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REVIEW

What are the psychological effects of mesothelioma on patients and their carers? A scoping review

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Abstract

Objective: Despite recent advances in research, malignant mesothelioma remains an incurable and devastating disease, typically bringing shock and emotional distress to patients and carers. Little research has addressed the psychological impact on either group. This scoping review examines the current state of evidence on the psychological effects of mesothelioma on patients and carers, and identifies areas for further research.

Methods: We searched PubMed, PsychINFO, CINAHL, the Cochrane Library and Web of Science for English-language peer-reviewed research articles published 1981 to 2019 reporting studies focussing on the psychological effects of mesothelioma on patients and carers. Following data extraction and quality appraisal, reflexive thematic analysis was used to identify themes.

Results: Seventeen articles met the inclusion criteria. Carers' experiences were generally amalgamated with patients'. Three themes were developed. *The Passing of Time* included the importance of timing of interventions; delays in the medical journey; awareness of different time-phases in mesothelioma; and uncertainty/certainty. *Dealing with Difficult Feelings* reflected ubiquitous negative emotions, feelings about identity and states of being and associated coping strategies. *Craving Good Communication* covered issues related to sharing of information and to positive/negative aspects of communication.

Conclusions: Though limited, the evidence indicates that mesothelioma, with its high symptom-burden, incurability, rarity and asbestos-related causation, leads to complex and inter-relating psychological effects on patients and carers. These effects are both negative and positive. The sparse literature gives a partial picture and demonstrates an urgent need for more nuanced research. Studies exploring the experiences of specific groups are recommended, with particular attention required to carers.

KEYWORDS

cancer, caregivers, communication, diagnosis, mesothelioma, oncology, palliative care, psychological distress, psycho-oncology, review

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1 | INTRODUCTION

Malignant mesothelioma (MM) is an incurable disease usually linked to asbestos exposure.[1] There are two main types: the most common, malignant pleural mesothelioma (MPM), affecting the membrane lining the lungs and chest wall, and peritoneal mesothelioma (PM), affecting the abdominal lining.[2] Symptoms appear after a long latency period (20-50 years), with the disease often progressing very quickly.[3] Mesothelioma is usually diagnosed in older people.[1] Survival rates are poor: for 2014 to 2016 the percentage of patients in England and Wales surviving 1 year post-diagnosis was 38%, and 3 years post-diagnosis was 7%.[1] Within these figures, there is a significant difference in survival times for different subtypes. In mesothelioma's initial stages, symptoms tend to be non-specific, meaning it is often diagnosed at a late stage.[4] However, occasionally, mesothelioma is diagnosed at an asymptomatic stage after an incidental finding.[5] Once disease is advanced, the symptom burden is severe, including breathlessness, chest wall pain, weight loss, sweating and fatigue, with severity increasing and sometimes proving difficult to palliate.[6]

Research into the lived experience of mesothelioma patients has been sparse. Cancer patients in general experience psychological distress, including anxiety, depression, existential concerns and post-traumatic stress.[7-9] They may also experience posttraumatic growth.[10] Carers of cancer patients in turn are more likely to experience depression, anxiety, hopelessness, isolation, somatic symptoms and financial issues.[11] Mesothelioma, with its high symptom burden, incurability, rarity and asbestos-related causation, has a unique psychosocial impact.[12]

Although mesothelioma remains incurable, recent advances in clinical research are providing more treatment options, such as immunotherapy.[13] Further research into the psychological aspects of mesothelioma is required to map any changes that may be occurring alongside the changes in medical treatment and prognosis. This applies to carers as well as patients, as their wellbeing is an important part of the picture.[13,14] However, the experience of carers has not been a particular focus of mesothelioma research to date.[15] Therefore, the aim of this scoping review was to examine the current state of evidence on the psychological effects of mesothelioma on patients and carers, and identify areas for further research.[16]

2 | METHODS

In line with scoping review methodology, the search question was suitably broad, but had clarity regarding the scope of inquiry[17]: what is the current state of the evidence on the psychological effects of mesothelioma on patients and their carers? The population was ‘patients and carers’, the intervention was ‘mesothelioma’ (covering all disease types), and the outcome was ‘psychological effects’ (positive and negative).

A scoping review does not aim to be exhaustive, but to give an initial assessment of the available literature.[18] Therefore, any potentially relevant articles identified from the reference lists of the retrieved articles or from Google Scholar were included, but grey literature was not, nor were attempts made to locate on-going, unpublished research in the field. This decision, made for feasibility reasons, provided a limitation to comprehensiveness.

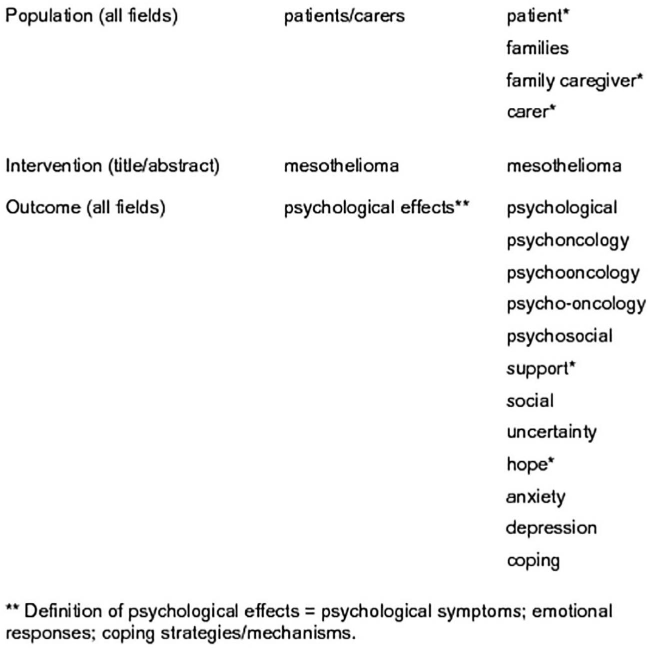
The review was conducted using the staged method described by Arksey and O'Malley[16] and Levac et al.[17] It was reported following the PRISMA Extension for Scoping Reviews Checklist,[19] with the aim of being systematic, transparent and replicable.[20] A protocol was not registered.

Keywords from published relevant articles were reviewed to inform this process (see Figure 1). Searches took place in May 2019 of these bibliographic databases: PubMed, PsychINFO via OvidSP, CINAHL, the Cochrane Library and Web of Science. Search parameters were adjusted to match individual database requirements.

An example search strategy (CINAHL) is given in the Appendix. The results for each database search were exported into EndNote and duplicates removed. A flowchart of the search strategy is given in Figure 2

For inclusion, articles had to be peer-reviewed research articles (reporting empirical qualitative, quantitative, or mixed methods studies and literature reviews). Other inclusion criteria were:

- in English (practical reasons);
- involving adult humans (mesothelioma extremely rare in children);
- dating from 1981 (seminal Lebovits article published[21]) to May 2019;
- focussing on psychological effects (not physical aspects of symptoms/treatment);
- focussing on mesothelioma (mentioned in title or abstract).



Population (all fields)	patients/carers	patient* families family caregiver* carer*
Intervention (title/abstract)	mesothelioma	mesothelioma
Outcome (all fields)	psychological effects**	psychological psychoncology psychooncology psycho-oncology psychosocial support* social uncertainty hope* anxiety depression coping

** Definition of psychological effects = psychological symptoms; emotional responses; coping strategies/mechanisms.

FIGURE 1 Relevant keywords identified

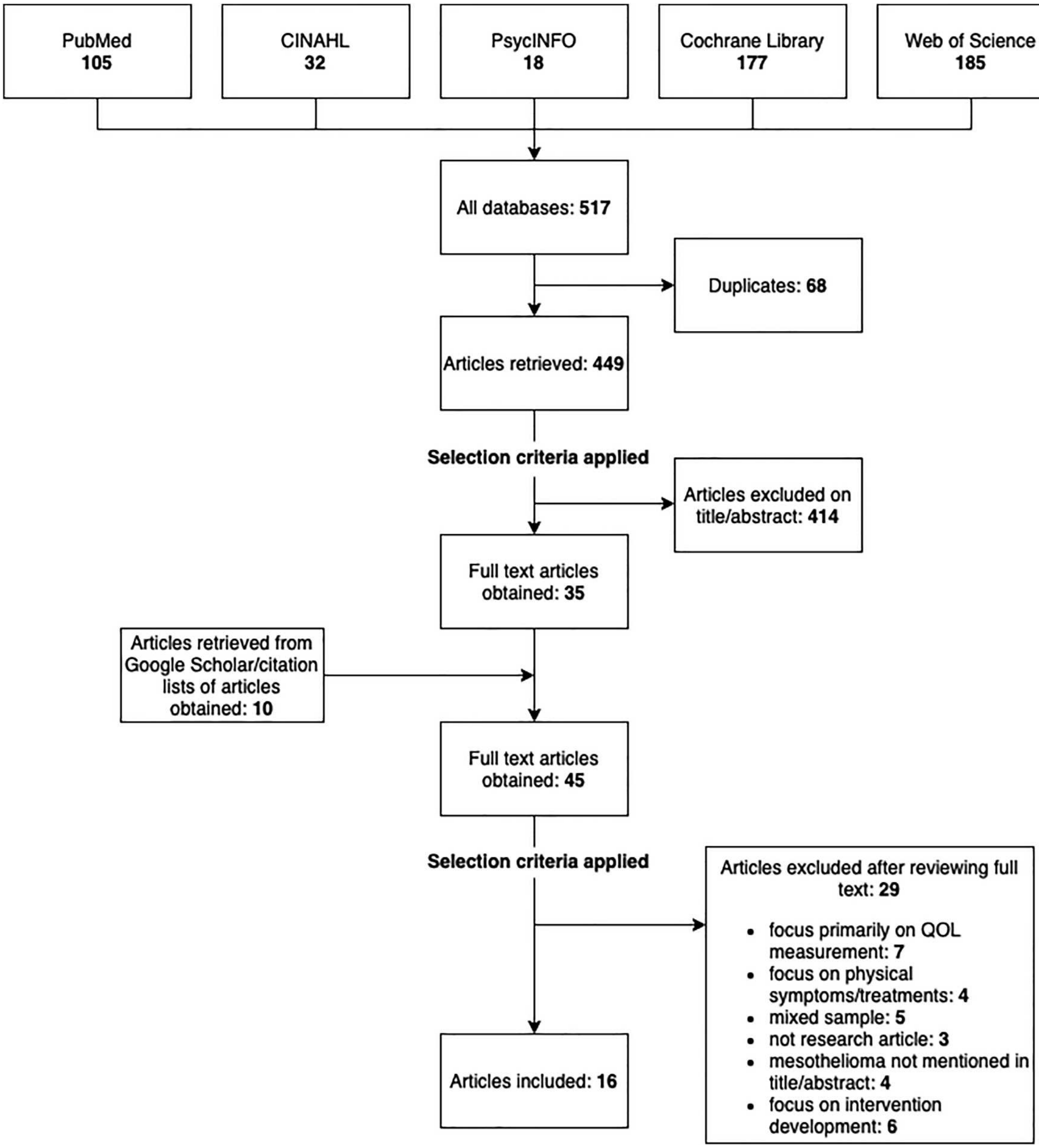


FIGURE 2 Possibly relevant articles identified from electronic searches

Exclusion criteria applied were:

- not in English;
- not involving adults;
- focussing on clinician's perspective, rather than patient's/carer's;
- about questionnaire development or focussing primarily on quality of life (QOL) measurement (eg, part of a clinical trial or QOL tool development), as these would not focus on content but on the tool's validity and reliability;
- about physical symptoms, treatments or epidemiology;
- focussing on intervention development;
- conference abstracts, dissertations, editorials, book reviews, individual case reports;
- concerning lung and pleural cancers (ie, mixed sample).

A single reviewer (VS) applied the inclusion and exclusion criteria to the retrieved articles after duplicate removal. Titles and abstracts were screened for relevance and irrelevant articles excluded. The remaining articles were obtained in full text and exclusion criteria were applied. Broadly following the team approach recommended to aid rigour,[17] the authors met to discuss eligibility decisions at the beginning of the process. The team also discussed and agreed inclusion/exclusion after the full text studies were obtained. Further inter-rater reliability measures were not undertaken for practical reasons and due to time constraints.

Data were extracted by VS from the articles into forms based on examples provided by Booth et al[18] for qualitative and quantitative articles. No testing or calibration of the forms was conducted. The following items were extracted: citation; location; research objectives;

participant details; recruitment and sampling methods; data collection and analysis methods; relevant findings and results; authors' conclusions; possible new relevant articles from references. To identify findings and results relevant to the research question, VS reviewed each article's abstract and results sections. Discussion sections were also scrutinised in case any extra findings had been presented here rather than in the results section.

We wanted to understand the range and quality of the existing evidence. While there is debate about quality appraisal in scoping reviews,[20,22,23] we decided to follow a quality appraisal process. The aim was to inform the review by giving an overview of the quality of the existing literature as a whole, including the quality of reporting, but without excluding any of the identified articles. (The authors noted quality appraisal was conducted by Ball et al.[6]) For our review, after data extraction the articles were critically appraised using CASP checklists.[24]

As is recommended to aid rigour,[16,17] our *Results* section included a descriptive numerical summary and qualitative thematic analysis of key relevant findings. Braun and Clarke's[25,26] reflexive thematic analysis was employed, using *Quirkos* QDA software. Steps completed were:

1. familiarization with the data: reading and re-reading, noticing interesting features, making notes and asking reflexive questions;
2. generating codes: inductively identifying clear labels for important features throughout the dataset and collating relevant extracts;
3. generating candidate themes: identifying meaning-based patterns in the codes and data:
4. reviewing themes: checking the candidate themes against the dataset, ensuring each relates to a central concept, and sensing how each theme relates to the others;
5. defining themes: naming and developing a detailed analysis of each.

To stay close to the data, VS generated semantic, rather than latent, codes, which stay at the surface of the data,[26] for example, loyalty; stigma; future. Developing the themes was a consciously creative process, requiring reflection and thoughtfulness.[27] Reflexive questions were useful throughout the analysis process, for example, 'Am I making assumptions about loyalty to former employers?' *Quirkos* enabled codes to be clustered and combined, helping VS identify meaning-based patterns. For example, clusters named 'difficult feelings', 'positivity' and 'coping strategies' combined, becoming the theme *Dealing with Difficult Feelings*.

3 | RESULTS

After duplicate removal, 449 articles were retrieved from searching the databases. Of these, 414 were excluded after review of title or abstract. The remaining 35 articles' full text was obtained, and their citation lists reviewed for possibly relevant articles. Along with Google Scholar searches, this process resulted in 10 further potentially relevant articles being obtained in full text. Eligibility criteria were applied, leading to exclusion of 29: seven focussed primarily on QOL measurement, four focussed on physical symptoms/treatments, five used mixed samples, three were not research articles, four did not mention mesothelioma in title or abstract, and six focussed on intervention development. This left 16 articles eligible for review (see Figure 2). VS subsequently learned from a nurse specialist (CNS) about an article[28] published December 2019, which met our search criteria. We included this.

The review's findings are presented in two ways: a basic analysis of the characteristics of the included studies, and a report of the themes developed from the data.[16]

3.1 | Characteristics of the included studies

An overview of the charted characteristics and critical appraisal data for each included article is presented in Supporting Information S1. The 17 articles comprised 11 qualitative, two quantitative and three literature reviews Moore et al,[29] Bonafede et al,[12] Ball et al[6] and one article[30] combining the reporting of a qualitative study with a literature review (see Supporting Information S2 for details). The precise definition of mesothelioma varied across the articles (see Supporting Information S2).

Considering the qualitative studies first, four were conducted in the UK, one in Australia, two in Italy, two in Japan, and three in the USA. Nine articles aimed to explore the subjective experience of mesothelioma and identify care and support needs. Two studies explored psychological issues around risk awareness.[21,31] One developed recommendations to improve the diagnosis experience.[32] The majority investigated MPM, while four looked at MPM plus peritoneal. The range of participants was 5 to 112. Eight studies were situated in large teaching hospitals. Two recruited via local specialist nurse referrals, and two via nationwide hospitals, groups and networks. The qualitative studies commonly excluded anyone judged 'not well enough' to participate, or who had a psychiatric diagnosis, or who might experience aggravated emotional distress. Only three included carers and relatives in their design.[30,32,33] In a few articles attention was paid to teasing out patient and carer experiences at different time-points in the disease's course: at diagnosis,[32,34] and in the first 6 months.[30] Kasai and Hino[35] conducted the first longitudinal qualitative study in this field, examining five transition points in disease progression with participants diagnosed 5 to 8 years previously. Whilst the majority of cases of mesothelioma in the literature were men who had been exposed occupationally, the Italian articles[12,15,30] included a higher proportion of females, as they studied people exposed by living in or near National Priority Contamination Sites (rather than occupationally exposed males as is typical).

Of the quantitative studies, one was conducted in the UK (with no specified mesothelioma type), one in Australia (MPM). Dooley et al[36] assessed 49 patients who were suing their employer, aiming to investigate stress and depression symptoms in men with mesothelioma. Henson et al[37] aimed to quantify suicide risk in patients with cancer and identify risk factors to help with psychological assessment. They covered the whole population of people who died by suicide after cancer diagnosis in England. Their statistical study allowed comparison of the first 6 months after diagnosis to the rest of the patient's life. For the handling of missing data in the quantitative articles, see Supporting Information S2.

In the three literature reviews, studies conducted in the UK, Europe, the USA and Australia predominated (see Supporting Information S2). Moore et al[29] aimed to identify what was known about the experience of living with mesothelioma. Bonafede et al[12] reviewed the research on psychological aspects of MM patients and asbestos-exposed people. Ball et al[6] evaluated if MPM and advanced lung cancer patients' psychological care needs differed. The number of participants ranged from 6 to 63,[12] 2 to 15[6] and 5 to 409.[29] Ball et al's[6] review only covered MPM, whereas the others looked at all mesothelioma types. Only Moore et al[1] included the experience of carers or families.

3.2 | Quality appraisal

The critical appraisal carried out informs the following overview of the field's quality. Of the qualitative articles, three were rated as low risk of bias[28,32,38]; the rest were rated unclear. Of the quantitative, Henson et al[37] was rated low, and Dooley et al[36] unclear. All three reviews[6,12,29] were rated unclear.

A limitation commonly reported was generalisability: numbers of participants were small, due to mesothelioma's rarity and recruitment difficulties caused by its debilitating nature. The only large-scale study was Henson et al,[37] which added a new dimension to the field by uncovering suicide risk. Kasai and Hino,[35] in the only longitudinal study, marked out the illness into five time-periods and provided a useful new framework, but could only follow five participants. All three literature reviews[6,12,29] highlighted the paucity of studies on psychological aspects and lived experiences of mesothelioma patients and carers. They also usefully drew out differences between the experience of mesothelioma patients and those with lung cancer or asbestos-exposed people. The reviews together gave a wider reach across the field, each having a different emphasis and scope of their search (see Supporting Information S2). The Italian group added a new psychoanalytical perspective.[12,15,30] Along with Dooley et al,[36] their articles were the only ones to refer specifically to trauma theory. Overall, the studies presented clear rationales, used appropriate methods, and gained appropriate ethical approval. They related their findings to practice and relevant research-based literature, suggesting areas for future research (eg, developing needs-assessment tools) and practice improvements. However, there was sometimes a lack of clarity around the purpose and extent of involvement of carers and family members in the interviews.

In terms of the standard of reporting, as assessed by the critical appraisal checklists,[24] only four articles could be considered excellent.[28,32,37,38] Amongst the others, there was some lack of transparency regarding reporting of methods. It is possible the journals' limited word counts had an effect. The most noticeable area of omission was detailing the relationship between researcher and participants. There was little critical examination of the researcher's own role, with potential for bias and influence, both in the formulation of questions and in data collection, and there was sometimes lack of clarity around the role of the patient's own medical team. However, more consideration was given to potential bias in the analysis process. In terms of representation, the voices of participants were heard more easily, and showed more range, in some studies than others.

This section has presented the findings relating to the characteristics of the 17 identified articles. Next, this review summarises the findings relating to key themes developed, which captured the range of data in the articles.

3.3 | Themes

Three themes relating to the research question were developed from the data: 'The Passing of Time', 'Dealing with Difficult Feelings' and 'Craving Good Communication'.

3.4 | The passing of time

This theme appeared in all 17 articles, in different guises: the importance of timing for various interventions; delays in the medical journey; awareness of different time-phases in mesothelioma; and the uncertainty/certainty axis (Table 1).

Four studies[6,12,15,30] identified the first time-period: pre-diagnosis. For mesothelioma, there is an extra dimension around causality, and the 'Damocles syndrome' (retrospective awareness of personal risk from asbestos exposure was identified as a cause of anxiety and distress.[6,12,15,30] These feelings could also be generated by awareness that the patient's own contact with asbestos may have led to the second-hand exposure of family members, for example, by washing work clothes.[12]

Two studies[15,32] highlighted another difficult aspect of this initial period: the long, frustrating journey to a definitive diagnosis. Diagnosis was a significant time-point in 14 articles, bringing shock, anger, anguish, numbness, anxiety and depression. The fact that the patient's time was now limited brought a terrible certainty. However, alongside the certainty came distressing *uncertainty* about disease progression and the future.[6,35] Issues of timing caused distress at diagnosis, for example, the appointment not being long enough; inappropriate levels of information about the illness and compensation.[32,33,40]

The initial phase of the illness is critical in terms of suicidality. 'Henson et al[37] showed that, when considering variation in suicide risk by years since diagnosis, out of all cancer types mesothelioma patients had the highest risk of suicide in the first 6 months, with an 8.61-fold risk compared with the general population'. Hopelessness was identified as a result of negative messages from healthcare professionals by Ball et al[6] and Girgis et al.[33]

TABLE 1 Participant quotations

Theme	Quotation	Source
The passing of time	Many friends of mine died because of mesothelioma. This makes you wonder who will be the next one.	Patient, Guglielmucci et al[15]
	When the ultimate diagnosis arrived, it killed me in a moment [...] I've been killed that day.	Patient, Guglielmucci et al[15]
	I do not know what tomorrow will bring or next month. I do not even know if I can look to Christmas…really, I do not know the speed of these things.	Patient, Ball et al[6]
	You need a little bit of time just to discuss or talk about it. You go away, you know nothing. You do not even know what mesothelioma is.	Patient, Taylor et al[32]
	We filled all the forms in…and we have not received anything yet. [...] I'm still waiting for some crazy doctor to come to disprove what the hospital proved. And that's my worry, that's my biggest worry.	Patient, Clayson et al[38]
Dealing with difficult feelings	It was a terrible ordeal. No pain, no. Not painful at all, but it's the weirdest experience [pleural drainage].	Patient, Moore et al[2]
	It's like living as rats in the hole.	Carer, Guglielmucci et al[15]
	He gets very frustrated and irritable [and] then he cries because he wants to be doing things. [...] it's very hard, I feel like a punch bag. There is a lot of anger, and it's not my fault.	Carer, Hughes and Arber[39]
	It does not pay to think too far down the road because that's bad news. As you say, head in the sand.	Patient, Arber and Spencer[34]
	He [husband] does not want to talk about my disease [...] He does not talk with anybody. [...] he is annoyed, because he says this is our business.	Patient, Guglielmucci et al[15]
	I ain't going away without a fight!	Patient, Girgis et al[33]
	I'm not just going to carry on. I'm going to crack on. Well what we are going to do is to enjoy each day.	Patient, Moore et al[29]
	I hope I've walked well in my life, to have spent it well and that's it. If [the treatments] will go well, I am really happy, because I still have some ambitions to realize. If it will go bad, it does not matter.	Patient, Guglielmucci et al[15]
Craving good communication	She was able to explain a lot of it and she used drawings and pictures and things to show me because I had not even got a clue.	Carer, Taylor et al[32]
	Being well-informed and knowing my results eases my anxiety and gives me a sense of control.	Patient, Nagamatsu et al[40]
	I want my doctor to tell me everything, including bad news.	Patient, Nagamatsu et al[40]
	Do not tell me the bad news. Just let me know something good.	Patient, Nagamatsu et al[40]
	I knew that she [CNS] would be there, she told me, she'd be on the phone, and I could ring her any time.	Carer, Taylor et al[32]
	I hope my doctor not only treats my tumour but also takes care of me. I am not a box with cancer; but a living person.	Patient, Nagamatsu et al[40]
	I do not have a companion. At night, I find myself alone. You cannot say: 'I have someone to whom I can talk about that'.	Patient, Guglielmucci et al[15]
	I wanted to talk to people, but they were [not] going through the same thing. And there was no one there for me.	Carer, Girgis et al[33]

After the initial period, the speed and unpredictability of disease progression caused intense anxiety, as three studies showed.[6,12,30] Sometimes, lack of continuity with medical staff left patients unsure about the next treatment steps, with an inability to plan ahead accompanied by distrust of medical interventions and HPCs.[12,15] In a study examining the communication of a mesothelioma diagnosis Taylor et al[32] aimed to understand how a diagnosis can be communicated well and distress can be minimised. They highlighted that breaking bad news (BBN) could occur at many different time-points. Within the mesothelioma patient journey there were multiple episodes of bad news: although diagnosis was the main one, there were others, such as not being eligible for a trial.

'The future' as a stimulus for worry about loved ones was a time-related feature reported by several articles.[6,15,36] Clinically significant posttraumatic stress symptoms were linked by Dooley et al[36] to physical symptoms, reminding patients they were going to die and making them think about their families' future. Legal and financial issues took up frustrating amounts of precious time, and the patient's death was not the end-point of the journey, as legal/financial matters dragged on further.[6,15,30,39]

3.5 | Dealing with difficult feelings

All 17 articles presented difficult feelings and allied coping strategies. 'Difficult feelings' includes negative emotions, and also feelings around identity and states of being (Table 1). These had a range of causes, some described above. Physical symptoms, for example, pain and sweating, were inherently upsetting or frightening, and also frustrating in their impact on independence and social roles.[6,12,34,39] Feeling socially isolated was mentioned in several articles, resulting from depression, apathy and stigma.[15,30,39]

The physical burden took its toll on carers, and patients worried about being a burden[6] or agreed to treatment to keep relatives happy,[35] who in turn could feel guilty.[29,33]

Distress sometimes resulted from the effect of professionals' activities. It was caused by medical treatments[29,30]; lack of continuity[6,32]; feeling abandoned if chemotherapy was not an option[39]; and feeling like guinea pigs during trials.[15] The anger that was identified was linked to two causes. The first was patients' frustration at not being able to do ordinary activities, with carers also feeling helpless or angry about changes in the patients, such as their sense of identity, willingness to live a normal life, or their irritability.[15,39] Second, complex medico-legal matters led, for some, to feelings of anger and betrayal towards employers. For others, conflicted loyalty towards former employers meant anger was redirected towards families or doctors.[6,12,39]

These many difficult feelings led patients and carers to experience a lack of control. This could include feeling powerless over the disease; having to relinquish family responsibilities; fearing total loss of agency at end-of-life; and insecurity about how to live and who could help.[28,34]To cope, they engaged in a wide range of strategies. Avoidance/denial was identified as the main mechanism.[12] Strategies included deciding that statistics do not apply; limiting information[33]; trying to live normally[6]; and denying negative emotions.[15] Refusing to talk or think about things was frequently used both by patients and carers.[15,30,39] However, this tended to increase social isolation, brought relationship difficulties, and came at a cost to the individual.

A fighting spirit was identified as helping to protect a sense of control.[33,35] Other factors giving a sense of control were accessing complementary/alternative medicine, support groups, palliative care, physiotherapy and maintaining fulfilling social and family roles.[6,12]

Some participants had an accepting attitude, reviewed their lives, mourned their losses and looked for the positive.[15,29,33,35] Patients were more likely to report acceptance than carers.[29]

Only the quantitative studies[36,37] highlighted suicide as a coping strategy. Henson et al[37] showed patients with mesothelioma had the highest suicide risk of all English cancer patients. All participants in Dooley et al's study[36] reported significant traumatic stress symptoms co-morbid with increased depression and anxiety, which could put them at risk of suicide. Hopelessness appeared as an important aspect of the mesothelioma experience compared with that of lung cancer,[6] with the difference explained by mesothelioma's incurability, poor prognosis and lack of treatment options.

3.6 | Craving good communication

Issues around the sharing of information and positive/negative aspects of communication (Table 1) were reported by 16 articles. In Nagamatsu et al's[40] study of patients' requests to doctors, most focused on communication. Inept or thoughtless information delivery caused huge distress and hopelessness. This happened at diagnosis,[6,32,33] when shock affected capacity to absorb information, or later, regarding specialist supportive care services and responsibility for treatment decisions.[6,39] The timing of compensation/benefits information needed special care.[6] Participants wanted clear, understandable explanations, with opportunity to ask questions.[32,40] Getting accurate information at the right time could be very helpful, for example, by lessening worries about progression, or giving comfort and a feeling of agency about finances.[6,30,40]

The importance of getting the balance right for each individual was stressed, using a customised, patient-centred approach to reflect the huge variation in what people want and can take in Reference 32,33,40. Whilst the majority of Nagamatsu et al's[40] participants wanted honesty, a significant minority preferred only good news.

As well as difficulties with doctor-patient information transfer, there were issues within families. Carers struggled to decide who to share with,[33] and worried about upsetting others.[6] Some patients were overwhelmed with shame and guilt which they could not verbalise.[15] The issue of risk information coming haphazardly, from non-employer sources, was highlighted.[12]

Participants clearly valued good communication skills and practices in health care professionals (HCPs). Effective multi-disciplinary team-working meant informing specialist nurses immediately mesothelioma was suspected; BBN was shared across the team; participants knew what to expect; and hope could be maintained.[12,32] A kind, warm, inclusive way of talking was appreciated.[32,40] Caseworkers were useful for communicating across the gap between physicians and patients/carers, and providing much needed individual emotional support.[15,33]

Several studies presented the need of carers and patients for communication with others who had the same experience and understood the nuances of this rare disease.[33,35,39] They valued the emotional support, and some patients found it helped them prepare for dying.[35] For some families, talking to each other about mesothelioma and its effects was extremely difficult, and they wanted to be helped by psychologists to find new ways to communicate.[15] Skilled listeners, for example, psychologists were identified as able to provide valuable emotional support.[15]

Hughes and Arber[39] found their participants were grateful for being heard, telling their stories urgently despite becoming very distressed. They also reported their participants had issues with sex and intimacy, as did Dooley et al,[36] though this was only alluded to in other studies.

4 | DISCUSSION

This review has provided insight into the literature of the psychological effects of mesothelioma on patients and carers. The characteristics of the studies were presented, along with quality appraisal. The majority of our 17 included articles were qualitative. Only two were quantitative. Studies conducted in Europe, North America and Australia predominated. Most of the literature related to the overall experience of mesothelioma over the course of the disease from the patient's perspective. The majority of our included studies were assessed as having unclear risk of bias, with only four having low risk. Three themes relating to the research question were developed from the data. The first showed aspects regarding time passing, which are specific to the mesothelioma journey. The second indicated the difficult feelings and allied coping strategies experienced by patients and carers. The third provided a picture of communication issues.

Until relatively recently, researchers did not place emphasis on psychological effects at different stages of the disease, or consider the variety of prognoses, treating the mesothelioma journey as uniform.[29] The general need for more nuance has been recognised and is starting to be addressed, for example, by Ball et al's[6] differentiation of mesothelioma from lung cancer. With attention now paid to the early stages of the disease, there is a need for focus on the impact of progression, taking into account the difference between indolent and aggressive types of mesothelioma.[29] This is important as new treatments come on line, and survival times vary even more.

The sparse nature of the field of evidence means there are many research gaps. Few studies included patients with PM. Where included, their experience was not differentiated from MPM, so more research is needed. The majority of qualitative studies had exclusion criteria such as existing psychiatric diagnosis, risk of aggravating distress, or being considered 'well enough'. In addition, mainly hospital patients were studied, omitting those receiving only supportive care.[6] Therefore, it is likely people who have more psychological difficulties (such as PTSD and dementia) or distress are missing from the picture, except in the quantitative data. There is potential for qualitative research to be opened up to such people, for example, those affected by military experiences, with sufficient ethical safeguards in place. Studies show that vulnerable participants can find benefit from participating, even if it is a distressing experience.[41,42] There is an important question about psychological trauma being caused by catastrophic diagnosis, frightening medical treatments, and symptoms such as breathlessness[32,43,44] which requires investigation in regard to mesothelioma.

Despite the review's search terms allowing for positive effects to be reported, the emphasis in the studies was mostly on the negative. The most recent article, by Walker et al,[28] was an exception, with its finding that participants frequently expressed hope and optimism. The wider cancer literature includes studies on posttraumatic growth, benefit-finding and hope.[10,45-47] There is therefore scope to explore positive aspects of the mesothelioma experience, which might help counter the hopelessness often transmitted by HCPs.

None of the studies explored the unique experience of carers. If included at all, they were mixed in with patients, so their particular concerns and needs were muted and overlooked. This lack of inclusion may in part be due to lack of recognition by carers themselves, since many relatives, friends or partners of patients might reject the term 'carer' as not applying to them.[48] It may also reflect a lack of recognition by researchers and healthcare systems.[49-51] A nuanced exploration of the psychological effects on this group is needed. The studies hint that there are issues related to intimacy and sex for people with mesothelioma and their partners, which could be explored in future research.

The studies included in the review came from a limited number of developed countries. The findings from Italy, which particularly showed stigma and social isolation where a whole community was contaminated, suggest that local variations in circumstance can bring different effects. It is important therefore to research the experience of mesothelioma in other countries, such as South Africa, where incidence is under-reported and healthcare is limited.[52]

So far, no studies have reported the effects on populations who differ by type of workplace (eg, education, healthcare), causation (eg, secondary exposure, unidentified), gender, social class or age.

4.1 | Study limitations

This review was conducted in partial fulfilment of a doctorate. A single researcher carried out the majority of the review using a reflexive process. However, the process and the themes identified were extensively discussed in doctoral supervision with the other authors. Existing studies with psychological effects as secondary outcomes could include valuable relevant information. Our decision not to include these was therefore a limitation. The scope of our search could have been wider (no inclusion of grey literature or attempt to find on-going research). In mitigation, the aim was to be reproducible through transparency in conduct and reporting, with provision of good documentation.[18]

4.2 | Clinical implications

This review has highlighted the importance of clinical practitioners being aware of the complex psychological impact and sequelae of mesothelioma. The findings indicate currently there is little evidence to inform clinical practice related to the psychological impact of mesothelioma, especially with regard to carers. However, our findings could inform the development of an assessment tool to identify psychological issues and address risk. They could also impress upon HCPs the importance of communication skills training.

5 | CONCLUSIONS

Though limited, the evidence indicates that mesothelioma, with its high symptom-burden, incurability, rarity and asbestos-related causation, leads to complex and inter-relating psychological effects on patients and carers. These effects are both negative and positive. The sparse literature gives a limited picture and demonstrates an urgent need for more nuanced research. Studies exploring the experiences of specific groups are recommended, such as people exposed in different workplaces. No study has addressed the unique experience of carers, so this is suggested.

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CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

ETHICAL BACKGROUND STATEMENT

Ethical clearance was not required. A preliminary version was accepted for presentation at iMig2020.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created/analysed.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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