Mental health and wellbeing in mesothelioma: a qualitative study exploring what helps the wellbeing of those living with this illness and their informal carers.

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Mental health and wellbeing in mesothelioma: A qualitative study exploring what helps the wellbeing of those living with this illness and their informal carers

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ABSTRACT

Purpose: Mesothelioma is an incurable, asbestos related cancer with a poor prognosis. Little is known about how patients and carers living with the condition manage their mental health and wellbeing needs. This paper reports findings on interventions being used by patients and informal carers living with mesothelioma and those which they find most helpful.

Methods: In-depth interviews with patients (n = 10) and (informal) carers (n = 11) living with mesothelioma in the UK. We analysed our data inductively using a reflexive thematic analysis approach.

Results: Participants described the importance of both smaller and larger actions and strategies which helped with their mental health. This included spending more time with family and friends and going on holidays. Professionals who participants said supported their mental health journey included not only specialist nurses and mental health professionals but also legal and Asbestos Support Group professionals. The latter demonstrates the unique needs and support required for this population. Exposure to asbestos as the cause of mesothelioma, has led to a social justice aspect of the experience of living with this cancer. Participants reported the importance of collective action to their mental health and wellbeing. The data indicate that patients and carers may have distinct mental health and wellbeing requirements and need to manage these in different ways at different times.

Conclusions: Findings have implications for nurses and other key professionals working in healthcare, community and legal settings supporting this client group, and for those living with mesothelioma who want to understand ways to enhance their own wellbeing.

1. Introduction

Mesothelioma is a rare, incurable cancer with a poor prognosis. In the UK, around 2700 people are diagnosed with mesothelioma each year. In 2020, there were an estimated 30,870 mesothelioma cases reported globally (Huang et al., 2023). There is a consensus that mesothelioma patients face unique challenges to their mental health and wellbeing compared with other cancers. This is due to its incurability, high symptom burden, and its cause, asbestos exposure Ball et al. (2016); Bates et al. These elements highlight the need for mesothelioma specific research into the mental health impact and interventions that may be beneficial for patients and their informal carers.

Recent literature reviews have found that psychological symptoms reported by patients and carers living with mesothelioma included stress, anxiety and depression (Sherborne et al., 2020; Ejegi-Memeh et al., 2022). These findings have been echoed elsewhere (Dooley et al., 2010; Mercadante et al., 2016; Walker et al., 2021). There is also evidence to suggest that some people living with mesothelioma may experience symptoms similar to Posttraumatic Stress Disorder (PTSD) (Dooley et al., 2010; Borgogno et al., 2015; Bonafede et al., 2018). The effects of receiving a diagnosis of mesothelioma are often devastating for patients and their informal carers (Taylor et al., 2019).

Recent studies in the field of mesothelioma have recommended that patients' mental health needs be addressed, for example, by supporting them 'to find meaning in their lives' (Walker et al., 2021) and referring to psychological counselling (Girgis et al., 2019). Informal carers'

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mental health needs have also been identified as important (Ejegi-Memeh et al., 2022; Harrison et al., 2021; Moore et al., 2023). An additional factor for consideration is that mesothelioma is an industrial disease. Those living with the condition in the UK and other countries may be eligible for financial compensation from the government or former employers. It is assumed that compensation can afford a higher quality of life for patients and their informal carers. Legal settlements sometimes enable people to access new evidence-based treatments not currently funded by the NHS. However, this element of the mesothelioma journey and the impact it has on mental health has not been explored before. To our knowledge, only one research group has focused on a specific intervention for mental health symptoms in mesothelioma patients and informal carers: group psychoanalytic therapy in a site contaminated with asbestos in Italy (Bonafede et al., 2020). However, there has not yet been an exploration of what patients and their informal carers do to alleviate mental health and wellbeing issues. This study therefore makes a significant and novel contribution to the evidence base around the quality of life for people living with mesothelioma. New treatments have led to increased longevity for people diagnosed with mesothelioma. Therefore, to focus on interventions that improve the quality of life alongside quantity of life is imperative.

This paper reports findings on interventions being used by patients and informal carers living with mesothelioma and those which they find most helpful.

2. Methods

This qualitative study was embedded within a larger mixed methods study which aimed to understand the impact of mesothelioma on the mental health of patients and informal carers (see Sherborne et al., 2024). Within this publication, we focus on the findings that indicate what current psychological interventions are being used by patients and their informal carers.

There is no explicit definition of what constitutes a 'psychological' intervention in the context of cancer care (Hodges et al., 2011). For the purposes of this study, we used a broad definition which encompasses 'anything that participants stated improved their mental health and wellbeing'. This included formal and informal interventions. Formal interventions were considered pharmacological therapies and psychotherapies (a general term which describes the process of treating psychological disorders and mental distress through verbal and psychological techniques (Cherry, 2021)). Informal interventions included any activities that generated a sense of mental health and wellbeing, for example, sitting in the garden, spending time with family or travelling.

Research ethics approval was obtained from the University of Sheffield Ethics Committee (044300) prior to beginning data collection. All participants were provided with an information sheet with study details and gave written and/or verbal informed consent prior to taking part in interviews.

2.1. Recruitment

Participants were recruited via a questionnaire which was distributed at an earlier stage of the study. The questionnaire was circulated by national and local organisations working with people with mesothelioma, and via social media. The questionnaire inclusion criteria stipulated that participants were living with mesothelioma or informal carers (current or bereaved) of someone living with mesothelioma, lived in the UK, were over 18, were able to read/write English and had the capacity to consent. A final question on the questionnaire asked for respondents to provide their email address if they were happy for the research team to contact them to take part in an interview. Fifty-two people who identified as patients and carers provided their email addresses. Purposive sampling was used to ensure a range of participant characteristics, for example, age, gender and location in the UK.

2.2. Data collection

Semi-structured interview schedules were developed drawing on the research teams prior experience and in consultation with the Mesothelioma UK Research Centres Patient and Public Involvement Panel. Ten people living with mesothelioma and 11 carers took part in audio-recorded semi-structured interviews between October 2022 and February 2023. Nineteen individual interviews and one joint interview were conducted. Individual interviews were preferred by the research team rather than dyads as it was thought that this would allow participants to express themselves more freely (Mellor et al., 2013). Interviews were conducted by female interviewers, VS, SEM or BT, either online or via a telephone call depending on the participant's preference. Participants and interviewers did not have established relationships prior to study commencement.

Mesothelioma is a rare cancer and as such, we describe demographics in narrative form to avoid participant identification. Patient participants ages ranged from 32 to 75. Four men and six women patient participants took part. Their length of time since diagnosis with mesothelioma spanned 3 months to 3 years. Seven patients were living with pleural mesothelioma and three were living with peritoneal mesothelioma (peritoneal mesothelioma is a less common form of mesothelioma). Informal carer participants ages ranged from 29 to 71. Two men and nine women took part.

All interviews lasted between one and 2 h. The interviewers had weekly team meetings with AT to discuss the interviews and data. Audio recordings were transcribed verbatim by an approved transcription service and reviewed for accuracy before anonymisation. Anonymised transcripts were uploaded to Quirkos, computer-assisted qualitative data analysis software.

2.3. Data analysis

We used Braun and Clarke's six phases of reflexive thematic analysis (familiarisation with the data, generating initial codes, searching for themes, reviewing potential themes, defining and naming themes and producing papers/reports) (Braun and Clarke, 2006, 2019). Reflexive thematic analysis was chosen because due to the sensitive and complex nature of mental health, we wanted to spend a considerable amount of time reflecting on the initial codes before developing the themes. A second reason for choosing reflexive thematic analysis was that our research team comprises mental health professionals, health care professionals and people with experience of a mesothelioma diagnosis. As such, this is a topic area that we all brought personal and/or professional experience to. Therefore, we did not feel able to separate ourselves from our interpretation of the data. This lack of separation between the researcher and the research is a central tenet of reflexive thematic analysis (Braun and Clarke, 2021)

We used flexible coding processes with codes added, merged and split throughout the analysis process. Semantic-level (descriptive) approaches to coding and theme development were used to capture and stay close to participants' verbatim statements. Initial codes were developed collaboratively with the data being coded by multiple researchers, VS, SEM, AT and BT. A shared Google document and weekly team discussions ensued. A preliminary list of 58 initial codes was drawn up which were subsequently merged into 24 codes.

Themes were generated by identifying patterns of shared meaning in the codes and data, united by the central idea of mental health interventions. Themes were developed in relation to our research question of "What current psychological interventions are being used by patients and informal carers living with mesothelioma and which do they find most helpful?"

2.4. Reflexivity

Our research team comprises academics, health care professionals, counsellors, and people with lived experience of mesothelioma and lung cancer. Throughout the process of developing and conducting the study, we have been deeply reflexive. All authors have engaged in discussions regarding the focus and wording of the study when it was in development. Interviewers kept reflexive journals and made notes during and after interviews. Reflection was also done through frequent conversations about our role in the data collection and analysis process and checking with each other about our interpretations of participants' words.

2.5. Quality

We have used Braun and Clarke's (2020) 20 question tool for guiding the assessment of reflexive thematic analysis. This is evidenced through justifying our use of reflexive thematic analysis, clearly articulating our analytical procedures and through reflecting on our positions as researchers and professionals.

As more general evidence of quality, the data collected is rich in nature. This is due to the openness of participants, the interviewers' extensive familiarity with the population and topic of mental health and wellbeing, and lived experience of one of the co-authors as a lung cancer survivor. Additionally, six of the 21 transcripts were coded by more than one researcher, and in our results section, we draw on data from across the data set.

3. Results

Three themes report on psychological interventions used by patients and informal carers living with mesothelioma to manage their mental health and wellbeing. These were: 'self-management strategies', 'support from professional services', and 'social connections and communication'.

A further cross-cutting theme of 'separate mental health journeys for patients and informal carers' is also discussed.

Pseudonyms are provided for participant quotes. The following identifiers are used.

First character: P= Patient/C=Carer
Second character/s: Interview number.
Third character: Gender (self-identified) M = man/W = woman.
For example, Ray P1M

3.1. Self-Management strategies

Participants managed their mental health and wellbeing in part by adopting small, quotidian ways. These included finding joy in exercise, nature, laughter and having family and mile-stone events to look forward to. The importance of these activities to mental health and wellbeing was evident through the frequency with which participants discussed them. Distraction was also often discussed as a useful tool for managing at times when mental health became challenging.

Participants were aware of the connection between good physical and good mental health and wellbeing with several participants noting the importance of exercise to promote good mental health. Patients used the amount of exercise that they could do as a measure of their physical health, but the act of exercising also improved their mental health:

> "… if I feel physically fine, I feel mentally fine." SIAN P2W

> " When I come back from my hour's cycle ride, for example, I'm ready to take on the day." SUSAN P4W

Aligned with this awareness of the connection between physical and mental health, some participants experienced a sense of loss because they could no longer manage what they used to do physically. Participants therefore made adaptations which meant that they could continue to do sporting activities that they enjoyed:

> "I love [my sport]. … And so last year in May, I did go back, and I could [play a bit] and that was it. I persevered and got myself in a position. I've found, I bought this stick because I need to use this stick to get around." ANN P3W

Closely linked to exercise was the value of nature to mental health and a sense of wellbeing. Susan's quote below highlights that participants were aware of what made them feel good even if the underlying mechanism to feeling good was unknown to them:

> "When I go out in the countryside, which I love to do all the time, and I go up the hills and I feel wonderful. Why do I feel wonderful when I go up into the fresh air and up the hill? The mental side of it. I mean, why? Emotion and feeling is a very interesting and important point, but I do, I feel terrific." SUSAN P4W

Humour was another strategy used. Participants acknowledged that they had developed a "morbid" sense of humour. Laughter was important and injected much needed lightness into their daily lives:

> "… you have to joke about it and we all say … so I tell them, I've got a cancer card and I'm only allowed to play the cancer card once a day. So we were in the kitchen and [husband] said, come on, it's your turn to make the cups of tea, and I said like, oh, I've got lung cancer, and [daughter] was like, you can't use it to make the bloody tea." ROSE P6W

Diagnosis, waiting for scan results and for the carers, bereavement, were described as challenging. Distraction was a useful tool at these times, particularly for patients:

> "my biggest coping strategy is keeping busy, and not having time to think." FREYA P5W

In contrast, informal carers often expressed a real need to be able to speak openly with others about the illness rather than using distraction as a coping mechanism:

> *" [Patient] just wanted to block it out, I suppose, what was going on. So he never really wanted to speak to anyone about it. So I think we kind of never did."* NATASHA C10W

This highlights that what is helpful for patients may not be helpful for carers at times. Other carers also discussed putting their own mental health and wellbeing needs aside to prioritise the person living with mesothelioma. Some bereaved carers highlighted that they neglected their own mental health and wellbeing needs whilst their loved one was alive:

> *"… it is imperative to look after your own mental health, because I spent a lot of time worrying about mum's mental health, and dad's mental health, and not really thinking about my own, and probably in hindsight I should have spent a bit longer thinking about my own"* AMBER C1W

Religion and spirituality were described as helpful in both practical and philosophical ways. However, this was sometimes challenging when patients and informal carers had different views on religion or when the informal carer wanted to have a frank discussion but the person living with mesothelioma did not.:

> *"she's incredibly religious, which is fine, but she doesn't … it's quite hard to get the human aspect out of her to be able to have a one to one chat on a human type level."* ISLA C8W

Participants reported the contribution of smaller, quotidian joys (e.g. spending quality time with family, going for walks) aa well as larger more extravagant ones (e.g. buying new cars, booking holidays, contributing to family members house renovations).

> " I had little things to look forward to so I'd be like … and honestly, I'm not kidding, I spend my life in garden centres, I really do. I wasn't

> joking when I said that but I have lunches and coffees and cakes and, you know, I fill my days with really lovely things" ROSE P6W

> "I always make sure that we've got a holiday planned or like a trip away. It doesn't even need to be like a big trip" SIAN P2W

This theme reflects both the range of self-management techniques participants reported but also different strategies used, or needed, by patients and informal carers at different times. Participants often had clear notions of what worked for their mental health and wellbeing or, particularly for bereaved carers, what they would have done differently to manage their mental health and wellbeing. In these strategies there was also a balance between being in the moment and planning for the future.

3.2. *Support from professional services*

A range of professionals were reported to support the mental health and wellbeing of people living with mesothelioma and their informal carers. This included healthcare professionals, Asbestos Support Groups, legal professionals as well as mental health specialists, such as psychologists and counsellors.

Healthcare professionals played a key role in providing emotional support and reducing stress through assisting with navigating health care systems. Symptom control was another area in which healthcare professionals made a difference to the mental wellbeing of participants.

Within the context of receiving a diagnosis of mesothelioma, feeling supported by health care professionals ameliorated the negative impact on mental wellbeing:

> " I ended up meeting Professor [consultant] and he was lovely and I met [mesothelioma clinical nurse specialist] and they were lovely and he was like very positive and [the mesothelioma clinical nurse specialist] was very nice and he was like, oh, we don't know what your journey's going to be like but we're going to be here to support you." SIAN P2W

Healthcare professionals played an important role in providing realistic hope and expectations. Participants reported several instances when this was done well. Participants did not expect their healthcare professionals to know everything. The provision of support and feeling that they were "held in mind" by their professionals was more important.

Participants accepted that death may be imminent but feared the associated suffering or poor symptom control. Healthcare professionals played an important role in either reducing this fear through the provision of information and reassurance or through the good management of symptoms:

> "I think if death has no fear for you, you can go into it in quite a calm. And there's nothing wrong with that. [But] Not being able to breathe. It's the breathlessness. And that feeling where, [gasping]." ANN P3W

Healthcare professionals and the associated healthcare organisations also play an important role in supporting the informal carers, with specific initiatives being mentioned as beneficial:

> "[Name] Hospice were very good about asking me, you know, if I needed anything. Before [husband] got really poorly, we used to go down to [name] Hospice, before COVID, and they had carers' day, you could go and get your nails done, you could have a chat with other people who had lost their husbands to cancer. So that was a way out for me, if you like." LAURA C5W

Several bereaved carers discussed the importance of Clinical Nurse Specialists and hospices in providing emotional support, particularly after the death. Instances where participants were provided with individualised care which paid close attention to their needs in the moment, were highly valued:

> "The head honcho in the hospice, she was a lovely woman, and I used to meet her on my visits there and she…she was good…you know, she was…gave me big hugs all the time, and one time she said, just after [wife] died, I saw her and she said, I'm sorry, I'm on my way to a meeting, and she said, oh bugger the meeting, she put down the stuff, gave me a huge hug and talked to me. She said I can be bloody late if I want, I'm in charge.
>
> I: Oh. How did that feel to you then when she did that?
>
> R: I felt warm and…you know, really warm and it was just like somebody giving me a blanket. You know, putting a blanket over me. It was…it was really lovely." SCOTT C9W

Our participants reported the variability regarding who has access to specialist mental health support, such as psychologists and counselling. Those who did have this support, however, spoke about the benefits:

> "I've never had any opportunity. Tell me who I've talked to? It's very difficult to talk to anybody. What I mean by that is, the only phone numbers I've got are call centres, that they'll put me on to a clinical nurse or a Macmillan nurse … I would have liked it [to speak to a mental health specialist] from the very beginning. What do I do? How can I manage? Who can I talk to?" SUSAN P4W

> "I did feel that the psychologist's sessions were useful, I would recommend it, 'cause they give you coping strategies, and things like that." FREYA P5W

The area of access to professional mental health support was another arena in which the needs of informal carers could be overlooked. As well as reports of informal carers neglecting their own needs, there were examples of professional services inadvertently overlooking the needs of carers:

> "There was definitely a lot of focus on [husband], which is absolutely right, but very little, unless you initiate it, I suppose, as a carer." LAURA C5W

Unique to mesothelioma, Asbestos Support Groups and legal professionals provided support for patients and informal carers, helping navigate complicated benefits and legal systems. This navigation role alleviates the administrative and financial burden for patients and informal carers which impacts upon their mental health and wellbeing. These services were reported to be pastoral and invaluable to their quality of life.

> I: How did it make you feel that she [ASG professional] was coming and doing all that [benefits paperwork]?
>
> *Fantastic. Absolutely fantastic, because I wasn't fully well myself and the thought of going through a 45 page form with [wife], which would be quite hurtful to her, you know, some of the questions asked, I was just totally elated by this person.* JIM C2M

> "I have had a call from the lady that manages [ASG], she checks in on me every now and then … it's nice to think that someone's looking out for you." JENNY P10W

Providing access to financial benefits and compensation ensured that patients could engage in activities described in the previous theme, access private healthcare and non-NHS funded treatments when necessary and were able to financially support their family members:

> Ray P1M*: With compensation, obviously, I know that I'm going to be leaving me children a nice little present.*
>
> Interviewer: Is that important to you?
>
> Ray P1M*: Yeah, it is because, look, beforehand, I'm a working man, but I had no money. Look, even though we're going through this current crisis, it's like … I don't mean to be blasé. I don't like it, but I know I can afford to do what I want to do. So the compensation has given me that luxury.*

> *But it's also going to mean that my children will get a nice little nest egg as well, so I'm glad that I can do that."*

> "at the moment, like, my daughter, she's having a lot of work done on her house, lot of alterations, walls coming down, et cetera. So this out here has been like a laundrette, but it was expected, you know. And that's probably one good thing that came out of it, was, I was able to financially support that."

The quotes above demonstrate the importance of financial compensation to the participants as one way of supporting their families through the mesothelioma journey. As we discuss in the next theme, the provision of and the receipt of familial support was important to the mental health and wellbeing of participants.

3.3. Social connections and communication

Focusing on relationships with loved ones, making links with others with lived experience of mesothelioma, and campaigning for change were ways in which patients and their informal carers dealt with a diagnosis of mesothelioma. Some participants also expressed that they had become "philosophical" about life, and expressed that the time post-diagnosis, and even post-bereavement, had provided an opportunity to prioritise their relationships and time with friends and family:

> "This last 18 months of my life has been really good, probably better than it would have been. You know, could have been without a disease, I mean, because I've done more and I've been more positive, and so have my friends and family, about doing it." SUSAN P4F

> "Since he's died, I'm very much I want to make as many memories with my kids as possible because I always think he missed out on all of these things, so let's still do them so that I have all these memories of my children. Because life is too short and you need to make the most of it and having things to look forward to is always really good, like living life as much as you can." AMBER C1W

One way in which the mental wellbeing of participants was improved was by ensuring that their loved ones were "doing well".

> "… so the things for me that I get enjoyment from are finding out how my daughter is doing at uni and, yeah, I got to hear her final exam results in May, and she's gone back and she's doing really well." ANN P3W

Outside of the family, participants expressed that making connections (in person and online) with others living with mesothelioma helped with the loneliness experienced after being diagnosed with this rare, asbestos related cancer.

Given the context of the Covid-19 pandemic, social media and online connections were frequently reported as a key way of nurturing social connections. Social media was an important source of information and support for mental wellbeing. Additionally, given the rarity of mesothelioma, social media provided an opportunity to feel part of a tight knit community despite being separated by geographical distance, through for example, mesothelioma Facebook groups. It was also a way to let people know that they were cared for.

> Like, obviously it's only Facebook posts, but a lot of people like it, or they put a caring emoji, or they'll put a comment. You know what I mean? We're thinking of you. That kind of … just supportive, right? RAY P1M

However, for some, social media spaces were perceived as negative due to frequent notifications of death. One participant mentioned silencing their social media notifications as a way to protect mental wellbeing. When individuals used social media in ways which they perceived as beneficial e.g. muting notifications, moderating the information they made public, this was advantageous for mental health and wellbeing:

> "I went to see him [counsellor] and he said, you know, why don't you just silence them? Like turn the notifications off and when you feel prepared or when you're ready, you can dip in them and read what you want and then dip back out of them again and you're not constantly reminded of those. I thought, what a good idea, so I silenced them all." ROSE P6W

Participants felt angry regarding their exposure to asbestos and having been diagnosed with mesothelioma and some channelled this anger into campaigning for the removal of asbestos or compensation from those who had exposed them. The ability to release and validate their anger and frustration provided therapeutic value:

> "I went recently to a demonstration about this asbestos company called Cape. [.] It was like sort of shouting therapy. I was really shouting, like 'Shame on Cape! Cape must pay!' [.] I came away just feeling really good, and expressed some of that anger. And being in a group of people with that same anger." OLIVIA C4W

However, one participant discussed the potential for activism to become obsessional. Participants expressed the importance to them of a public recognition of the injustice of being exposed to asbestos and that they were a part of a larger social justice movement:

> " I went to that church service, obviously it did touch a nerve because I sat there and cried through it. I suppose, yeah, be aware that you are part of … you're not … you're part of a group, it's an individual thing but you're all part of a group, we're all linked by this tragedy of asbestos […] it's like a recognition, isn't it, of my dad is caught up in this collective trauma tragedy of asbestos." OLIVIA C4W

Olivia's phrase "collective trauma tragedy of asbestos" highlights the devastating impact of contracting this asbestos related disease, and how recognition of this fact can also provide therapeutic value.

4. Discussion

Our findings show that patients and informal carers used a wide and varied range of techniques to manage their own mental health and wellbeing. Through rigorous qualitative analysis, we have been able to capture the type of strategies used by patients and informal carers living with mesothelioma. Navigating complex legal and health services is a unique aspect of living with this rare, asbestos caused cancer. For some, this brings with it a sense of injustice and drive to campaign for change. This highlights the important position and role of legal professionals and advocates in supporting people affected by mesothelioma and shaping their experiences, in addition to health care professionals. The role of familial and friendship networks, both in person and online, play a key role in the mental health and wellbeing of patients and carers living with mesothelioma.

Our findings make a novel contribution to the existing evidence base in three key areas. They improve understanding of the strategies patients and informal carers use to manage their mental health in the context of mesothelioma, they highlight the contributions that legal and Asbestos Support Group professionals make, and they focus on the importance of social connections when living with mesothelioma.

The wider mesothelioma literature often focuses on developing vital recommendations for health care professionals and systems to improve the care provision for individuals and families living with mesothelioma (Ejegi-Memeh et al., 2021a,b; Henshall et al., 2021; Taylor et al., 2019; Warby et al., 2019). Our findings complement this work by also bringing to the fore, actions that people living with mesothelioma adopt to improve and maintain their own mental health and wellbeing. This included doing things that they enjoyed (both in the short term and cautiously planning longer term activities), using humour, distraction and spirituality.

Often the importance of the little things that bring great joy to people in the context of a rare and incurable disease are overlooked in the literature, therefore we felt it important to capture this here. However, it is necessary to note that we fully acknowledge the devastating impact of a diagnosis of mesothelioma and the challenges that it can bring. It is not our intention to inadvertently cause harm to wellbeing through the enforcement of a positive thinking narrative (see Tod et al., 2011).

A recent study reported coping mechanisms in patients living with mesothelioma (Demirjian et al., 2024). Their findings align with ours with emotional support and self-distraction scoring highly. Humour as a coping mechanism was also found in our study of veterans living with mesothelioma (Ejegi-Memeh et al., 2021a,b). Many of our participants were using ecotherapy to manage their mental health and wellbeing. Ecotherapy comprises different types of nature-based methods to increase physical, but especially psychological wellbeing, including self-help (Rueff and Reese, 2023). Participants' nature-based activities such as dog-walking and cycling with friends combined multiple mental health and wellbeing benefits, i.e., social connection, exercise, distraction and gaining control. Ecotherapy has been shown to bring improvement in anxiety, depression, fatigue, and pain for cancer survivors, with participants reporting nature as their most important resource in coping with their illness (Timko Olson et al., 2023).

The role of hope and posttraumatic growth are rarely explored in the mesothelioma literature (Walker et al., 2021; Sherborne et al., 2020). This may be because, until very recently, life lengthening treatments were limited. The wider cancer literature touches on the subject of empowerment and positive aspects of life in the context of a cancer diagnosis but in the mesothelioma literature, there is little exploration (Avery et al., 2023; Li and Loke, 2013; Brown and Brown, 2014). In reporting the times when people living with mesothelioma described feeling good, we have provided information which may be used to improve experiences of other patients and carers.

Our findings reflect the wider literature to show that a range of professionals contribute to the mental health and wellbeing of patients and carers living with mesothelioma. Mental health professionals played an important role in supporting mental health and wellbeing. Some interventions were expected for those living with advanced cancer, such as talking therapy and support from health care professionals (Malakian et al., 2022). Within the wider mesothelioma literature there is a consensus of the important role that Clinical Nurse Specialists play in supporting the mental and physical needs of people living with mesothelioma (Moore et al., 2015; Davey and Henshall, 2021; Harrison et al., 2021; Henshall et al., 2021). Our study reinforces this finding. The wider cancer literature also highlights the importance of ensuring that patients and their informal carers have access to Clinical Nurse Specialists (Kerr et al., 2021). However, the pastoral contribution that other professionals make to the mental health and wellbeing of those living with mesothelioma is a key finding of this study. Legal and Asbestos Support Group professionals in particular are highlighted. Legal and ASG professionals not only provide access for patients and carers to financial aid but also alleviate the mental burden of navigating complex benefit and compensation systems. They also provide or fund a range of services including support groups and talking therapy.

Our data demonstrates that for patients, financial compensation and benefits can contribute to mental health and wellbeing through the ability to access private health care and knowing that the family is taken care of. The role of the Asbestos Support Groups and legal professionals is therefore crucial in the context of mesothelioma. While the 'little joys' of daily life were important, the financial compensation provided freedom to plan and undertake important family events and future proof the financial wellbeing of their family. The participants who had access to this compensation often used it to improve their mental health through caring for their families, using it for leisure activities or for their care. However, it is important to note that some patients and carers struggle to gain access to compensation and benefits. Our prior work shows that women living with mesothelioma may be less likely to seek and receive compensation (Ejegi-Memeh et al., 2020; Senek et al., 2021). This may suggest a gender inequality in terms of who has access to private healthcare, non-NHS funded treatments and some of the more expensive forms of promoting mental health and wellbeing.

Family and friends played an important role in the mental health and wellbeing of patients and carers. Actions which ensure that carers are taken care of impact on the mental health of the patient and vice versa. Here it is relevant to note that the delineation between patients and carers is problematic as several of our "patient" participants were also carers for their partners or children with disabilities. Carers were also living with other life limiting conditions. Patients and carers alike cared for each other and fulfilled different needs in each other's lives. Developing interventions that take both patients and carers into consideration is important.

The intention is for this knowledge to be shared with relevant professionals and to be applied in practice. Our findings highlight the need to focus on the informal carers' distinct needs too. When nurses and other key professionals are considering the needs of informal carers, specialist charitable and support services outside of the NHS could potential play a vital role in meeting those needs. The study also highlights that the social justice elements of mesothelioma may be important to consider in relation to mental health. This, as well as other coping mechanisms highlighted in our study shows how patients and carers use diverse adaptive approaches to maintain wellbeing so healthcare staff should take their cues from patients and carers to ensure they support their approaches. Our recommendation is that future research focuses on the evaluation of mental health and wellbeing interventions for patients and informal carers living with mesothelioma, so that we can understand what works for whom and when.

As far as we are aware, these data are the first sources of insight into patient and informal carer description of interventions in relation to mesothelioma and mental health and wellbeing and as such form a valuable foundation for future research and practice. However, there are some limitations to this study; in particular, recruitment via the questionnaire means that only people who had access to the questionnaire participated in the study which may have led to the exclusion of people without access to the questionnaire. Despite efforts to recruit additional men to interview, our carer sample predominantly consists of women. Awareness of this imbalance meant that during analysis we were careful to reflect on the contributions of male participants.

5. Conclusion

Within this paper, we provide insight into what can help people with their mental health and wellbeing. Our findings demonstrate the range and interlocking nature of factors which contribute to good mental health and wellbeing for patients and carers living with mesothelioma. However, we have also shown that there are complexities within these interventions as what works for patients may not work for carers at a given time and also what works for some may not work for others. Going forward, a focus on mental health and wellbeing, considering both how patients and carers manage their own needs, as well as what support nurses and other key professionals can contribute, would be beneficial for those living with this condition.

CRediT authorship contribution statement

Stephanie Ejegi-Memeh: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Writing – original draft, Writing – review & editing. **Virginia Sherborne:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Writing – original draft, Writing – review & editing. **Catriona Mayland:** Funding acquisition, Methodology, Writing – review & editing. **Angela Tod:** Conceptualization, Formal analysis, Funding acquisition, Methodology, Supervision, Writing – review & editing. **Bethany H. Taylor:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Supervision, Writing – review & editing.

Declaration of competing interest

No conflicts of interest to declare.

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