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Sherborne, V. orcid.org/0000-0003-1106-765X, Wood, E., Mayland, C.R. orcid.org/0000-0002-1440-9953 et al. (6 more authors) (2024) The mental health and well-being implications of a mesothelioma diagnosis: a mixed methods study. European Journal of Oncology Nursing, 70. 102545. ISSN 1462-3889

https://doi.org/10.1016/j.ejon.2024.102545

European Journal of Oncology Nursing 70 (2024) 102545

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

The mental health and well-being implications of a mesothelioma diagnosis: A mixed methods study

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ARTICLE INFO

Keywords:
Incurable cancer
Mental health
Mesothelioma
Well-being
Mixed methods
Posttraumatic growth
PTSD

ABSTRACT

Purpose: Mesothelioma is an incurable, asbestos-related cancer with a poor prognosis. There is scant evidence about the mental health and well-being impacts on patients and carers living with the illness. This study aimed to investigate mesothelioma's impact on mental health and well-being and the scale of mental health conditions in patients and informal carers.

Methods: A mixed-methods design was used: a cross-sectional survey of mesothelioma patients and informal carers plus semi-structured interviews with patients and carers. The survey used validated scales collecting data on mental health aspects of mesothelioma: the EQ5D to assess health-related quality-of-life; the Hospital Anxiety and Depression scale; the PCL-5 to assess Posttraumatic Stress; and the Posttraumatic Growth Inventory. The datasets were integrated during analysis.

Results: 96 useable survey responses were received. A clinical level of depression was reported by 29 participants (30.21%), of anxiety by 48 (50%), of posttraumatic distress disorder by 32 (33.33%), and of posttraumatic growth by 34 (35.42%). Carers had worse scores than patients. Three main themes were developed from interviews with 10 patients and 11 carers: 'Prognosis', 'Support from services', and 'Social connections and communication'.

Conclusions: Healthcare professionals delivering a mesothelioma diagnosis require regular training in communication skills plus updating in current treatment options, so they provide an appropriate mix of realism and hope. Better signposting to mental health support is needed for patients and carers. Our introduction of posttraumatic growth into the mesothelioma literature is novel. We recommend specialist nurses are trained to recognise, understand, and foster posttraumatic growth.

1. Introduction

Mesothelioma is a rare asbestos-related cancer, currently without a cure. Roughly 2700 people receive this diagnosis every year in the UK. Worldwide estimated mesothelioma cases are around 31,000 (Huang et al., 2023). Mesothelioma is acknowledged to bring a unique set of mental health and well-being (MHWB) challenges for patients beyond other cancers, thanks to its aetiology, long latency period (30–50 years), hard-to-control symptoms and incurability (Prusak et al., 2021; Lond et al., 2022; Moore et al., 2023). People diagnosed with mesothelioma may be able to claim compensation, depending how they were exposed, which can involve extended legal cases. Although mesothelioma is currently incurable, new treatments, such as immunotherapy, are being developed to treat symptoms, and the number of clinical trials is increasing (Bibby et al., 2022). Alongside these developments, which are improving the prognosis for people living with mesothelioma, an up-to-date focus on psychological impacts is required. Research tailored to mesothelioma is needed to understand its mental health impacts and which interventions may be helpful for those living with the disease.

In research on patient experience, participants often report the way

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https://doi.org/10.1016/j.ejon.2024.102545
Received 31 October 2023; Received in revised form 21 February 2024; Accepted 3 March 2024

mesothelioma impacts their MHWB (Lee et al., 2022; Taylor et al., 2019), but there are scant studies focussing specifically on mesothelioma and MHWB. Existing studies call for more qualitative and quantitative research to illuminate the scale and experience of mental health impacts for patients and informal carers (Bonafede et al., 2020; Girgis et al., 2019). A study is needed specifically on the MHWB impacts of mesothelioma due to its poor prognosis, causation by asbestos, terminal nature and difficulties with timely diagnosis.

The complex and variable nature of the mesothelioma journey means there are many time-points where negative psychological impacts may occur for patients and their informal carers. See Fig. 1 for a schema developed by the authors to conceptualise the complexities of the mesothelioma pathway. This was informed by a literature review and the team's previous research experience. Reviews of the literature have recently highlighted the depression, anxiety and distress experienced by patients with a mesothelioma diagnosis and their informal carers (Breen et al., 2022; Ejegi-Memeh et al., 2022; Sherborne et al., 2020). The devastation and shock often experienced from receiving this diagnosis have been emphasised (Lond et al., 2022; Taylor et al., 2019). Depression has been reported across cultures (Demirjian et al., 2024; Nagamatsu et al., 2022). Traumatic stress symptoms (TSS) have also been reported by participants living with mesothelioma (Dooley et al., 2010; Bonafede et al., 2020). Symptoms of posttraumatic stress are known to include reliving aspects of what happened (e.g., flashbacks, intrusive thoughts); alertness/feeling on edge (e.g., panicking, irritability, hypervigilance); avoiding feelings/memories (e.g., avoiding reminders, feeling detached from your body, doing reckless things); and difficult beliefs/feelings (lack of trust, self-blame, feeling unsafe). Posttraumatic stress symptoms can occur in patients due to the threat-to-life experienced and related shattered assumptions (Janoff-Bulman,1992), and in carers due to witnessing the patient's suffering and/or anticipating/experiencing their death (de Padova et al., 2021).

The broader cancer literature covers positive as well as negative dimensions of the patient and carer experience, including deepened relationships, benefit-finding and posttraumatic growth (Nouzari et al., 2019; Daneault et al., 2023). There has been little consideration of such positive aspects in the mesothelioma literature, with none on posttraumatic growth (PTG) (Sherborne et al., 2020). Adding to current knowledge by exploring these aspects may enable healthcare professionals to provide MHWB support to patients and families, improving their quality of life. Clinical nurse specialists (CNSs), such as the network of mesothelioma CNSs funded across the UK by the charity Mesothelioma UK, are ideally placed to provide such support (Hargreaves et al., 2023).

The Mental Health Implications of a Mesothelioma Diagnosis and Developing Resources to Optimise Well-being Study (MINNOW) was developed to add to the existing research literature by combining quantitative and qualitative approaches in a mixed methods design.

MINNOW aimed to address these research questions:

1. How does mesothelioma impact on patients and informal carers' mental health and well-being (MHWB)?
2. What is the scale of mental health conditions in patients and informal carers living with mesothelioma?
3. What current psychological interventions are being used by patients and informal carers living with mesothelioma and which do they find most helpful?

In this publication we report part of the MINNOW study, focussing on the two questions regarding the impact of mesothelioma on MHWB and the scale of mental health conditions in patients and carers.

2. Methods

2.1. Design

This study had a two-stage design:

1 Cross-sectional survey of mesothelioma patients and informal carers with open and closed questions
2 Qualitative interviews with patients and informal carers

To strengthen the reporting of this study, we have used the Mixed Methods Appraisal Tool (Hong et al., 2018).

Taking a mixed methods approach enabled us to generate a deeper understanding of the mesothelioma mental health and well-being experience. It also enabled us to triangulate and verify the findings (Creswell et al., 2004). Our mixed-methods model was 'explanatory': the quantitative phase provided statistical results, and the subsequent qualitative phase obtained interview data to illuminate and expand on the quantitative results (Creswell et al., 2004). We integrated the quantitative and qualitative data at the analysis stage (Creswell et al., 2004). The University of Sheffield Ethics Committee gave approval (044, 300) before data collection.

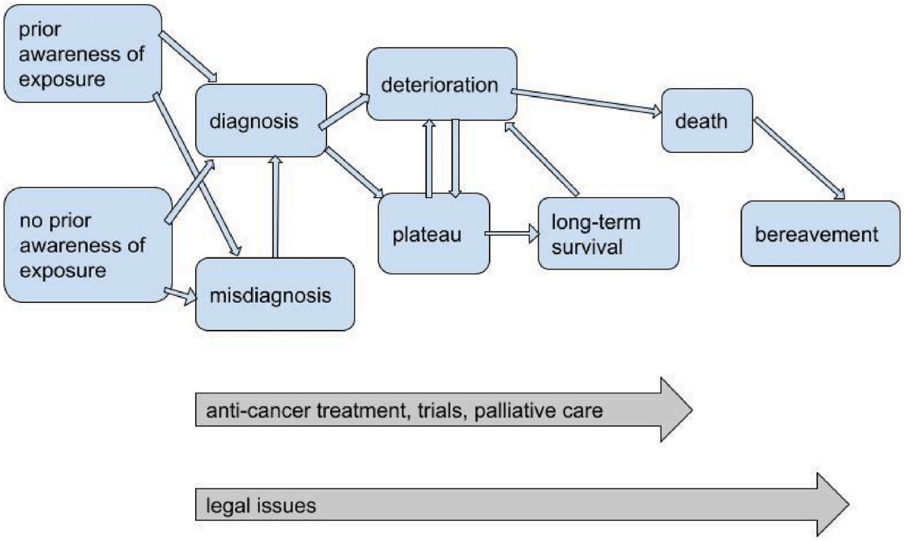

Fig. 1. The complex and variable mesothelioma journey.

2.2. Data collection

2.2.1. Questionnaire design

The questionnaire content was informed by the 2019 Mesothelioma Outcomes Research Experience survey and Sherborne et al.'s review (2020). The questionnaire used validated scales, with permission, to collect data on both positive and negative mental health aspects of mesothelioma:

- the EQ5D to assess health-related quality of life (QOL) (5 questions and visual analogue scale)
- the Hospital Anxiety and Depression scale (HADS) - 14 questions
- the PCL-5 to assess Posttraumatic Stress - 20 questions
- the Posttraumatic Growth inventory - 21 questions

The piloted questionnaire was available to participants online via Qualtrics or in hard copy on request. Completion of the questionnaire implied consent. We sought demographic information (age, gender, ethnicity, marital status, patient or informal carer, type of mesothelioma, length of time living with mesothelioma, co-morbidities, functional status, employment status, whether they lived alone, whether they had an informal carer, financial security). We also asked about previous and current use of psychological interventions.

2.2.2. Questionnaire participants

The questionnaire inclusion criteria stated participants must live with mesothelioma or be informal carers (current/bereaved) of someone living with mesothelioma, in the UK, be aged 18+, competent to read/write English and able to provide informed consent. Bereaved carers were included as they could provide insight into MHWB needs and support for both patients and informal carers throughout the illness journey. Including bereaved carers helped avoid biasing the sample towards carers of the longest-lived and healthiest patients. No time limit was put on the period since bereavement.

2.2.3. Questionnaire recruitment

A convenience sample of patients with mesothelioma and their informal carers was recruited via stakeholders' networks, including social media, e.g., Twitter, Facebook. Mesothelioma UK provided study information and the questionnaire link via their website, mailing list and information line. Mesothelioma UK Clinical Nurse Specialists also disseminated study information to potential participants in their caseload. UK Asbestos Support Groups informed their clients and provided the link via email and newsletters. The Mesothelioma UK Research Centre (MURC)'s mailing list was used similarly. Snowball sampling was encouraged to extend recruitment in this small population. The aim was to recruit 100 participants (50% patients). This sample size was based on previous similar projects (Senek et al., 2022) and time constraints.

2.2.4. Interview recruitment

The final questionnaire item asked respondents to give their email address if they consented to contact regarding an interview. Fifty-two patients and carers did so. Purposive sampling ensured a range of interview participant demographics e.g., age, time since diagnosis, gender, MHWB experiences.

2.2.5. Interview data collection

A semi-structured interview schedule was developed and piloted. Interview topics included participants' experience at diagnosis, the (positive and/or negative) impact of mesothelioma on MHWB, any MHWB interventions offered/accepted/declined, interventions that helped participants (and why), any that did not help (and why), any interventions they were aware of and might (or might not) consider accessing in future. Semi-structured interviews are suitable for gathering in-depth information in areas where little research exists and when exploring people's experiences (Creswell et al., 2004). Before consenting, participants received a study Information Sheet, including details concerning confidentiality and right to withdraw.

We aimed to recruit up to 12 patients and 12 caregivers. The sample size was considered sufficient to ensure data saturation based on existing literature (Baker and Edwards, 2012) and previous studies in this field (Ejegi-Memeh et al., 2021; Taylor et al., 2019). Ten people with a mesothelioma diagnosis and 11 caregivers, aged 32–75, participated in audio-recorded interviews (nineteen individual, one joint). The researchers preferred individual over joint interviews to avoid participants feeling inhibited (Mellor et al., 2013). The interviewers were VS (a researcher and counsellor) and SEM (a researcher), both female and experienced in qualitative research on sensitive topics. Participants and interviewers did not know each other previously. Brief details were given about interviewers' motivations as interviews commenced. Only interviewers and participants were present. Interviews, lasting 1–2 h, occurred from October 2022 to February 2023, either via GoogleMeet or phone. Field notes were made. Weekly discussions about the process took place between VS, SEM, BT and AT. An approved service made verbatim transcriptions. The interviewers reviewed these for accuracy pre-anonymisation. Anonymised transcripts were uploaded to Quirkos data analysis software.

2.3. Data analysis

2.3.1. Questionnaire analysis

Descriptive statistics were used to summarise participant characteristics. Survey responses were described using means and standard deviation (for parametric data) or medians and interquartile range (for non-parametric data), stratified by patient/carer group. Differences in survey responses between patients and carers were investigated using chi-squared tests (categorical data), t tests (parametric continuous data) or Kruskal Wallis test (non-parametric continuous data). SPSS (version 26) was used to manage and analyse the data.

Prior to completing the PCL-5, participants were asked to state, as free text, what they had found to be the most stressful aspect of living with mesothelioma, and to answer the subsequent questions with regard to that aspect. These answers were analysed by CL and VS using content analysis, chosen as it allows a descriptive approach in coding of the data and its interpretation of quantitative counts (Vaismoradi et al., 2013). CL and VS developed categories of codes from manifest contents and organised these into 13 clusters (Vaismoradi et al., 2013).

2.3.2. Interview analysis

We chose to conduct inductive reflexive thematic analysis as this matched our approach to enquiry and was tailored to the characteristics of the subject matter and our experience as researchers (Levitt et al., 2017). We followed Braun and Clarke's six phases of 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, 2019). We used a descriptive/semantic-level approach to flexibly code and develop themes, allowing us to stay close to participants' data. Using Quirkos, SEM, VS, AT and BT collaboratively developed 58 initial codes which were clustered into 24. Finally, identifying patterns of shared meaning led to four themes being named.

2.3.3. Mixed methods integration

We used qualitative data to explore the quantitative survey results in an explanatory sequential design, following good practice guidance (Wisdom and Creswell, 2013). The interview phase directly built on the survey phase. By integrating both datasets during the analysis stage in a whole-team process, we were able to explain the quantitative findings in more detail. The integration process allowed us to triangulate data and test out what was said in the two datasets, with no divergence being observed. The process gave the survey participants a voice and made sure the quantitative findings were grounded in lived experience.

3. Results

3.1. *Quantitative results*

3.1.1. *Demographic data*

157 people completed at least part of the survey. However, 12 were excluded as they were not living in the UK. Others completed the first page of the survey only, giving no information about their mental health experiences, so their data could not be analysed. 96 useable responses were received. See Table 1 for a summary of participants' demographic data. Some participants did not give their status as patient/carer/bereaved carer. We therefore excluded their data when comparing scores of patients and carers.

3.1.2. *General well-being*

General well-being was assessed using the EQ5D for health-related quality of life. The average score for the five dimensions (mobility, self-care, usual activities, pain and discomfort, and anxiety and depression) was 8.21 (SD 3.198) and for the EQ5D visual analogue scale was 72.31 (SD 18.462).

Fig. 2 shows the way mesothelioma impacted the daily lives of patients and carers. The majority could walk and look after their hygiene needs. However, there were greater impacts on the level of pain and discomfort people were suffering, and the anxiety and depression that accompany living with a terminal diagnosis.

Table 1
Survey participants' demographic data.

Demographic		Number (%)
Patient/carer/bereaved status	I live with mesothelioma	35 (36.5%)
	My family member lives with mesothelioma	13 (13.5%)
	My family member died from mesothelioma	34 (35.4%)
	Didn't say	14 (14.6)
Gender	Female	76 (79.2%)
	Male	20 (20.8%)
Ethnicity	White British	92 (95.8%)
	White Irish	1 (1.0%)
	Black	1 (1.0%)
	Other/didn't say	2 (2.1%)
Age	<30	2
	30–39	8
	40–49	14
	50–59	19
	60–69	22
	70+	26
	Didn't say	5
Sexual orientation	Heterosexual	87 (90.6%)
	Homosexual	2 (2.1%)
	Bisexual	3 (3.1%)
	Other	2 (2.1%)
	Didn't say	2 (2.1%)
Marital status	Single	12 (12.5%)
	Married	46 (47.9%)
	Domestic partnership	5 (5.2%)
	Separated/divorced	5 (5.2%)
	Widowed	15 (15.6%)
	Other	12 (12.5%)
	Didn't say	1 (1.0%)
Highest level of education completed	Primary school	2 (2.1%)
	Secondary school	18 (18.8%)
	Further Education (A levels etc)	18 (18.8%)
	Higher education (degree)	31 (32.3%)
	Postgraduate	27 (28.1%)
Concerned about finances	Not at all worried	30 (31.3)
	Not very worried	40 (41.7%)
	Somewhat worried	23 (24.0%)
	Very worried	3 (3.1%)

Table 2 and Fig. 3 show the difference in impact on patients and carers. Patients showed more problems with mobility and pain/discomfort than carers. Both groups showed difficulties with anxiety and depression.

3.1.3. *Anxiety and depression*

58 participants reported a lifetime mental health diagnosis (32% of the total had depression, and 26% had anxiety). For depression, the mean score on the HADS-D was 5.83 (SD 4.120), where a score of 7 or less indicated no depression. 29 people (30.21%) scored 8 or more, indicating a clinical level of depression. Regarding anxiety, the mean score on the HADS-A was 7.91 (SD 4.180), with a score of 7 or less indicating no anxiety. 48 participants (50%) scored 8 or more, indicating a possible clinical level of anxiety, which would need confirming by diagnostic interview.

The HADS-A was highly significantly correlated with a formal diagnosis of anxiety (Pearson statistic $= -0.333$, $p < 0.01$, $n = 90$), HADS-D (Pearson statistic $= 0.681$, $p < 0.01$, $n = 90$), EQ5D (Pearson statistic $= 0.272$, $p = 0.01$, $n = 90$), PTGI (Pearson statistic $= 0.296$, $p < 0.01$, $n = 81$) and PCL (Pearson statistic $= 0.700$, $p < 0.01$, $n = 82$). The HADS-D was highly significantly correlated with EQ5D (Pearson statistic $= 0.435$, $p < 0.01$, $n = 90$) and PCL-5 (Pearson statistic $= 0.574$, $p < 0.01$, $n = 82$).

3.1.4. *Posttraumatic impacts*

The average score on the posttraumatic stress checklist (PCL-5) was 39.14 (SD 13.954), where a score of 43 or less indicates no PTSD. 32 participants (33.33%) scored 44 or more, indicating a possible clinical level of posttraumatic stress disorder (PTSD), which would require confirmation by diagnostic interview. Regarding posttraumatic growth, the PTGI explores personal growth in five dimensions: new possibilities, relating to others, personal strength, spiritual change, and appreciation of life. The average score on the PTGI scale was 42.16 (SD 23.270). 34 participants (35.42%) scored 46 or more, indicating a significant level of PTG (Mazor et al., 2020). The PTGI significantly correlated with the PCL-5 (Pearson statistic $= 0.263$, $p = 0.017$, $n = 84$).

3.1.5. *Carers compared with patients*

We considered the differences between the patients and the carers (current and bereaved combined). The score on the EQ5D was significantly different ($t = 3.00$, $df = 80$, $p = 00.002$), as were the HADS-D ($t = -2.026$, $df = 78$, $p = 00.046$) and the PCL-5 ($t = -3.218$, $df = 79$, $p = 00.002$). In all cases, carers had the worse score (a higher score on HADS-D and PCL-5 and a lower score on EQ5D). These scores were statistically significant, but this does not necessarily mean they were clinically significant. There was no statistical difference in diagnosis. There were no differences between current carers and bereaved carers in anxiety, depression, PCL-5, PTGI or EQ5D. However, with only 13 current carers in the sample, this analysis is almost certainly statistically underpowered and therefore may not be accurate.

3.1.6. *Most stressful aspects of mesothelioma*

To prepare participants to answer the PCL-5 scale, they were asked to state in free text what they had found to be the most stressful aspect of living with mesothelioma. The number of participants providing answers for each clustered code was as follows: 'scanxiety' (anticipating scans and waiting for the results), 19; diagnosis 17; medical interventions 13; death 17; uncertainty 10; symptoms/deterioration 11; triggers in media 1; interactions with HCPs 5; loss of lifestyle 2; exposure 2; own coping ability worries 1; helplessness/patient's pain 9; overall experience 6. (For the split between patients and carers (see Fig. 4). Some participants wrote longer answers covering various aspects; these were split into different codes.

For patients, the most frequently mentioned aspect was scanxiety, followed by 'diagnosis' and 'medical interventions'. The cluster

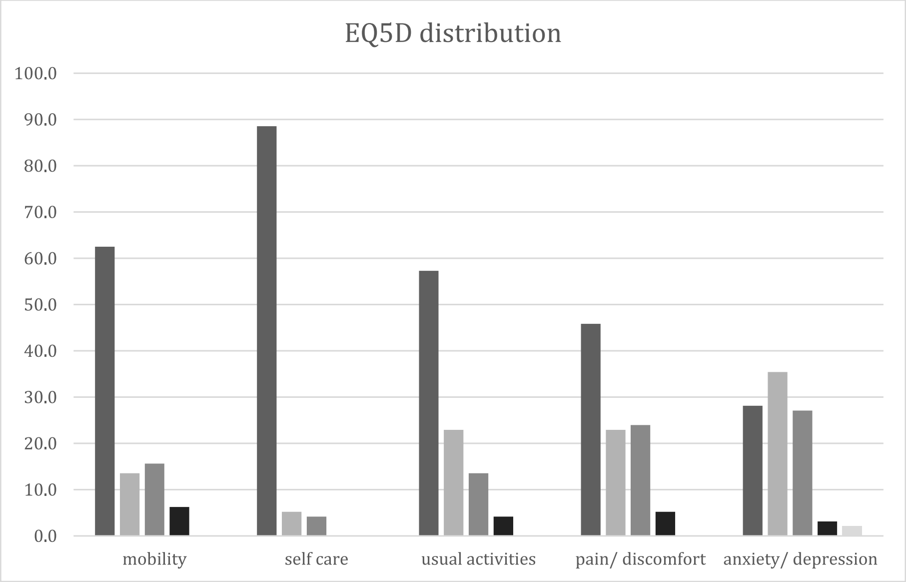

Fig. 2. The distribution of scores on the EQ5D for patients and carers living with a mesothelioma diagnosis.

Table 2
The frequency of reported problems by patient and carer groups.

		patient	carer	totals
EQ5D mobility binary	No problem	13	35	48
	Problem	21	11	32
EQ5D self-care binary	No problem	27	43	70
	Problem	7	3	10
EQ5D usual activities binary	No problem	12	32	44
	Problem	23	13	36
EQ5D pain/discomfort binary	No problem	8	27	35
	Problem	27	19	46
EQ5D anxiety/depression	No problem	9	13	22
	Problem	25	32	57

'diagnosis' did not just refer to receiving the shocking mesothelioma diagnosis itself. It also contained themes relating to lack of information and support after diagnosis, and the difficulty of reaching a diagnosis. 'Medical interventions' which patients found stressful were having a pleural effusion drained, chemotherapy and immunotherapy. They also worried about where to find appropriate treatment. The next highest cluster for patients was 'death'. This covered their fears about dying, and the effect of news that others had died. For carers, the most mentioned cluster was 'death', which included the experience of their loved one's death or fears about it in the future. The next most frequent was 'diagnosis'. This was followed by 'helplessness/patient's pain', a cluster developed to reflect that carers could be tormented by being unable to do anything to relieve their loved one's pain and distress.

3.2. Qualitative results

Three main themes were developed relating to the mental health and well-being impacts of a mesothelioma diagnosis for patients and their informal carers. These were: 'Prognosis', 'Support from services', and 'Social connections and communication'. A further cross-cutting theme

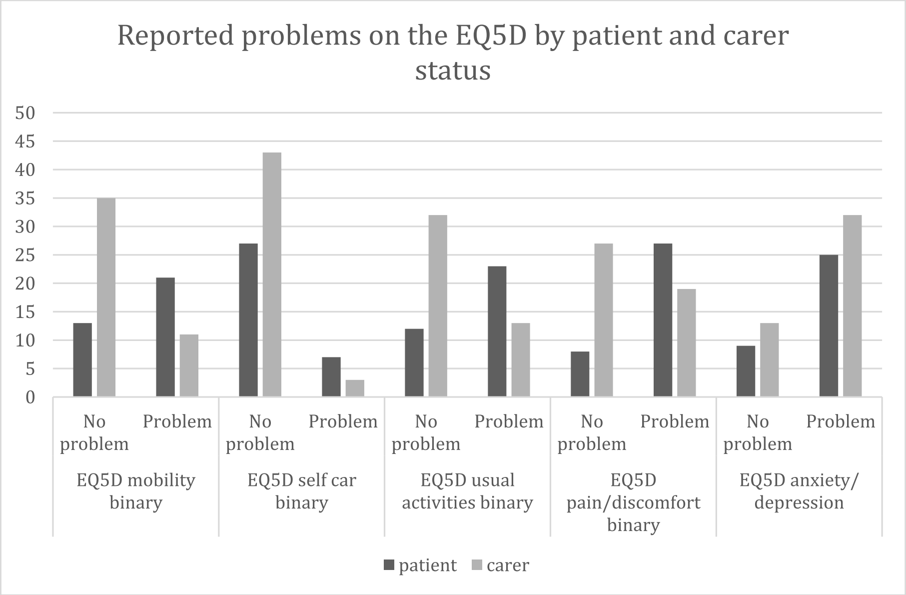

Fig. 3. The distribution of reported problems on the EQ5D between patients and carers.

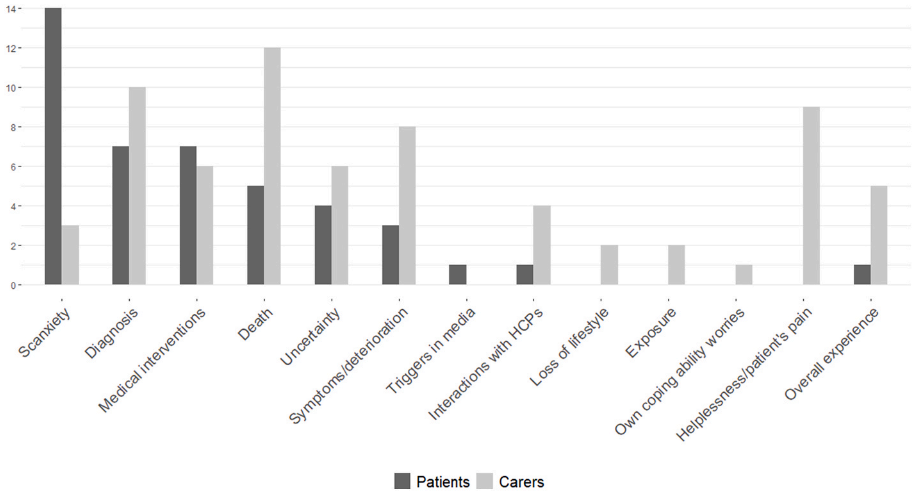

Fig. 4. The most stressful aspects of living with mesothelioma.

of 'Separate mental health journeys for patients and informal carers' was identified. This has not been reported under a separate heading. Instead, differing MHWB aspects of the journey for patients and carers have been highlighted where relevant within the three main themes.

Pseudonyms plus identifiers are used for participants:

First character: P= Patient/C=Carer

Second character/s: Interview number.

Third character: Gender (self-identified) M = man/W = woman.

3.2.1. *Prognosis*

Receiving a prognosis was a major cause of negative psychological impact for both patients and carers. A prognosis covers the disease's expected development, including whether symptoms may worsen and how quickly; how quality of life may be affected; and likely life expectancy. Participants were generally told the prognosis at the time of diagnosis and/or may have searched for more information, e.g., on the internet.

3.2.1.1. The death sentence. The idea of being handed a 'death sentence' was often mentioned by patients and carers. This was experienced as highly traumatic:

> It's like being on the Green Mile but you haven't got any chance of appeal. Susan (P4W)

> [Husband] might have only died two years ago but he died three years ago in my eyes. The day he found out, he changed. Laura (C5W)

Participants used violent metaphors to convey the extent of the shock/horror they felt on learning the prognosis, e.g., "a wrecking ball" Dawn (C11W); "an absolute slap" Isla (C8W). However, for those participants left waiting for their prognosis, it was like "living in limbo" Graham (P9M).

Some participants searched for more information on the internet, often despite warnings from HCPs not to. Information there was bleak and not always up-to-date, something they did not realise till later:

> My heart sank. As soon as you Google it, the thing that comes up, incurable, incurable. Crystal (C7W)

Participants explained how the language used by healthcare professionals (HCPs) regarding prognosis was crucially important. Some HCPs understood this better than others. Sian (P2W) had a positive experience, as her consultant said:

> "We don't know what your journey's going to be like, but we're going to be here to support you; we're going to work on a plan and we're going to get you there".

Graham (P9M) would have liked similar reassurance but was left thinking he had to prepare to die soon. Susan (P4W) was told initially she had three to six months to live. She said:

> It would be much better, in my view, not to mislead them [patient and family], but to say, 'We haven't found a cure yet. But people are living this far [several years]'.

Some professionals spelled out how the patient's health was likely to deteriorate over time.

Understanding the expected progression led many patients to feel anxious. Worrying aspects included the idea of becoming a burden, being breathless and in pain:

> He wasn't frightened of dying, he was frightened of *how* he was going to die. Laura (C5W)

However, some patients, over time, were able to come to terms with their 'death sentence':

> Once I realised that I was scared to die, I then found, I could actually get on with living. Because I'd voiced the fear. Ann (P3W)

3.2.1.2. Depression. When participants talked about depression or feeling depressed, this covered patient and carer experiences ranging from severe clinical depression to occasional dips in mood. Jim (C2M)'s depression, coming on two weeks after his wife's diagnosis, was so serious he became a psychiatric inpatient for six months. Ann (P3W)'s husband was "in a very bad way for at least a year". Different stages in the illness journey could cause lowered mood. For example, "the immunotherapy door closing" made Laura (C5W)'s husband depressed, as it meant death was nearer. New challenges could arise when someone lived beyond their original prognosis, as new uncertainty was introduced:

> I've had the treatment, I've done whatever, but it's now, this year … It's this reality now … I'm going to die. That's the truth, out loud, and it's hit me. Ray (P1M)

3.2.1.3. Suicidality. For a few patients and carers, the prognosis drove them to suicidal thoughts. Ann (P3W)'s husband [experienced] was stricken by what she called "survivor guilt", insisting "it shouldn't be you, it should be me", and repeatedly saying, "I just want to die. I don't want to be here without you." Ann found this "horrific". Serena (C6W) was put in a very stressful position as her husband wished to die from an exercise-induced heart attack, rather than mesothelioma:

> He said, if I die on my bike, just leave me at the side of the road, let what happens happen … it wasn't a joke, you know, he really, really meant it. Serena (C6W)

3.2.1.4. Anxiety. Anxiety was an impact occurring throughout the mesothelioma journey, with transitions unexpectedly bringing the prognosis back into focus. Waiting for scans/results brought regular bursts of 'scanxiety', sometimes intensified by delays. As treatment options ran out, meaning death came closer, patients and carers could start to panic:

> You look around like a headless chicken for something else. Scott (C9M)

However, some patients explained they were able to manage anxiety, e.g., Jenny (P10) used mindfulness; Ann (P3W) was "very chilled … I'm not a worrier".

3.2.1.5. Psychological trauma. Three patient and five carer participants described aspects of their experiences which appeared to match traumatic stress symptoms, though only five said HCPs referred to these as trauma-related. The term 'traumatic stress symptoms' (TSS) refers to symptoms, such as flashbacks, dissociation and avoidance, which are included in the criteria for posttraumatic stress disorder (PTSD) (American Psychiatric Association, 2013). Various experiences at different time-points triggered TSS, including feeling powerless to help the patient, and witnessing their death. In the 'Prognosis' theme, we focus solely on the impact of receiving this. Sian (P2W) needed psychotherapy to cope with her recurring thoughts/images plus avoidant behaviour. Her PTSD began when her oncologist revealed, unasked, her short life-expectancy when discussing egg-harvesting. The consultant implied that there was no point to the procedure.

A neurologist diagnosed Ann (P3W) with trauma-related dissociative symptoms beginning a week after diagnosis. Debbie (C3W) was haunted by witnessing her father receiving a morphine-driver, as it signalled death was inevitable/imminent. Alongside experiencing flashbacks, she spent money on extensive travel after his death, which in hindsight she saw as an avoidant response. Crystal (C7W), pregnant during her grandfather's illness, described her TSS, including recurring nightmares about his future death.

We found several examples of patients and carers experiencing posttraumatic growth related to the prognosis. These fell into the dimensions 'personal strength' and 'appreciation of life'. Enhanced appreciation of life meant not taking things for granted; cherishing loved ones; making the most of the present and having things to look forward to:

> We're obviously stronger in certain ways as well. How we've coped with it really well. Given the patience we've had to have and optimism in the face of the unknown. We are getting on with things and we've got a really strong relationship. Jenny (P10W)

> This last 18 months of my life has been really good, probably better than it would 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 (P4W)

> It makes me realise these things can come out of the blue no matter how healthy and fit you are. I think you don't take anything for granted these days as a family. Serena (C6W)

3.2.2. Support from services

The MHWB support available from services was a key concern for participants. They pointed out the focus of HCPs and carers was usually on the patient. Yet patients and carers had different MHWB support needs. Carers often started out viewing their own MHWB as irrelevant:

> They [HCPs] always asked after dad. They never really asked how you were … I've never ever thought about talking about how I was feeling. Serena (C6W)

Day-to-day caring tasks plus other responsibilities made carers too busy to be aware of MHWB effects on themselves. Preoccupying tasks for carers included finishing off legal claims, which could extend long after the patient's death. Amber (C1W) thought she wouldn't be able to "grieve properly" until the legal case finished. Some only realised after the death they weren't coping, whilst others hid MHWB impacts to spare the patient. Several mentioned they felt all attention *should* be on the patient, using judgemental terms regarding their own needs, like "self-pity" Scott (C9M) or "selfish" (Debbie C3W, Jim C2M). Carers often took cues from their loved one, matching *their* coping strategies:

> He just didn't want to know that he was dying. So, we just … not kept it from him but we took the brunt. Natasha (C10W)

If a carer *did* assert their own MHWB needs, it could be distressing for the patient. For example, Laura (C5W) needed to sleep separately but her husband felt he'd been "shoved in another room out of the way".

Both patients and carers stressed the importance of carers' MHWB needs being met. Participants thought the availability of support should be reinforced to carers, as it was only provided "if you initiate it" (Laura C5W). Bereaved carers recognised with hindsight they and family members needed advice and encouragement *earlier on* regarding self-care:

> "I don't think I've dealt with it … Probably because we never got any help at the time." Natasha (C10W)

One area that was considered missing in terms of support for carers was advice about how to handle receiving financial compensation, as this could cause MHWB difficulties:

> It's like death money. That's how I view it. There's no enjoyment … That's stress in itself, what do I do with it, where do I put it? Laura (C5W)

3.2.3. Social connections and communication

Social connections and good communication were reported by participants as vital for maintaining their MHWB. When they experienced disconnection and/or poor communication, they were aware of detrimental effects. Support groups, for example, those run by Mesothelioma UK and ASGs, provided connection with others who shared understanding. However, some issues were identified by participants regarding access. Sometimes bereaved carers did not realise they were eligible, and working carers might not have the flexibility for daytime attendance. Other issues included the format putting off older men and those coping by not thinking about mesothelioma:

> "In [husband]'s case it was 'I'd rather be at home, I'm wasting a bit of my time that I haven't got'. But we'd go every now and again. In the end he said, 'I don't want to go up and see what I'm going to get like' … Not only did that depress him, it scared him as well." Dawn (C11W)

Another context for social connections and communication to cause MHWB impact was where there were complex family issues. Talking frankly could be helpful:

> Her stepson is with us. Obviously, you know, I've said to him that he's always got a home with me, which I think has quite reassured him and reassured my wife. Scott (C9M)

Participants often had expectations about support they ought to give and receive within their families. Sometimes these were unmet. Sian

(P2W), "technically cancer-free" after surgery, found that her family didn't want to talk about it anymore, yet she was "still trying to catch up" and would appreciate being able to "offload all the feelings". Isla (C8W)'s husband's ex-wife insisted on delaying telling his children the diagnosis. This meant "extra worry" because they knew the disease could progress quickly. Expectations about the family context increased the pressure Crystal (C7W) put on herself:

> I got so anxious when [new baby] was round everyone that it made her cry. Because she could feel that I was anxious. And I'd convinced myself that she was here to save everybody. And I gave myself such bad depression and I ruined my whole year of maternity leave.

Even planning special family celebrations and holidays, which many participants found helped their MHWB, could also have a downside:

> It was just tick, tock, let's plan fun things to do. But again, it's like, horrible, because you're trying to have forced fun. Debbie (C3W)

For younger carers, employers were another key source of social support for MHWB. Experiences varied. Some employers were willing to be flexible and understanding.

Other participants had their expectations of support shattered. Two were so negatively impacted by perceived lack of loyalty and empathy, plus poor communication, that they left their employment:

> I thought, God, I spent eight years with this business and I've no idea why, because it's meant nothing to them, it was really awful. So yes, angry, disappointed, bitter towards them. Debbie (C3W)

One aspect of social connection with MHWB implications for some participants was a higher awareness of risk from toxic substances. Getting involved in campaigning about justice regarding asbestos exposure could have its own negative effects:

> It is a ticking time bomb, teachers and school children … We've hit a brick wall with it, so I have got to draw a line under it, or it could really affect my mental health. Serena (C6W)

Some bereaved carers reported negative personal change in relating to others, e.g., feeling "less bothered about other people" (Natasha C10W), "more cynical" (Isla C8W), and "hardened" (Amber C1W).

We also found many examples of posttraumatic growth from patients and carers in the 'relating to others' dimension, with an emphasis on better communication. Positive change in 'relating to others' included increased emotional openness; growing closer to loved ones; being less argumentative and less selfish.

> As a family, we are very now open to saying I'm not having a good day and acknowledging each other. Serena (C6W)

> Something big has happened and it brings you closer. Graham (P9M)

> I'm more calmer. I don't want to go into any arguments or disagreements with people because it ain't worth it. Sean (P7M)

A smaller number of examples matched 'new possibilities', generally in terms of social connection. 'New possibilities' included being open to new relationships and becoming involved with others in asbestos activism:

> I channelled some of my energy, my grief, my anger into saying, I don't think this is right, I think this needs to change. Debbie (C3W)

Some participants also felt more able to resist social pressure and choose how to spend time:

> I suddenly thought to myself, I'm only going to spend my days with the people I want to spend my days with. I'm going to get rid of these people who don't really enhance my life. Rose (P6W)

> I try to fill every minute … I'll only do what I want to do … If I don't fancy doing something, I won't … I've made new friendships, I've done new things, I try everything. Yeah, and probably a sort of renewed, if you like, zest for life really because I know how precious it is and how quickly things can change for you. Laura (C5W)

4. Discussion

Our mixed-methods approach allowed us to generate unique insight into the psychological impact of mesothelioma. It identified the level of our sample's anxiety, depression, traumatic stress and posttraumatic growth, and illuminated these impacts by developing three themes: 'Prognosis', 'Support from services', 'Social connections and communication', plus a cross-cutting theme of 'Separate mental health journeys for patients and informal carers'.

4.1. *Contribution to existing literature*

Anxiety has been reported as a significant issue for patients living with mesothelioma and their carers (Lond et al., 2022; Sherborne et al., 2020), and our findings support this. However, there has been no research specifically regarding mesothelioma and scanxiety. For our participants, scanxiety was linked to having awareness of the prognosis and the limited treatment options available to stave off deterioration and death. Scanxiety for cancer patients has been linked to emotionally draining uncertainty which can be mitigated by positive relationships with trusted HCPs (Langmuir et al., 2023). A study exploring scanxiety in lung cancer patients found it was associated with impaired quality of life, was a common problem among the sample, and its severity was not linked to time since diagnosis or having a recent scan (Bauml et al., 2016). Scanxiety may be worse for those living with mesothelioma as it is a terminal illness.

Depression is very common in cancer patients, varying depending on the treatment setting and cancer stage (Caruso and Breitbart, 2020). Our finding that a significant number of the sample had experienced depression symptoms supports Demirjian's (2024) study on mesothelioma patients' well-being, where 14% of participants reported significant depression. Our finding that carers had worse depression than patients chimes with Moore et al.'s (2023) study, which indicated 74% of carers for mesothelioma patients were at risk of depression, linked to the burden of caregiving plus impacts on their own physical health and employment. A recent study of depression and complicated grief in family members of mesothelioma patients, Nagamatsu et al. (2022) reported that 19% of participants had depression, with higher scores for those who had not received financial compensation. Complicated grief (intense grief lasting longer than usual and causing impairment in daily functioning) was more likely in those who did not receive compensation, who's relative had surgery, and who were dissatisfied with their care when critically ill.

There has been debate about whether a cancer diagnosis can cause PTSD. The Diagnostic and Statistical Manual of Mental Disorders – 5th Edition accepts this may occur with a sudden, catastrophic diagnosis (American Psychiatric Association, 2013). The experience of many of our participants would meet this description, due particularly to mesothelioma's poor prognosis. Our study aligns with prior research showing that receiving a cancer diagnosis is the most frequent traumatic stressor (Springer et al., 2023). In recent mesothelioma literature, the adverse impact of receiving a poor prognosis has been emphasised (Johnson et al., 2022; Lond et al., 2022). PTSD rates across all cancer patients have been found to be only slightly increased compared to the general population (Vehling et al., 2022; Swartzman et al., 2017), so our results suggest mesothelioma has a stronger traumatic impact.

4.2. *Recommendations for practice*

Those living with rare cancers may be impacted by HCPs' lack of awareness affecting their nursing care (Charalambous and Biagioli, 2022). The high level of TSS our study found in patients and carers may not be recognised by HCPs who work with mesothelioma. Training is needed therefore in how to assess TSS and signpost effectively for mesothelioma CNSs and those in other specialities, such as gynaecology, who may be supporting these patients and families. Two assessment tools have undergone preliminary development to measure the psychological distress (including TSS) specifically of patients with malignant mesothelioma (the MPDT-P) (Guglielmucci et al., 2022) and their family carers (the MPDT-C) (Bonafede et al., 2022). Identifying individuals experiencing TSS would allow CNSs to signpost them to psycho-oncology services offering trauma-informed interventions, such as CBT and EMDR (Dimitrov et al., 2019).

Recommendations have been made previously about the importance of sensitivity and skill when breaking bad news to mesothelioma patients and carers (Taylor et al., 2019). Our findings underline the vital role that CNSs and other HCPs have in avoiding negative impacts from delivering this prognosis. HCPs who rarely encounter mesothelioma patients have reported feeling hopeless because of the poor prognosis, compared to those with more frequent experience who feel more therapeutic optimism (Henshall et al., 2022). Nurses and other HCPs who may need to break this bad news require regular training in communication skills plus updating in current treatment options for mesothelioma. This would enable them to provide the mix of realism and hope which patients and carers are asking for.

Our novel introduction of the concept of posttraumatic growth into the mesothelioma literature has shown its importance for enhancing patient and carer MHWB. We recommend mesothelioma CNSs and other professionals, such as Asbestos Support Group workers, are trained to recognise, understand, and foster PTG. This is a complex impact of trauma and is not simply about 'being positive'. It is therefore vital professionals avoid causing inadvertent detriment to MHWB by presenting this as a simplistic idea about positive thinking (Tod et al., 2011). In incurable illnesses with a high level of uncertainty, HCPs are recommended to implement targeted psychological interventions focussed on resilience and hope to enhance PTG (Wang et al., 2023). For example, mindfulness-based supportive group courses in oncology clinics have been shown to improve cancer patients' PTG, resilience, and self-compassion. Other cancer nursing-based interventions around hope include brief one-to-one programmes (Feldman and Corn, 2022). Interventions to encourage carers' resilience are equally important (Seiler and Jenewein, 2019). HCPs who listen to patients and carers, developing a closeness based on authentic presence, can support them to find meaning in the face of the inevitable (Daneault et al., 2023).

4.3. *Recommendations for future research*

We recommend Bonafede et al.'s (2022) and Guglielmucci et al.'s (2022) assessment tools are further validated to allow CNSs to confidently screen patient and carer MHWB. Due to the variability in experiences of and access to counselling and psychotherapy (CAP) reported by participants, we suggest research is urgently needed into provision of CAP for those living with mesothelioma. This should cover exploring barriers to access and the type/effectiveness of interventions, including whether these are trauma-informed. The need for further multi-site research on complicated grief after the death of a loved one from mesothelioma has been recommended (Nagamatsu et al., 2022), and we echo this in the European context. Lastly, the issue of scanxiety in mesothelioma has not yet been explored, despite being a key concern of patients and carers.

4.4. *Limitations*

The MHWB impacts we present were self-reported by participants. The gold standard investigation would have been to add diagnostic interviews, but this was impractical. However, we report our findings about cancer-related PTSD in conjunction with the stressors identified by participants, enabling our findings to be validated and compared (Springer et al., 2023). Our sample had a high proportion (28%) of postgraduate degree-holders compared to the general UK population (6%). We recruited relatively few current carers compared to bereaved, likely due to the demands of their caring role. Therefore, our results regarding carers' depression may be reflecting grief responses typical for close bereavement. Our sample's high proportion of female patients, where mesothelioma's incidence rate is much higher in males (Huang et al., 2023), may mean our results are skewed towards internalising mental health issues experienced more often by females, e.g., depression and anxiety (Otten et al., 2021). The known 1.7-fold higher incidence of depression in women could be a factor in our results (Albert, 2015). However, this difference declines with age, and 74% of our sample were aged 50+.

5. Conclusion

Using rigorous methods to obtain, analyse and integrate our quantitative and qualitative data allowed us to gain a rounded picture of the mental health and well-being impacts of mesothelioma experienced by both patients and informal carers. We hope that our study will help to address some of the inequalities identified in providing nursing care for those living with this rare cancer, mesothelioma.

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Funding

Mesothelioma UK funded the study (Grant Number 2102) but took no part in the study's design, conduct or writing-up.

Declaration of competing interest

There are no conflicts of interest declarable. Mesothelioma UK funded the study (Grant Number 2102) but took no part in the study's design, conduct or writing-up.

Acknowledgements

We are very grateful to all our interview participants. We thank Mesothelioma UK for funding the study via the Mesothelioma UK Research Centre (MURC) in alliance with the University of Sheffield, United Kingdom. The views expressed are those of the author(s), and not necessarily those of Mesothelioma UK/University of Sheffield.

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