiting opportunities for social interaction and resulting in social and emotional alienation and isolation; factors that would result in an increased risk of severe depression [30]. Patients may also lack confidence following treatment to engage in physical activity [31]. Psychosocial barriers, such as a lack of motivation, low social support and low confidence/skill, have been identified as barriers towards physical activity participation in women with breast cancer [28]. Dealing with a diagnosis can result in feelings of hopelessness and needing time to adjust to the devastating blow and loss of future [29]. The complex trauma experienced by patients mean psychosocial support pathways are crucial for patients to face end-of-life care [32]. Indeed, underlying co-morbid psychological conditions experienced throughout the mesothelioma pathway are key influences to consider when designing physical activity interventions for this population. Social support is a motivator and a facilitator of physical activity engagement [25]. Caregivers and healthcare practitioners are integral support networks for patients with mesothelioma, particularly in navigating information and accessing psychosocial support pathways [33]. Yet, robust interventions that incorporate psychosocial care are yet to be designed for this group.

The third theme, unpredictability and maintaining control, highlighted the participants concerns for the future and strategies to overcome the barriers. Participants were worried about becoming increasingly sedentary and this centred on the lack of control around symptoms and disease progression. Concerns about maintaining an active role in their family life was key for this group. Continuation of enacting key social roles within the family such as 'the fun grandpa' were seen as motivating for maintaining or increasing physical activity in the future. Participants highlighted a requirement for tailored support on adequate physical activity while experiencing symptoms. Access to exercise professionals, particularly after cancer treatment, access to information about physical activity in different formats, supervision from health professionals and peer support may help to achieve sustainable increases in physical activity in lung cancer [34]. Exercise needs to be individually tailored while taking into consideration diagnosis and other factors that could affect safety [35]. Patients could be referred to a cancer exercise specialist for prescription of tailored physical activity programmes. Encouragement from healthcare professionals, along with individualised advice and guidance, is often highly valued [36,37] and could help to encourage this group to engage in physical activity.

Mesothelioma has a multidimensional impact on physical symptoms and emotional functioning, and has social consequences [5]. Coming to the end of a planned course of treatment can bring relief, but also can increase anxiety about the future [29]. Persistent symptoms may lead to disorders in physical functioning [38]. Optimisation of symptom management is required [5] and physical activity may play a role. Physical activity is recommended in individuals living with advanced cancer. It is advantageous for symptom management and for decreasing the severity of the side effects of lung cancer treatment and improving quality of life, with positive impacts on mental health in cancer [9,39]. Patients with mesothelioma should receive rehabilitation early after diagnosis and throughout the continuum of care [12]. However, intervention development will need to account for individual patients' strength and endurance to participate in physical activity [40]. Activities that are familiar may increase motivation [25].

Given the variability in the amount of physical activity performed in this group, the type of physical activity should depend on the condition of the individual patient. Research is required to determine if interventions that enhance skeletal muscle mass could improve participation in daily physical activity for patients with mesothelioma [7]. Alongside adequate physical activity, interventions that also combine nutrition support may maximise the benefits on clinical outcomes in cancer patients whilst enhancing their quality of life [41]. In a feasibility study, a multimodal exercise, nutrition, and palliative care intervention in advanced lung cancer showed potential benefits on quality of life, including clinically meaningful reductions in fatigue, tiredness, depression, pain and increases in energy and well-being [42].

Study Strength and Limitations

This study captured views of participants throughout the diagnosis and treatment pathway, which is a strength of this study. Data sufficiency was reached, but it is acknowledged that most of the participants were men, and gender bias may influence the findings. This study attempted to interview informal carers of patients and most of the interviews were joint. Few carer-specific issues were therefore identified. Future studies should focus on the specific needs of informal carers of patients with mesothelioma and in this study, those who were on immunotherapy noticed positive improvements in their activity, and this needs to be explored further to establish if there are any longer-term benefits.

5. Conclusions

This exploration of patients' and caregivers' experiences of physical activity following a mesothelioma diagnosis identified how the disease burden of mesothelioma and symptoms impacted physical activity. There were psychosocial consequences of reduced physical activity, and the findings are embedded within the biopsychosocial model. A holistic understanding of symptom burden and optimisation of symptom management is important to devise strategies to support patients and informal carers with physical activity. Allied health professionals may play a role in providing tailored support, and we may need to consider specific physical activity guidelines for patients with mesothelioma.

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Informed Consent Statement: Informed consent was obtained from all of the participants involved in the study.

Data Availability Statement: Due to maintaining confidentiality of the participants, the interview transcripts will not be made publicly available.

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Appendix A

- (1) When I say physical activity what does this mean to you?
- (2) Thinking of a typical day, is there anything that you do that you would consider to be physical activity?
- (3) How would you describe your overall level of physical activity?
- (4) How important is being physically active to you?
- (5) What do you think the benefits are of being physically active?
- (6) What do you think the disadvantages of being physically active are, and is there anything you are afraid of?
- (7) How much thought do you give to physical activity?
- (8) Can you describe how pleasant or unpleasant physical activity is for you?
- (9) How has mesothelioma impacted on your physical activity?
- (10) How would you describe your general mood and well-being, and does this impact your physical activity in any way?
- (11) What strategies or approaches have you used to maintain physical activity?

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