

Title: Patients with Mesothelioma and their carers experience of diet and appetite: a qualitative insight from the Help-Meso Study.

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Conflict of Interest Statement

The authors declare no competing interests.

Author Contribution Statements

LD, CH, AA, and LT conceived and designed the research, LD conducted the interviews and LD and KS interpreted the data. LD wrote the first draft of the manuscript, and all other authors approved the final version. LD agreed to be accountable for all aspects of the work in

ensuing that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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ABSTRACT

Objective: People living with mesothelioma have a high symptom burden that can affect dietary intake and the development of malnutrition, subsequently impacting on patient-related and treatment outcomes. The aim of this study was to develop a better understanding of the experiences of diet and appetite in people living with mesothelioma and their informal carers.

Methods: Twenty-three participants took part in semi-structured interviews including twelve people living with mesothelioma (10 pleural and 2 peritoneal) aged 56-83 years and twelve informal carers, predominantly their spouses. Open ended questions focussed on experiences of appetite and diet as well as approaches to maintain adequate food intake. Thematic analysis was applied.

Results: Four themes were generated that included unintentional weight loss and poor appetite during diagnosis and while undergoing medical intervention, participants managed their appetite and diet by taking each day at a time and this was influenced by the physical and emotional experiences of mesothelioma, the informal carer took on the lead role of managing their relatives' diet and implemented their own nutritional strategies and there were challenges with dietary advice.

Conclusions: Appetite was viewed as a multidimensional experience and was grounded within the biopsychosocial model. The findings offer important insights into opportunities towards informing the development of effective interventions that provide meaningful benefits for individuals living with mesothelioma and their family.

Key words: appetite, diet, living with mesothelioma, and informal carers' experiences

Key Points

- Weight loss and appetite problems are common in mesothelioma and are a multidimensional experience.
- Better management of patient's symptoms may improve appetite.
- There is scope to develop effective interventions that provide meaningful benefits for people living with mesothelioma and their family.

Background

Malignant mesothelioma is a rare cancer that can develop in the pleura or the peritoneum. It is typically caused by prior asbestos exposure (1,2). People living with mesothelioma have a high symptom burden including fatigue, dyspnoea, pain, weight loss, anxiety and low mood (3,4). High symptom burden can result in the development of malnutrition, subsequently impacting on patient-related and treatment outcomes (5,6). Therefore, the relief or control of these symptoms should be included in patient management to optimise quality of life and maximise response to treatment (6).

The prevalence of malnutrition in people living with cancer is high and often undertreated (7,8). Factors altering nutritional status may include the adverse effects of advanced lung cancer treatments (9,10) and side effects that can impact an individual's ability or desire to eat (10). Cancer related weight loss can be complex due to cancer-related cachexia which is not a cause of reduced dietary intake alone. Cachexia occurs when people with advanced cancer experience a complete loss of appetite (anorexia) that leads to weight loss and loss of lean body mass, and is one of the most common and challenging whole-body response syndromes occurring during the progression of many diseases (11). Cancer cachexia cannot be fully reversed by conventional nutritional support and leads to progressive functional impairment (12). Clinical guidelines for nutrition support during cachexia mostly focus on

the later and end stages of disease (12). People living with cancer and their carers' are rarely aware of cachexia syndrome but do report the manifest symptoms of loss of appetite and weight (13).

Other factors altering nutritional status include decreased physical activity, catabolic metabolic derangements, and poor appetite (9,14). Loss of appetite has a significant impact on nutritional status and quality of life, especially when anorexia and early satiety are combined (14). Reduced food intake is a commonly found problem in people with cancer and impacts health perception, role function, fatigue, lower weight, and body mass index (14). Including appetite assessment as part of nutritional screening and assessment in cancer patients is therefore recommended as improving the nutritional status of patients may lead to improved outcomes (9). However, those living with cancer often do not receive nutritional support (7,8)

The prevalence of malnutrition was 38% in sixty-one people living with malignant pleural mesothelioma (15) and poor appetite is a commonly reported symptom in mesothelioma (16). In people living with mesothelioma admitted to home palliative care, poor appetite was rated amongst the most frequent symptom with the highest intensity (17). Although patients may present less commonly with systemic symptoms of weight loss if they do, this is a poor prognostic sign, since the disease is likely to be more advanced (18). Malnutrition leads to the loss of lean body mass index which in turn adversely impacts muscle function, strength, increases disability, and is associated with worse health outcomes including survival and affects response to treatment (14,16,19,20). In people living with mesothelioma, at post-mortem, cachexia was common, and a quarter had a body mass index (BMI) of <17 (21). Interventions that target malnutrition and their impact on the quality of life of mesothelioma patients are yet to be addressed (22). To date, there has been limited investigation of the experiences of appetite and diet of people living with mesothelioma. Such work is needed to

enable healthcare professionals to deliver interventions that provide meaningful benefits for individuals living with cancer and their family (13).

The overall aim of the Help-Meso study (Health and Lifestyle of People living with Mesothelioma) was to describe the nutrition, appetite and physical activity experiences of people living with mesothelioma from the perspectives of those living with mesothelioma, their informal carers and health professionals (23). Findings were gathered to improve understandings of health behaviours in people living with mesothelioma and to consider the development of effective interventions.

This paper reports the findings from the qualitative study that utilised semi-structured interviews with people living with mesothelioma and their informal carers about their experience of appetite and diet. The findings could offer important insights to identify opportunities for future interventions for this group.

Methods

The Help-Meso study was granted ethical approval from 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 (www.mesothelioma.uk.com).

Participants and Recruitment

People living with mesothelioma and informal carers (i.e., relative) of people living with mesothelioma were invited to participate in this study. Participants were recruited from a secondary care specialist mesothelioma service in the United Kingdom who were identified as eligible to participate by a mesothelioma clinical specialist. Potential participants were provided with a participant information sheet and were then contacted by a member of the

research team to discuss the research in further detail. Participants were made aware that their participation was voluntary and if they declined to take part, this would not affect their medical care or treatment. Study inclusion criteria included people ≥ 18 years diagnosed with mesothelioma, able to provide informed consent and willingness to take part in the qualitative interview and/or nutritional screening.

Fifteen people living with mesothelioma were approached to participate in the study, three of whom declined to participate due to feeling too unwell and twelve informal carers were approached. Twelve people living with mesothelioma (10 pleural and 2 peritoneal) were interviewed, aged 56-83 years (mean age 74 years), eleven were male, all the participants were White British, and two lived alone. Eleven informal carers were interviewed, this included one son, one daughter, one daughter-in-law and 8 spouses (wives). In total, fourteen interviews were conducted, five people living with mesothelioma were interviewed on their own, seven were dyad interviews whereby the person with mesothelioma was interviewed with their informal carer (wife), one interview was carried out with two informal carers (wife and daughter) of a participant with mesothelioma and one interview was carried out with two informal carers (son and daughter in law) of a person with mesothelioma who did not participate in the study. The final sample consisted of twenty-three participants.

Interviews

In-depth semi-structured interviews were performed between August 2022 – June 2023. All interviewees provided informed consent prior to the interview and the interviews were conducted in the participants' home. Interviews lasted thirty minutes to one hour. The interviews utilised open-ended questions and focused on participants experiences of diet and appetite. For example, 'can you tell me about your appetite?' and 'how does mesothelioma impact on your appetite/diet?' (Appendix 1). Interviewees were asked about any current

approaches they utilised to maintain adequate food intake. The first author (XX) conducted all interviews, transcription, and analysis. The interviews were audio-recorded and transcribed verbatim. All interview transcripts were anonymised, and participants were assigned a pseudonym.

Data Analysis

Reflexive thematic analysis was utilised (24,25) to allow for a rich and detailed account of data by the first author (LD). The initial steps were familiarisation by reading and re-reading each data transcript. Whilst reading over the transcripts, initial codes were generated by identifying interesting aspects of the data. Codes were reviewed and refined, and connections were identified and clustered together. Once codes were established, they were collated into potential themes with supporting quotations. The final themes were discussed within team meetings and themes were refined and consensus reached in defining and naming the themes. The relevant quotations to each theme were selected.

Results

Thematic analysis generated four themes: 1) Unintentional Weight Loss and Poor Appetite; Diagnosis and Medical Intervention, 2) Taking Each Day at a Time: Physical and Emotional Experiences, 3) The Informal Carers Role: Managing Diet and Coping and 4) The Challenges with Dietary Advice.

Theme 1: Unintentional Weight Loss and Poor Appetite; Diagnosis and Medical Intervention

Participants described having unintentionally lost weight during their mesothelioma journey, typically during the diagnostic pathway. The participants described how they experienced uncertainty and worry about the diagnosis and treatment; weight loss exacerbated this

anxiety. As one carer explained waiting for a diagnosis/treatment and experiencing weight loss was anxiety provoking:

'And all she keeps saying is 'you're not going to die in the next fortnight, hang on' because when you're waiting that's what you think is going to happen and when he was losing that weight fast, you would think gosh 'if he doesn't get treatment soon' he's not going to be here...it's a lot of pressure, anxiety, the waiting, I'm telling you that's what does it, the mental health issues are phenomenal' (Carer 12, Wife)

However, one participant did not know why he had lost weight, but he attributed this to physiological reasons such as feeling fuller quicker due to the mesothelioma progression, for example:

'I don't think it's anything to do with my mental state... I think that is to do with the disease itself...nothing to do with the diet, the weight was just going' (Person living with mesothelioma, 03)

Whereas, for another participant as illustrated in the following quote, her experience of symptoms was multifaceted including physical symptoms and low mood, that impacted on her appetite:

'I don't know if I was just getting a bit too concerned about why I should be so breathless...I just didn't want to eat anything...I just didn't fancy much...I think my mood was a little bit, because your brains just thinking what can be wrong... I would get to the top of the stairs; I would have to stop and think 'gosh I've just walked up the stairs...why should I be like this, and I thought there's something not right here' (Person living with mesothelioma, 10)

Participants described a loss of appetite whilst undergoing treatment for mesothelioma, such as surgery, chemotherapy, immunotherapy, and/or a pleural effusion. This was attributed to

treatment side effects such as changes in taste and smell. Some of the participants described being less physically active during receiving treatment, highlighting problems with sleep and treatment related symptoms such as pain and fatigue, which may have affected appetite. The following described how a pleural drain caused painful symptoms, lack of sleep and fatigue which in turn impacted physical activity:

'I've got a drain because they had to drain some stuff of us now it is hurting... and at night time if I move it just, 'oh the pain just shoots', it's just like instant like a stab, it wakes us up...a few times during the night, and I'm not getting a lot of sleep and I feel tired during the day...see I used to go for a walk every day, at least eight thousand steps and now I'm that tired I don't bother' (Person living with mesothelioma, 01)

Others described that appetite loss may be a normal part of ageing since retirement and because of problems with chewing/swallowing food. Informal carers recognised that their relative experienced weight loss and appetite problems.

Theme 2: Taking Each Day at a Time: Physical and Emotional Experiences

Participants described taking each day at a time in opting to eat foods that were appetising, and this was influenced by how they felt physically and emotionally, for example, feeling bloated, pain, fatigue, and low mood. Some of the participants reflected on inactivity and muscle weakness/loss of strength as contributing to their experiences. As illustrated in the following quotes:

'The only thing I can think of is nerves, depression due to the fact I can't do anything... when you're just sitting you can't clear your mind' (Person living with mesothelioma, 07)

'I might be fatigued, I might feel tired, I get tired a lot, I get fatigued really badly and it's a bit of a chore sometimes rather when I just want to lie down' (Person living with mesothelioma, 05)

Symptoms impacted the participants desire for food. They explained that they 'couldn't be bothered to eat', as at times it was too much of a physical effort. They had lost interest in food due to changes in taste. Eating habits were altered including smaller portion sizes because of early satiety. As presented in the following quotes, participants described a change in their eating habits:

'Even though I was enjoying it two minutes ago, I just get bored of it, and I leave it... It is an effort if there's too much, it's an effort if there's too much of it' (Person living with mesothelioma, 08)

'My eating habits are poor; I don't eat enough food... my eating habits have change dramatically since I was diagnosed with mesothelioma... because I've lost my appetite and I've lost my get up and go in relation to food to be honest...I've lost interest in food and cooking' (Person living with mesothelioma, 05)

Coping with mesothelioma and undergoing medical intervention was a physical and emotion journey contributing to psychological well-being, therefore affecting appetite. Appetite was not impacted when individuals felt that they were in good physical and emotional health typically those who were not symptomatic. The influences on poor appetite are represented in Figure 1.

Theme 3: The Role of the Informal Carer: Managing Diet and Coping.

The informal carer (wife spouses of relatives) took on the lead role of managing their relative's diet. They encouraged eating and discussed their understanding of the importance

of adequate food intake. They reflected on their relative's weight loss and appetite loss and attributed this to mesothelioma. Carers managed their relative's diet by also taking each day at a time, but this came with challenges. It became part of the daily thought process in thinking about what their relative may want to eat and in planning their relatives' meals. One carer maintained a daily record of meals to avoid repetition. Planning meals was therefore difficult as appetite constantly changed, depending on physical and emotional symptoms. The following carers described how they coped with their relative's relationship with food, from finding ways to encourage them to eat to accepting their new eating habits:

'This moment in time it's really difficult to tempt him to eat things and you've got to go through the whole rigmarole of what we've got in the house to tempt him to eat, but you start on this process and you think you're first reaction is, when he was diagnosed, 'right got to get you fit, eating well' and then off course you go through the period where he just doesn't want to eat at all so you're quite happy for him to eat anything' (Carer 11, Wife)

'It is stressful but it's just the way it is, I can't change it so I've just got to try and accommodate it best I can...well for me if he wants it he's going to have it, so as much as I say to him today 'no we'll have sausage and mash with a load of veg' he's 'no I want a Chinese and that's that' ...I just eat whatever he wants, I just go along with it for peace and quiet, it's easier' (Carer 04, Wife)

'I would like him to eat more but I think I've accepted that it's not going to happen, and I've just got to give him what he fancies at the time and then sometimes I'll say, 'do you want a bit more or' but it's not usually the case' (Carer 08, Wife).

Some of the participants described how they would eat less if their carer did not manage their diet and prepare a meal. Some of the carers experienced dietary changes in opting for

readymade meals, and one carer had lost their own appetite due to the psychological impact of the uncertainty of the diagnosis and treatment of their relative.

Theme 4: The Challenges with Dietary Advice

Approaches to ensuring adequate food included the use of oral nutritional supplements that were self-sourced or provided by the hospital and support from family and friends such as providing food, but this often went to waste because of the changes in appetite. For one participant who lived alone, they described a range of approaches to self-manage their diet i.e., bulk cooking, family and friends prepared his food for him and the use of new cooking appliances to ease his difficulties. The following quote highlighted the perceived benefit of using oral supplements to prevent weight loss but they impacted on dietary intake due to feeling fuller quicker:

“Because my wife’s getting us some supplement...I’ve got to mix with milk and I drink that in the morning and maybe that is filling us up and I don’t want to eat...I would have lost a lot more weight if I wasn’t taking this” (Person living with mesothelioma, 01)

For those participants who had received nutrition advice from a nurse, they were advised to add high calorie foods into their diet (i.e., cream, whole milk, and chocolate) however, this approach was not felt as being tailored to their specific dietary needs and nutritional habits as illustrated within the following quotes:

‘If you have a word with the dietician and she, he or she is having to say, ‘well feed him a cream cake’ I’m sorry that’s a no go because I’ve never been into them for years, well never really, you walk past the counter and you see the nice look, this bun with cream, ‘oh no’ (Person living with mesothelioma, 07)

'They told me I've to eat a lot of chocolate and mars bars and cheese and stuff I never ate you see...the doctors and the nurses to keep the weight on, but you see I'm not used to shoving a chocolate down my neck and I'm not a drinker...well everything I ate came out the garden, I'm eating Spring Cabbage' (Person living with mesothelioma, 10)

All the participants who were interviewed were open to receiving further dietary advice and support from a dietician. They would seek advice from the mesothelioma specialist nurse, and they would access the internet for dietary resources.

Discussion

The aim of this study was to develop a better understanding of the experiences of appetite and diet in people living with mesothelioma and their informal carers. The findings offer important insights into opportunities towards informing the development of effective interventions that provide meaningful benefits for individuals living with mesothelioma and their family.

Four themes were generated that provide useful data for healthcare professionals to consider when providing best supportive care for people with mesothelioma and their informal carers. In this study, the participants with mesothelioma described unintentional weight loss and appetite loss during treatment with symptoms that fluctuated over time. In patients with malignant pleural mesothelioma protein needs to exceed recommendations to preserve skeletal muscle mass (5) and a whole food approach is the best approach to maintain nutritional need (9). However, some individuals may find a whole food approach difficult as they have a poor appetite due to their cancer (26). Nutritional therapy alone may therefore be of limited efficacy in cancer patients whose nutritional statuses have already deteriorated (27).

The participants in this current study managed their diet by opting to take each day at a time depending on how they felt both physically and emotionally, and some had lost a desire to eat. The impact of mesothelioma is multidimensional on physical symptoms, emotional functioning, and has social consequences (4). When patients are malnourished, they are more likely to feel fatigued and have a poor quality of life (15). However, for some individuals manipulating dietary intake and consuming certain foods have found to be used to help people live with other symptoms, such as weakness and fatigue (28). The difficulty of controlling physical symptoms is challenging and sometimes embarrassing for patients (29) and severe symptoms can trigger psychological reactions (30). A lost desire to eat can lead to feelings of inadequacy, self-blame, and guilt (28). In this current study, some of the individuals experienced low mood and in people with advanced cancer, anxiety and depression can worsen appetite. People with advanced cancer expressing a high frequency and intensity of physical symptoms could be screened for mood disorders to determine appropriate treatment (31).

As identified in this current study better symptom management has previously been highlighted as an area of improvement in mesothelioma, including better management of the uncertainty of the diagnosis and of treatment outcomes (4). These factors may intensify the illness burden and interventions could focus on symptom control (4) while differentiating between symptoms that could be attributed to mesothelioma and those attributed to treatment. For example, Williams and colleagues (2018) reported that both mesothelioma and treatment of mesothelioma lead to pain, fatigue, and shortness of breath whereas nausea, vomiting, trouble remembering things and poor sleep quality were symptoms attributed to treatment rather than the mesothelioma itself (32). For some individual's symptoms seem poorly controlled despite healthcare interventions (4). Yet, simple interventions such as non-

pharmacological breathlessness management (e.g., relaxation exercises) can play an important role in coping with symptoms (33).

In this current study, the participants who were carers played a role in managing their relative's diet. Many people living with mesothelioma are concerned with the effects of the illness on family (3). A family member who assumes the role of the caregiver (usually a spouse) supports the patient throughout the various stages of mesothelioma (34). Undertaking this role impacts on carers' own physical, emotional, and social well-being (4). Caregiver burden can often be overlooked, and carers are at risk of developing their own problems (35). Dietary intake patterns may change, they experience poor nutrition, sleep disturbances, tiredness, feelings of anxiety and helplessness (34). Carers of people living with mesothelioma have expressed that they would like to talk to someone by themselves, require more time with doctors, psychological support, and clearer information (36).

Loss of appetite is a source of anxiety and conflict within the family and relatives of cancer patients are more likely to report anxiety in relation to anorexia (37). Some family caregivers have reported controlling the patients' food intake to the point of calculating calories (38) and tension around food and eating can cause mealtimes to become difficult or even dreaded events (28). Previous work has reported that caregiver anxiety is more pronounced in female than in male carers because the inability to eat impacts upon her customary role identity (33). For example, preparation and serving of food is an expression of love and care, underpinned by knowledge that intake is necessary for survival (39). Although people with cancer appreciated the family assistance particularly relating to food preparation and dietary advice provision they viewed appetite problems to be of less concern than other problems, and voiced a preference to have their family members focus less energy on encouraging them to eat and respect their wishes to cope with eating problems their way (39). The adherence to a

specific diet may increase patients' sense of control over the disease, fostering the idea of having a positive impact on quality of life (35).

In this study, participants with mesothelioma had experienced unintentional weight loss and the participants who were carers described ways in which they promoted food intake. Some implemented their own nutritional strategies and various challenges were identified with dietary advice. For example, the advice to consume high calorie foods was not individualised to their dietary habits. Other studies have highlighted that dietary advice provided by dietitians was not specific to each patient's needs (28,38). Health care professionals could work towards optimising the patient's nutritional situation from the time of cancer diagnosis. Integrating dietitians as members of the health care team would enable to offer better dietetic advice and assist in developing coping strategies throughout the illness process (38).

People living with cancer and family caregivers have previously been identified as having their own unique ways to deal with symptoms of weight loss and malnutrition. They have expressed how they have used diet and exercise regimes as interventions to improve their mental health and well-being. However, there are differing support needs for men/women, patients/carers, and military/civilians (40). Other strategies have included obtaining dietary information from the mass media and internet and testing strategies suitable for meeting patients' nutritional needs such as use of ingredients, tastes, consistencies, sizes, or texture of food (41). In this current study, the participants described how they would seek dietary advice and support from the mesothelioma clinical nurse specialist (CNS). Mesothelioma United Kingdom (UK) CNS's play a crucial role in supporting patients' and families palliative care needs and are highly skilled in providing this care (40). Dietary advice is more frequently provided by dietitians to improve the nutritional status of patients, compared to nurses delivering the advice (42) and nurses had low expectations of being able to help alleviate the difficulties patients and their families faced in consequence of changed eating habits (28).

Little is known about how mesothelioma CNSs provide nutritional care for people living with mesothelioma and their informal carers and their perspectives would be invaluable in shaping how care pathways and service delivery can be improved.

Study Strength and Limitations

A strength of the study was that the participants varied in the time from their diagnosis, enabling to capture views throughout the diagnosis and treatment pathway. This represents the variability of prognosis in mesothelioma patients. However, most of the participants were men, and this limits the views of women diagnosed with mesothelioma. We did not capture the appetite status of those living with mesothelioma to classify good, average, or poor appetite.

Conclusion

This qualitative research study has provided a more holistic understanding of how people living with mesothelioma and their informal carers experience appetite and diet. Appetite was viewed as a multidimensional experience and was grounded within the biopsychosocial model. The findings offer important insights into opportunities towards informing the development of effective interventions that provide meaningful benefits for individuals living with mesothelioma and their family.

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