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Living with Mesothelioma: A Systematic Review of Patient and Caregiver Psychosocial Support Needs

Lauren J. Breen¹

Taha Huseini^{1,3}

Anne Same¹

Carolyn J. Peddle-McIntyre^{4,5}

Y. C. Gary Lee^{3,6}

¹Curtin School of Population Health, Curtin University, Perth, Western Australia, Australia.

²Curtin enAble Institute, Faculty of Health Sciences, Curtin University, Perth, Western Australia, Australia.

³Department of Respiratory Medicine, Sir Charles Gairdner Hospital, Perth, Western Australia, Australia.

⁴Exercise Medicine Research Institute, Edith Cowan University, Perth, Western Australia, Australia.

⁵School of Medical and Health Sciences, Edith Cowan University, Perth, Western Australia, Australia.

⁶Centre for Respiratory Health, University of Western Australia, Perth, Western Australia, Australia.

Corresponding author at: Dr. Lauren J. Breen, Curtin School of Population Health, Curtin University, GPO Box U1987, Perth Western Australia 6845, Australia. Email lauren.breen@curtin.edu.au

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Abstract

Objective: Practice guidelines emphasize the importance of investigating psychosocial distress in mesothelioma patients and family caregivers. We aimed to synthesize research on the psychosocial support needs of mesothelioma patients and their family caregivers.

Methods: We conducted a systematic review with a narrative synthesis and quality assessment. The review process adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

Results: MEDLINE, EMBASE, Scopus, PsychArticles, and PsycINFO were searched until December 2020 and 37 studies in English met inclusion criteria. Most (n=24) included mesothelioma patients as a very small proportion of their cancer samples. A narrative synthesis was conducted on the 13 studies including only mesothelioma patients (n=297) and/or caregivers (n=82). Patients and caregivers want improvements in the diagnosis delivery and access to palliative care. Patients want emotional support, patient-centered treatment, improved information about illness progression and death, and to meet others with mesothelioma. Caregivers want one-on-one practical and emotional support. Study quality varied.

Conclusions: Few studies focus on the psychosocial support needs relevant to mesothelioma.

Mesothelioma patients and family caregivers highlight targeted psychosocial care as an unmet need.

Practice Implications: Efforts are required to design and test psychosocial interventions for this vulnerable and overlooked group.

Protocol Registration: PROSPERO (registration number CRD42020167852).

Keywords: cancer; caregivers; mesothelioma; oncology; patients; psychosocial aspects; quality of life; systematic review

1. Introduction

Mesothelioma is an aggressive, fatal, but potentially preventable cancer. Its global incidence continues to rise, particularly in developing countries.¹ More than 80% of cases are caused by occupational exposure to asbestos fibers.² The risk increases with age and it is more common in men than women.³ Establishing the number of deaths per year is challenging due to under-reporting¹ and errors on death certificates.⁴ Five-year survival rates are very poor, about 4.5% for men and 13.4% for women.⁵ Treatments are being developed and tested,^{6,7} but the overall impact on survival rates and quality of life remains limited.^{8,9} Mesothelioma remains an incurable cancer with a median survival of 10 to 12 months from diagnosis.¹⁰ During this time, pain from pleural and chest wall invasion can be difficult to control.¹¹ Palliation, or care to prioritize symptom management and quality of life, is therefore the key goal.

Most mesothelioma cases originate from the pleura. Occasionally, they can arise within peritoneal or pericardial cavities or the tunica vaginalis. Fluid build-up within the pleural space (pleural effusions) and associated breathlessness, pain, and weight loss are the most common presenting features.² Breathlessness affects all patients and is often disabling.² Although mesothelioma arises from a well-defined predisposing factor, only a small percentage of asbestos-exposed individuals develop mesothelioma, commonly 30-40 years after initial exposure.¹² The long latency of decades after exposure before disease development and the frequent involvement of medicolegal processes are stressors specific to mesothelioma but not to other cancers.¹³ Current and emerging treatments emphasize the management of physical symptoms.^{7,10}

Several national and international guidelines have articulated the importance of evaluating psychosocial factors for people diagnosed with mesothelioma and their family caregivers.^{2,11,14-16} Scoping¹⁷, systematic,^{13,18} and integrated¹⁹ reviews show that the psychosocial experience of mesothelioma for patients and caregivers encompasses hopelessness, blame, financial/legal issues, and high levels of psychological distress. Studies of people diagnosed with mesothelioma highlight the centrality of uncertainty, lack of control, concerns about the speed of deterioration, emotional distress, and the need for improved psychosocial support;²⁰ medico-legal concerns, a desire to interact with others with mesothelioma, and late or no referral to palliative care;²¹ and a high symptom burden.²² Less is known about the psychosocial support needs of mesothelioma patients and their family caregivers.

We aimed to provide an updated systematic and comprehensive account of research on the psychosocial support needs of people living with mesothelioma and their family caregivers. A synthesis of this kind is important to determine both what is known and the quality of evidence underpinning what is known. Such knowledge is necessary to develop interventions that aim to address unmet psychosocial support needs.

2. Methods

We conducted a systematic review of studies reporting primary data about psychosocial support needs of people living with mesothelioma and their family caregivers. The search strategy, screening criteria, and analysis plan were specified *a priori* and registered with the International Prospective Register of Systematic Reviews (PROSPERO; registration number CRD42020167852). The review is reported according to the updated Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.²³

2.1 Inclusion and Exclusion Criteria

Studies were limited to those published or available for translation in English. All study types and designs were eligible for inclusion and no date restrictions were placed on the search. Intervention studies were included if psychosocial support needs were reported at baseline. We included only studies that were available in full, peer-reviewed, and described original research, upon first publication.

2.2 Search Strategy

Five major academic databases spanning various disciplines (MEDLINE, EMBASE, Scopus, PsychArticles, and PsycINFO) were subject to a rigorous search strategy determined in consultation with a health sciences librarian. Key concepts and terms as employed in the database search along with the Boolean connector were: [mesothelioma OR pleural mesothelioma OR lung cancer OR lung neoplasms] AND [psychosocial stress OR psychosocial adaptation or psychosocial experience OR psychosocial needs OR psychosocial factors OR psychosocial rehabilitation OR psychosocial support OR psychosocial care OR social support OR attitude to death OR existential OR existentialism OR death and dying]. A reference list search was also conducted to identify any further articles. We conducted the initial search during March 2020. Studies were included up to March 2021.

2.3 Screening, Selection, and Data Extraction

Two authors (TH and AS) conducted the article screening, article selection, and data extraction from selected articles. After the initial databases search, the titles and abstracts of all retrieved articles were reviewed as per the prescribed inclusion criteria. These two authors then independently reviewed a random 10% (n=532) of retrieved articles to ensure consistency in the application of the inclusion criteria, with an almost perfect level of agreement (Cohen's $k = 0.83$).²⁴ Following a team discussion of these minor discrepancies in the application of the criteria, the same two authors selected the remaining articles based on the full-text publications and independently extracted data from each study (e.g., sample size and characteristics, study aim and design, findings) using a standardized, pre-piloted spreadsheet to ensure consistency of reporting. Only minor differences were noted and were resolved by the first author.

2.4 Data Analysis

We report the median sample size due to the positive skew in the number of patients and caregivers, determined by the Shapiro-Wilk test. We calculated normality tests and descriptive

statistics using SPSS v25. We conducted a narrative synthesis following the Guidance on the Conduct of Narrative Synthesis in Systematic Reviews.²⁵

2.5 Quality Assessment

Due to the variability in study designs, methodological quality was assessed using the Quality Appraisal for Diverse Studies tool,²⁶ a revision of the Quality Assessment Tool for Studies with Diverse Designs.²⁷ The tool has 13 criteria (e.g., statement of research aims, description of research setting and population). Each study received a score for each criterion, ranging from 0 (no mention at all) to 3 (explicit and specific treatment of the criterion). Overall scores range from 0 to 39 and are expressed as a percentage of the maximum possible score. Scoring of all included studies was conducted independently by the first author and a research assistant to ensure rigor. There was very good interrater reliability (Cohen's $k = .81$).²⁴ Differences were resolved via a discussion between the two raters. No study was excluded based on poor quality; however, limitations are considered in the reporting of findings.

3. Results

After removal of duplicates, 5320 articles were identified in the searched databases and reference list searches. A total of 5057 were excluded following title and abstract screening, leaving 263 articles for full-text review. Studies were excluded because they were not relevant to mesothelioma (n=159), did not present original peer-reviewed research (n=19), did not mention psychosocial support needs from the perspective of patients and/or informal caregivers (n=35), were not available in English (n=3), the full article could not be sourced (n=10); some articles were excluded for more than one of these reasons. A total of 37 studies were subject to data extraction and analysis (Figure 1).

3.1 Quality Appraisal and Risk of Bias

Overall quality of the included studies ranged from 41.03% to 82.05% (Mean=63.7%, SD=12.9%; see Supplementary Table 1). The likelihood of selection bias was high due to unrepresentative sampling and mixed response rates.

3.2 Study Characteristics

From the 37 studies, we identified two “types” of studies: those including only mesothelioma patients and/or caregivers (n=13) and those including mesothelioma patients and/or caregivers within a much larger sample of cancer patients (n=24).

3.2.1 Studies focused only on Mesothelioma Patients/Caregivers.

Of the 13 studies focused solely on people diagnosed with mesothelioma and/or caregivers (see Table 1), nine were based on interview data^{20-22, 28-33} and four from cross-sectional or longitudinal surveys.³⁴⁻³⁷ Some were complemented by data from focus groups,²⁹ medical records,²⁸ and media reports and historical documents.³² These studies were published between 1983 and 2021. Four studies originated from Australia,^{29,32,34,35} 3 from the United Kingdom,²⁰⁻²² two each from Italy^{30,35} and the United States^{31,33} and one each from Brazil²⁸ and Japan.³⁶

The sample sizes of patients were small, ranging from 2³² to 73.³⁶ A total of 297 people with mesothelioma were included in these studies (Mdn=12.5). Of these, 246 were men and 49 were women and typically aged in their 50s to 70s; neither sex nor age was specified in one study³² Caregivers' perspectives on their psychosocial support needs were included in five studies^{28-30,32,35} including a total of 82 caregivers (Mdn=6.00).

3.2.2 Studies including Mesothelioma Patients/Caregivers in a Larger Sample.

In the 24 studies including mesothelioma patients within a large sample, sample sizes ranged from 5³⁸ to 4,020³⁹ participants (NB: two studies^{40,41} were based on the same sample). The number of participants diagnosed with mesothelioma was very small, ranging from being unspecified^{38,42} to 22.³⁹ The total number of patients in these studies was 6,903 and only 116 of them had mesothelioma. That is, people with mesothelioma were only 1.68% of the samples. Of these, 12 were men and four were women; sex and age of the people with mesothelioma was not specified in 17 studies.³⁸⁻⁵⁴ Caregivers' perspectives on their psychosocial support needs were included in seven studies.^{47,52,53, 55-58} These studies and their findings are summarized in Table 2.

Of these studies, 10 were based on interviews,^{44,45,46,49,55,57-61} six were RCT designs,^{40-43,52,53} six used cross-sectional or longitudinal surveys,^{39,46,49,50,54,56} one had a mixed-method design,³⁸ and one was based on nurses' notes of discussions with patients.⁵¹

As for country of origin, 11 were from the United Kingdom,^{38,43-45,48,49,51,55-58,61} six from Australia,^{42,46,49,50,53,54} two each from Canada,^{40,41} Netherlands,^{52,58} and the United States^{59,60} and one from Germany.³⁹ These studies were published between 1999 and 2017.

3.3 Synthesis of Findings

The very small percentage of mesothelioma patients included in studies summarized in Table 2 means that a synthesis of findings from those studies is likely to be misleading in their potential application to mesothelioma. Thus, we synthesized the findings from the 13 studies focused only on people with mesothelioma and/or their family caregivers. The analysis revealed psychosocial support needs relevant to diagnosis, disease/symptom management, receiving and providing care, and coping. In summarizing the needs below, we articulate which relate to patients, caregivers, or both groups.

3.3.1 Diagnosis.

Family members were instrumental in guiding patients towards diagnosis.²⁸ The time taken to achieve the diagnosis was often lengthy^{30,32} and a particularly difficult and frustrating period for patients and caregivers.^{29,30} The diagnosis was experienced by patients and family caregivers as a shock^{29,32} or death sentence³² and involved feelings of anger, anxiety, and disbelief,^{22,29,31} even though the risk of prior asbestos exposure was known.³² There was conflict between loyalty to employers and feelings of anger and betrayal.³² The diagnosis could be improved via the delivery of balanced (rather than predominantly or only negative) information in a clear, understandable, customized, and timely fashion, with the opportunity to ask questions.^{29,34}

3.3.2 Disease and Symptom Management.

Patients experienced problems with memory, concentration, and problem-solving³⁵ and suffered from clinically significant trauma symptoms, which correlated with somatic complaints, anxiety, depression, and social dysfunction.³⁴ Management of the disease involved coping with increasing symptoms, particularly shortness of breath, fatigue, insomnia, pain, and physical deterioration^{21,22,33,36} and feelings of uncertainty and lack of control,²⁰ leading to emotional, physical, and psychosocial distress.²⁰ Patients and caregivers experienced shame, guilt, blame, loss of intimacy, social isolation and stigma, and the illnesses/deaths of multiple friends.^{21,30,32} Legal processes for compensation were experienced by patients and caregivers as a battle and a burden,^{21,30} particularly as patient health declined.³²

3.3.3 Receiving and Providing Care.

Establishing relationships with healthcare providers was often a challenge.³² Medical interventions ranged from the tolerable to the distressing.²² Chemotherapy improved some symptoms like cough and pain but led to hair loss and more nausea and vomiting.³⁶ Patients experienced the physical deterioration as distressing and requiring dependence on others.³⁰ Family caregivers provided much of the day-to-day care²⁸ and the tasks of caregiving affected their physical and emotional health, particularly in the form of fatigue, fear, problem-solving difficulties, helplessness, and eschewing their own needs^{32,35} Access to palliative care was often delayed due to late referral.³²

3.3.4 Coping.

For patients, coping involved acceptance and stoicism, and they described having less hope than if they had a typical cancer diagnosis.^{22,32} Coping strategies varied from “fighting” to acceptance.²⁹ Patients focused on the short-term but expressed worry about the long-term outcome, rapid deterioration, potential for suffering, and impact on their families.^{20,30,33} Patients reported developing a new appreciation for the value of life and relationships with loved ones.³³ Caregivers described the loss of the person they once knew, as the disease took its toll.³⁰ For caregivers, beliefs about spirituality/religion were important to providing hope.²⁸ Caregivers reported being challenged by the physical and emotional tasks of care and would like one-on-one practical and emotional support.²⁹ Patients wanted emotional support and empathy, patient-centered treatment, improvements in the access and effectiveness of treatments, improved information about the progression of their illness and how or when death would occur, specialist supportive and palliative care services, and the opportunity to meet with others with mesothelioma.^{21,32,33,36}

4. Discussion and Conclusion

4.1 Discussion

This systematic review provides a timely and comprehensive account of research on the psychosocial support needs of people living with mesothelioma and their family caregivers. We found 13 studies that focused solely on mesothelioma and narratively synthesized those findings. Psychosocial support needs were centered on themes of diagnosis, disease and symptom management, receiving and providing care, and coping. Patients and caregivers want improvements in the diagnosis

delivery and access to palliative care. Patients want emotional support, patient-centered treatment, improved information about illness progression and death, and to meet others with mesothelioma. Caregivers want one-on-one practical and emotional support.

Mesothelioma is often difficult to diagnose and may require multiple invasive procedures to achieve diagnosis,⁶² which likely explains why patients and caregivers wanted improvements in the diagnosis process. Specifically, patients and caregivers identified a need for the diagnosis to be delivered in a way that is clear, understandable, customized, and timely, with the opportunity to ask questions.^{29,34} Studies of other progressive and incurable diseases such as amyotrophic lateral sclerosis (also known as Lou Gehrig's disease and motor neuron disease) indicate that managing the delivery of the diagnosis is important for patient and caregiver wellbeing.^{63,64} That the diagnosis process elicited feelings of shock, anxiety, and disbelief, even when the risk of prior asbestos exposure was known,³² suggests a need for strategies to minimize these experiences.

Once diagnosed, the symptoms of mesothelioma encompass a range of distressing physical, cognitive, psychological, and social outcomes that are difficult to manage.²² Attempts to access compensation are very common for people with mesothelioma and their families and a point of difference from other cancer experiences.¹³ However, the research shows that compensation processes are challenging for patients and caregivers, especially as the diseases progresses.³² As a result of such challenges, patients identified needs for emotional support, patient-centered treatment, and improved information about illness progression and death. Caregivers, too, are challenged by the consuming nature of caregiving^{28,32,35} and identified needs for practical and emotional support. Patients and caregivers identified a need for earlier access to palliative care. Palliative care is a holistic form of support for people living with terminal and life-limiting illnesses and their family caregivers. Palliative care aims to manage symptoms, provide person-centered and family-centered care, promote quality of life, and assist with preparations for caregiving and for death.⁶⁵ Early access to palliative care is recommended for mesothelioma patients and caregivers¹⁵ and would help meet several of the psychosocial support needs they identify. Evidence shows that access to palliative care for mesothelioma patients improves caregiver satisfaction.⁶⁶ Studies not focused on mesothelioma show that the palliative care increases patients' quality life⁶⁷ and meets caregivers' needs for one-on-one practical and emotional support.⁶⁸

Mesothelioma has a variable lifespan. Although survival following diagnosis is relatively short,¹⁰ a small number of long survivors have been reported.^{10,69,70} A few prognostic scoring systems have been proposed to predict survival in mesothelioma patients⁷¹⁻⁷³ but these remain suboptimal. Many at-risk individuals are aware of older literature that described mesothelioma patients dying from drowning (due to effusions) and suffocation in amidst severe pain.⁷⁴ These issues likely explain caregivers' efforts to maintain feelings of hope³³ while expressing the need for more information about the prognosis and progression of their illness and how or when death would occur. Similarly,

the variable lifespan might explain patients who report a greater appreciation for the value of life.²⁸ These positive could be useful as a basis upon which to build to reduce psychosocial distress.

Patients identified a need to meet others with mesothelioma.²¹ A study of one support group developed specifically for people with mesothelioma and their family caregivers showed good attendance, and that participants evaluated the information they received as useful.⁷⁵ They also described that the group made them feel less alone in their journey.

4.1.2 Limitations

This review offers transparency of process and peer review of methods through the publication of a PROSPERO systematic review protocol. Quality appraisal, study eligibility, and data extraction processes were conducted independently by two authors, increasing the rigor of the review. Some non-English language articles may have been missed, limiting cross-cultural generalizability. Although a review of studies focused only on mesothelioma patients and/or caregivers might have enabled a more targeted analysis, the purpose of this review was to conduct a broader examination of the full literature.

We found 24 studies that included a very small number of people with mesothelioma and their caregivers. Given the very small percentage the mesothelioma patients account for in the large cohorts, applying the conclusions from these studies to people with mesothelioma and their caregivers might result in missing nuances specific to mesothelioma. Thus, it is important to emphasize that what is known is based upon a small number of studies, small sample sizes, and variable study quality. Further, only three of these 13 studies^{34,35,37} included quantitative measures. A qualitative approach is important due to the limited literature base, but a variety of study types are needed to understand and address patients' and caregivers' psychosocial support needs. Hence, Girgis et al.²⁹ recently called for quantitative data to complement qualitative approaches. Five studies^{28-30,32,35} included the perspectives of family caregivers. Including caregivers in future studies will provide a more comprehensive understanding of caregivers' psychosocial support needs including those that are similar to and different from patients'.

Addressing the psychosocial care needs of mesothelioma patients is therefore an area of high priority. Given the limited and piecemeal approach to examining the psychosocial support needs of people with mesothelioma and their family caregivers, further research is clearly warranted to inform person-centered care in line with practice guidelines. Specifically, we recommend studies where researchers focus on mesothelioma, aim for a robust sample size, include patients and family caregivers, articulate psychosocial support needs; provide guidance as to the implementation of psychosocial care interventions, and use rigorous approaches to data collection.

4.2 Conclusion

This review provided a systematic synthesis of what is currently known and the quality of evidence underpinning what is known about the psychosocial support needs of people living with mesothelioma and their family caregivers. Overall, the knowledge produced over the past four

decades is limited. Most studies combine mesothelioma patients and/or caregivers within much larger cancer cohorts, there is a small number of studies focused on mesothelioma, sample sizes in these studies are small, and study quality varies. That there are 13 studies of variable quality available in English, based on a total of 297 mesothelioma patients and 82 caregivers, suggests much research is needed to provide a complete picture of the psychosocial support needs of people with mesothelioma and their family caregivers. We anticipate that the psychosocial support needs identified thus far in the literature and articulated in this paper, could be used to inform the development, testing, and implementation of strategies to meet these needs.

4.3 Practice Implications

Key findings from the narrative synthesis of studies of the psychosocial support needs of mesothelioma patients and their family caregivers are their needs for improvements in diagnosis, access to palliative care, practical and emotional support, centered treatment, improved information about illness progression and death, and opportunities to meet others with mesothelioma. The unmet needs we identified provide a strong base for future research to develop and test targeted psychosocial care interventions that are likely to address patients' and family caregivers' psychosocial support needs. The lack of targeted psychosocial care for mesothelioma is an important area warranting further study to enable the design of future intervention strategies that will achieve the implementation of practice guidelines for this vulnerable group.

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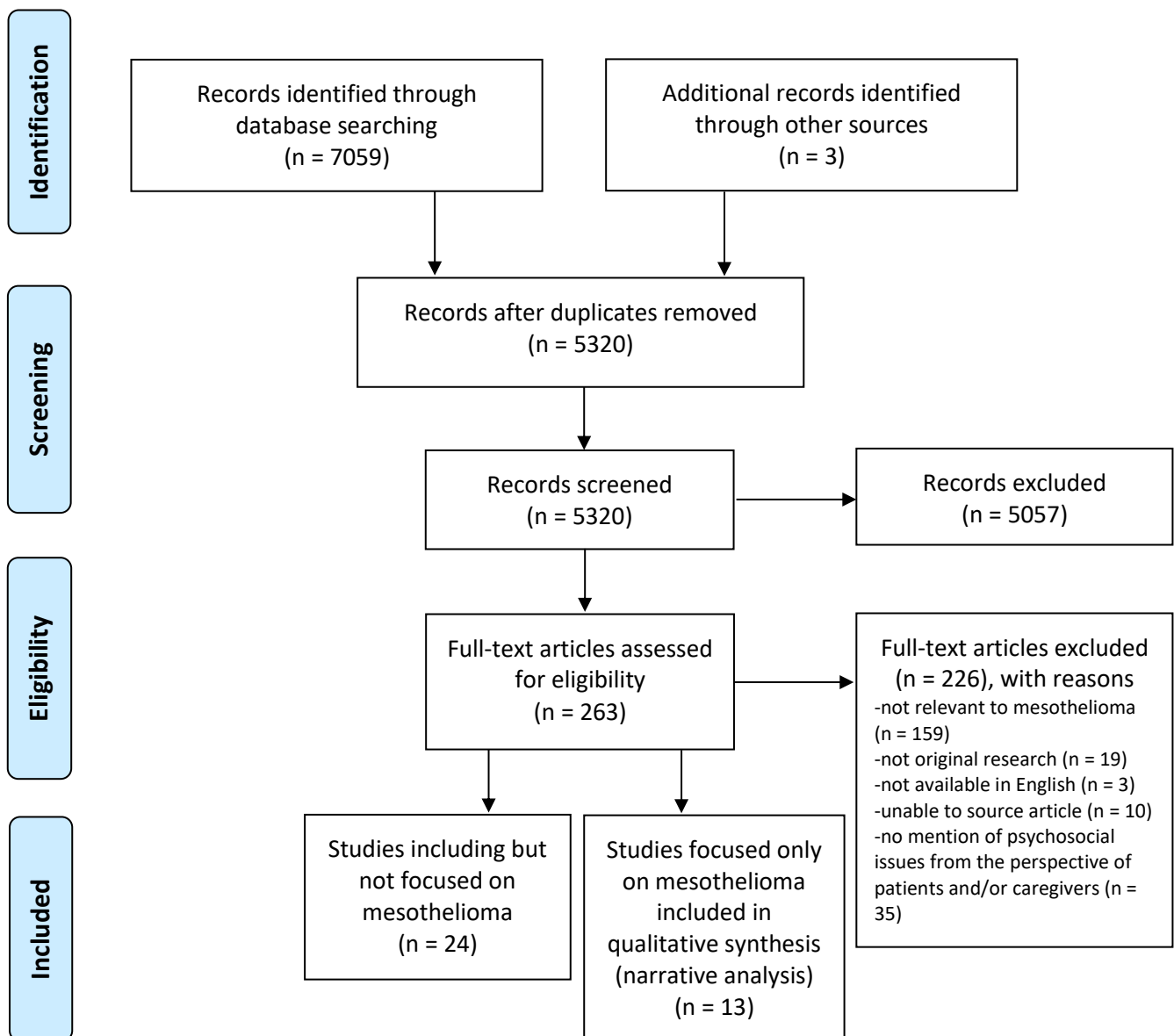


Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow chart of study selection and results.

Supplementary Table 1
Quality Assessment of Included Studies

Study	Theory	Aims	Setting	Design	Sampling	Choice of tools	Format and content of tools	Data collection procedure	Recruitment data	Justification of analysis	Appropriateness of analysis	Stakeholder involvement	Strengths and limitations	Total
Arber & Spencer 2013 ²⁰	2	3	3	3	2	2	1	2	1	1	0	0	2	22
Baran et al. 2019 ²⁷	1	1	3	1	2	2	2	1	1	0	1	0	1	16
Booth et al. 2003 ⁵⁴	2	2	2	2	2	2	1	1	1	0	2	0	0	17
Bredin et al. 1999 ⁴²	2	1	2	3	1	1	2	0	2	2	2	0	3	21
Carlson et al. 2010 ³⁹	2	3	3	3	3	2	3	3	3	2	3	0	2	32
Carlson et al. 2013 ⁴⁰	2	3	2	3	2	2	3	2	3	2	2	0	3	29
Chapple et al. 2004 ⁴³	2	1	1	2	2	0	1	1	1	0	3	0	1	15
Chapple et al. 2004 ⁴⁴	2	2	1	2	2	0	1	1	1	0	3	0	2	17
Clayson et al. 2005 ²²	1	2	3	2	1	2	3	2	1	0	2	0	0	20
Devitt et al. 2010 ⁴⁵	2	3	1	2	3	2	3	3	3	0	3	0	3	28
Dooley et al. 2010 ³³	3	3	0	2	1	3	3	2	1	2	3	0	3	26
Ellis et al. 2012 ⁴⁷	3	3	3	3	1	0	1	2	1	0	2	0	2	21
Girgis et al. 2019 ²⁸	3	3	3	3	1	1	3	2	1	3	3	0	3	29
Granieri et al. 2013 ³⁴	2	3	3	3	2	2	3	1	3	2	3	0	2	29
Guglielmucci et al. 2018 ²⁹	2	3	3	3	1	0	1	2	1	1	3	0	2	22
Hartung et al. 2017 ³⁸	2	1	3	3	2	1	2	1	3	3	3	0	3	29
Hughes & Arber 2008 ²¹	2	1	1	3	1	3	1	2	1	3	3	0	2	23
Krishnasamy et al. 2001 ⁵⁵	2	3	3	3	3	0	0	0	3	2	3	0	1	23
Krishnasamy et al. 2007 ⁵⁶	2	3	3	3	3	1	0	1	3	3	3	0	3	28

Lebovitz et al. 1983 ³⁰	2	2	2	3	3	2	2	2	1	2	2	0	0	23
Lee et al. 2009 ³¹	2	1	3	3	2	1	0	1	1	1	3	0	2	20
Molassiotis et al. 2011 ⁴⁵	2	3	2	3	3	3	3	3	3	2	3	0	2	32
Mulcare et al. 2011 ⁴⁸	3	3	3	3	3	2	3	2	1	3	3	0	3	32
Mulcare et al. 2013 ⁴⁹	3	3	3	3	3	2	3	2	1	2	3	0	2	30
Nagamatsu et al. 2019 ³⁵	2	3	2	3	3	2	2	2	2	1	3	0	2	27
Nowak et al. 2004 ³⁶	2	2	1	3	2	2	1	2	1	2	3	0	2	23
O'Driscoll et al. 1999 ⁵⁰	2	2	0	2	1	2	1	2	1	0	2	0	1	16
Quinn et al. 2011 ⁵⁸	3	3	2	2	2	1	3	2	1	1	1	0	1	20
Rohan et al. 2016 ⁵⁹	2	3	2	2	2	1	1	1	2	1	1	0	2	20
Roulston et al. 2012 ³⁷	3	3	3	3	3	1	3	2	1	3	2	0	0	27
Roulston et al. 2018 ⁶⁰	2	3	3	3	2	1	3	2	3	1	3	0	2	28
Schellekens et al. 2017 ⁵¹	2	3	2	3	3	2	3	1	3	1	3	0	3	29
Schofield et al. 2013 ⁵²	2	3	2	3	3	1	3	3	3	2	3	0	3	31
Schook et al. 2014 ⁵⁵	2	3	2	3	3	1	3	2	3	1	3	0	3	29
Sinclair et al. 2017 ⁴¹	2	3	3	3	2	1	3	2	3	2	3	0	3	30
Ugalde et al. 2012 ⁵³	2	3	2	3	3	2	3	1	2	1	2	0	3	27
Walker et al. 2021 ³²	2	3	2	3	3	2	2	2	1	3	3	0	2	28

Note. DC=Data collection; RQ=Research question(s).

Table 1
Summary of Included Studies Focused Solely on Mesothelioma Patients and/or Caregivers

Author(s), Year of publication, Country	Sample characteristics	Study design/methods	Study aim/focus	Key findings	Quality appraisal (%)
Arber & Spencer, 2013, United Kingdom ²⁰	10 patients (8 men, 2 women, M _{age} =70.3 years)	Semi-structured interviews, grounded theory methodology and analysis	To explore patient experiences within the first 3 months from diagnosis	Uncertainty and lack of control, which led to emotional, physical, and psychosocial distress. Patients focused on the short-term but expressed worry about the long-term outcome and rapid deterioration.	56.41
Baran et al., 2019, Brazil ²⁷	6 family members of patients	Case studies of medical records and semi-structured interviews, comparative and content analysis	To describe the therapeutic itinerary	Family members directed patients to professional diagnosis and intervention and provide much of the care. Spirituality/religion was important to providing hope.	41.03
Clayson et al., 2005, United Kingdom ²²	15 patients (13 men, 2 women, M _{age} =69.0 years)	Interviews, grounded theory analysis	Experiences of mesothelioma and its meaning	Living with mesothelioma involved coping with symptoms (e.g., shortness of breath) and physical deterioration. Medical interventions ranged from tolerable to unpleasant and distressing. Diagnosis involved anxiety and disbelief. Coping involved acceptance, stoicism, and less hope than for a typical cancer diagnosis.	51.28
Dooley et al., 2010, Australia ³³	49 patients (all men, M _{age} =51.1 years)	Cross-sectional survey	To investigate specific psychological outcomes of mesothelioma	Patients' trauma symptom scores were in the clinical range (particularly anxious arousal and intrusive experiences) and higher than the general population. Trauma symptoms correlated with somatic complaints, anxiety, depression, and social dysfunction.	66.67
Girgis et al., 2019, Australia ²⁸	8 patients (6 men, 2 women, M _{age} =64.0 years) and 6 family caregivers	Semi-structured interviews and focus groups, thematic analysis	To explore patients' and family caregivers' experiences and needs in 5 domains (physical, psychological, social, information, and caregiver)	The time of diagnosis is a particularly difficult period, involving shock and anger. Information could be provided in a timelier and more balanced (i.e., not so negative) fashion. Coping strategies varied from "fighting" to acceptance. Caregivers are challenged by the physical and emotional tasks of care and would like one-on-one support (practical and emotional).	74.36
Granieri et al., 2013, Italy ³⁴	27 patients (19 men, 8 women, M _{age} =61.4 years), 55 first-degree family members, and 40 healthy controls	Cross-sectional survey	To compare quality of life and personality between patients, relatives, and controls	Patients and relatives reported poorer physical health than controls. Patient reported more problems with memory, concentration, and problem-solving than controls. Relatives reported more fear, difficulties in problem-solving, and helplessness than controls.	74.36

Guglielmucci et al., 2018, Italy ²⁹	10 patients (6 men, 4 women, M _{age} =62.6 years) and 9 caregivers	Open-ended interviews, thematic analysis	To investigate the lived experience of patients and their caregivers	Time taken to achieve the diagnosis was lengthy and frustrating. Physical deterioration was distressing and led to dependence on others. Patients and caregivers were hesitant to describe the emotional impacts of the disease. They experienced shame, guilt, blame, social stigma, and the illnesses/deaths of multiple friends. They described focusing on each day; looking to the future was upsetting. Legal processes for compensation were a battle. Patients expressed worry for their families. Caregivers described the loss of the person they once knew, as the disease progressed.	56.41
Hughes & Arber, 2008, United Kingdom ²¹	5 patients (4 men, 1 woman, aged 54-76 years)	Unstructured interviews, hermeneutic phenomenology	To explore emotional and psychological needs	Described challenge from the physical deterioration, loss of intimacy, social isolation, and lack of information about specialist supportive and palliative care services. Involvement in complex medico-legal matters in relation to asbestos exposure was an additional burden for them and their spouse or caregiver. They welcomed the opportunity to meet with others in their situation.	58.94
Lebovitz et al., 1983, United States ³⁰	38 patients (31 men, 7 women, M _{age} =58 years)	Semi-structured interviews, methodological and analytical orientation not stated	To explore awareness of increased risk, receipt of risk information, and the subsequent response, especially in relation to smoking	The majority become aware of the risk of asbestos from friends and the media, not the workplace. The majority smoked cigarettes and did not stop following awareness of mesothelioma risk. Almost half denied or minimized their risk of mesothelioma and expressed disbelief that exposure to asbestos was responsibility for their illness. Some felt grateful for their employment and most did not feel anger towards the asbestos industry.	58.94
Lee et al., 2009, Australia ³¹	2 patients (sex and age not reported), 6 family caregivers; 5 legal and healthcare providers	Case studies from in-depth interviews, media reports, local authority and employer reports and historical data, analyzed via constant comparative method	To identify commonalities and explore the needs and experiences of patients, family caregivers, and service providers	Diagnosis was a shock, despite awareness of risk. There were delays in receiving the diagnosis, challenges in establishing relationships with healthcare providers, and reduced treatment options due to the rural location. The diagnosis was feared and viewed as a death sentence. Attempts to cope with stoicism increased social isolation. Some felt conflicted by loyalty to employers and feelings of anger and betrayal. Seeking compensation took time and effort and was particularly burdensome as health declined. The burden of caregiving was characterized by fatigue and own needs being overlooked. Palliative care access was delayed due to late referral.	51.28

Nagamatsu et al., 2019, Japan ³⁵	73 patients (61 men, 12 women, M _{age} =66.8 years)	Cross-sectional survey, content analysis of 2 open-end questions	To determine the health service needs of patients	Patients wanted clear and understandable information about mesothelioma and time to ask questions, patient-centered treatment, improvements in treatments and support systems, emotional support and empathy, customized delivery of bad news, and dedication to mesothelioma treatment.	69.23
Nowak et al., 2004, Australia ³⁶	53 patients (45 men, 8 women, aged 47-76 years)	Longitudinal assessment at baseline and at day 1 of chemotherapy cycles 2, 4, 6, and 8-weekly thereafter	To assess the feasibility and validity of the European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire and Lung Cancer Module to describe patients' health-related quality of life	Before chemotherapy, role, social, and emotional function were the most impaired domains; physical and cognitive functions were the least impaired. Patients rated fatigue, insomnia, breathlessness, and pain as the most troublesome symptoms. Patients' functional scale scores did not improve during chemotherapy; cough and pain improved but hair loss and nausea/vomiting were worse.	58.94
Walker et al., 2021, United States ³²	7 patients (4 men, 3 women, M _{age} =72 years)	Semi-structured interviews, descriptive phenomenology methodology and analysis	To explore patients' lived experience and identify unmet needs	Patients reported a lack of clarity about illness progress and how or when death would occur. They attempted to maintaining hope and optimism but were also concerned about future suffering. They described having to adapt to the illness, including the high symptom burden (e.g. breathlessness, fatigue), physical deterioration, and lifestyle changes. They described developing a new appreciation for the value of life and relationships with loved ones. They forged new relationships with their healthcare team and other mesothelioma patients.	71.79

Table 2
Summary of Included Studies with a Minority of People with Mesothelioma and/or Caregivers

Author(s), Year of publication, Country	Sample characteristics	Study design/methods	Study aim/focus	Key findings	Quality appraisal (%)
Booth et al., 2003, United Kingdom ⁵⁵	10 COPD patients, 10 cancer patients (1 mesothelioma, a 66-year-old man), and their spouses	Semi-structured interviews, methodological and analytical orientation not stated	To describe the experience of breathlessness for patients and caregivers	Breathless experiences ranged from unpleasantness and terror. Disability and dependence on others are a major adjustment. Current treatments and strategies were not always effective. Caregivers experienced worry, anxiety, helplessness, terror, vigilance, and sleeplessness.	43.59
Bredin et al., 1999, United Kingdom ⁴²	119 lung cancer patients (14 mesothelioma, sex and age not reported)	RCT–assigned to intervention or control group	To determine the effectiveness of a nursing intervention for breathlessness	High distress at baseline (distress from breathlessness, anxiety, depression, psychological and physical symptoms, and low quality of life).	53.85
Carlson et al., 2010, Canada ³⁹	1034 patients with breast or lung cancer (14 mesothelioma, sex and age not reported)	RCT–three levels of distress screening	To determine the efficacy of different screening programs on distress 3 months later	High distress at baseline (62.5% of lung cancer patients scored ≥ 4 on distress thermometer).	82.05
Carlson et al., 2013, Canada ⁴⁰	549 patients with lung cancer (14 mesothelioma, sex and age not reported)	RCT–three levels of distress screening	To determine the efficacy of different screening programs on pain, fatigue, and psychosocial, practical, and physical problems 3 months later	High distress at baseline (47.9% reported pain, 69.5% reported fatigue).	74.36
Chapple et al. 2004, United Kingdom ⁴³	45 patients with lung cancer (4 mesothelioma—a 55-year-old man and a 62-year-old man—sex and age not reported for remaining 2)	Narrative interviews, methodological and analytical orientation not stated	To explore the experience of stigma	Participants reported stigma due to the self-inflicted nature of the disease. Feelings of being blamed unjustly for the disease. Some concealed their illness to avoid stigma and blame, making it harder to get support and medical care.	38.46
Chapple et al. 2004, United Kingdom ⁴⁴	45 patients with lung cancer (4 mesothelioma—a 55-year-old man; sex	Narrative interviews, methodological and analytical orientation not stated	To explore the experience of access to financial benefits	Variability in knowledge about benefits and difficulties in obtaining knowledge about rights, claim forms and processes were experienced as complicated and described as “a struggle”.	43.59

	and age not reported for remaining 3)			Advice was sometimes available within the health system but not timely.	
Devitt et al., 2010, Australia ⁴⁵	100 patients with lung cancer (5 mesothelioma, sex and age not reported) and 145 cancer support group facilitators	Cross-sectional survey	To explore the views of patients and support group facilitators on lung cancer support group programs	12% of patients had attended a support group but 53% of patients expressed interest in participating. Patients preferred facilitation by a health professional and in a hospital setting whereas facilitators preferred volunteer facilitators and community venues. Patients preferred content centred on information whereas facilitators preferred emotional support. Both groups highlighted the group environment, discussing cancer, parking, and travel as barriers to attendance.	71.79
Ellis et al., 2012, United Kingdom ⁴⁷	37 lung cancer patients (2 mesothelioma, sex and age not reported) and 23 primary caregivers	Semi-structured interviews, framework analysis	To explore how patients and family caregivers cope with the diagnosis and the key factors that mediate distress	Coping involved accepting the reality of lung cancer, denial, having a positive attitude, engaging in avoidance and distraction, seeking information, and maintaining normality. Patient and caregiver stress was lessened by hope, having a supportive social network, having positive prior experience with cancer and other chronic conditions, alignment of patients' and caregivers' coping strategies, predictable nature of patient's behavior; understand changes in symptomatology; supportive health professionals, and minimal/no delays in diagnosis.	53.85
Hartung et al., 2017, Germany ³⁸	4020 cancer patients (22 mesothelioma, sex and age not reported) and 5018 general population controls	Cross-sectional survey	To identify depressive symptoms and risk of depression	1 in 4 patients (24%) reported elevated depressive symptomatology. Depressive symptoms were 5.4 times more likely than for the general population and more likely for patients who were middle-aged, unemployed, single, received chemotherapy and/or cancer rehabilitation, and had been diagnosed with metastatic and/or stage IV cancer.	74.36
Krishnasamy et al., 2001, United Kingdom ⁵⁵	209 lung cancer patients (8 mesothelioma, 5 men, 3 women, age not reported) and 70 family caregivers	Cross-sectional survey	To describe patients' and informal caregivers' perceptions of care	Most patients and caregivers reported receiving clear information at diagnosis. For 69% of patients, the diagnosis was conveyed with sensitivity; 31% reported it was conveyed unsensitively. 38% of patients reported they had the opportunity to ask questions. 49% of patients reported depression and 66% reported worries/anxiety. Half reported breathlessness but only 15% had received advice about its management. The most common patients' complaints were pain, fatigue, and breathlessness. The most common caregivers' complaint was social/financial problems. Patients reported the hospital doctor, GP, and spouse as key sources of support. A minority reported wanting more support from the hospital team and community services. Only 29% of patients identified caregivers as having	58.94

				needs in relation to their illness but caregivers reported fear about the future, depression, and anxiety.	
Krishnasamy et al., 2007, United Kingdom ⁵⁶	23 cancer patients (1 mesothelioma, sex and age not reported) and 15 family caregivers	Longitudinal, 3 in-depth interviews over 6 months	To explore patients' and family members' experiences of care provision	The time leading to and immediately after the diagnosis was difficult and characterized by delays, frustration, and anger. Communication of the diagnosis, treatment options, and prognosis was inconsistent and information often conflicting. Communicating the diagnosis to family and friends was often traumatic for patients. Receiving the diagnosis alone contributed to isolation, anxiety, and distress. Patients were concerned about their physical deterioration and being a burden on family members. Caregivers were not supported to care or in their own emotional needs. Patients reported feeling unsafe in between treatment or appointments, due to delays or inadequacies in communication between the hospital and GP. Caregivers reported worry and distress about managing potential complications.	71.79
Molassiotis et al., 2011, United Kingdom ⁴⁷	26 lung cancer patients (1 mesothelioma, sex and age not reported)	Semi-structured interviews, and framework analysis	To explore patients' experience of cough	Coughing was associated with breathlessness, panic, fatigue, embarrassment, and stigma. Patients tried many strategies to cope with and manage their cough. They limited their social life/public outings to avoid embarrassment and disrupting others.	82.05
Mulcare et al., 2011, Australia ⁴⁸	73 lung cancer patients (2 mesothelioma, sex and age not reported)	Cross-sectional survey	To investigate the relationship between adjustment to cancer and information needs	High levels of the adjustment styles Fighting Spirit and Anxious Preoccupation correlated with a high need for disease-oriented information. High levels of the adjustment style Cognitive Avoidance correlated with a low need for disease-oriented information. High levels of Anxious Preoccupation correlated with a high need for action-oriented information.	82.05
Mulcare et al., 2013, Australia ⁴⁹	59 lung cancer patients (2 mesothelioma, sex and age not reported)	Longitudinal survey, 2 questionnaires 1 month apart	To test the influence of adjustment to cancer on information seeking	Participants access information from more sources over time. Information goals at time 1 predicted information seeking at time 2. Type of Information needs at time 1 did not predict information seeking at time 2. Adjustment styles had little impact on the number of information sources accessed at time 2.	76.92
O'Driscoll et al., 1999, United Kingdom ⁵⁰	52 lung cancer patients (4 mesothelioma, sex and age not reported)	Content analysis of nurses' notes from discussions with patients	To explore how patients described breathlessness and its impact on their lives	Patients described breathlessness as a physical and emotional experience, comprising exhaustion, fatigue, frustration, anger, anxiety, panic, fright, fear, and feelings of impending death. Breathlessness triggers included walking, talking, laughing, excitement, and crying. Most experienced intermittent breathless; it was constant for a minority. Patients tried many	41.03

				strategies to cope with and manage breathlessness yet it substantially restricted their personal and social activities.	
Quinn et al., 2011, United States ⁵⁸	21 lung cancer patients (2 mesothelioma—a 50-year-old man and a 72-year-old man)	Semi-structured interviews, content analysis	To apply the theory of planned behavior to understand patient decisions about participating in a clinical trial	Patients reported fear was the initial reaction to diagnosis and described being scared, overwhelmed, and shocked. They felt numb, horror, terror, a loss of control, and worried about death.	51.28
Rohan et al., 2016, United States ⁵⁹	21 lung cancer patients (1 mesothelioma—a 46-year-old man)	In-depth semi-structured, telephone interviews, open coding	To understand patients' subjective experiences and psychosocial concerns	Patients reported feeling distress at being blamed and stigmatized for their cancer (regardless of smoking status); surprise and guilt for survival; and desiring more public support and attention for lung cancer.	51.28
Roulston et al., 2012, United Kingdom ³⁷	5 lung cancer and mesothelioma patients (number with mesothelioma and their sex and age not specified)	Mixed-methods pilot study was of patients attending the Breathing Space clinic over a 4-week period. Semi-structured interviews analyzed using thematic content analysis	To explore patients' anxiety, depression, and quality of life	At baseline, 3 reported mild or moderate anxiety and 4 reported mild, moderate, or severe depression. Concerns included survival time, physical deterioration, hopelessness, negative thoughts, social isolation, and stigma.	69.23
Roulston et al., 2018, United Kingdom ⁶⁰	12 lung cancer and mesothelioma patients (1 mesothelioma – a woman, aged not specified)	Longitudinal, semi-structured interviews 1 month apart, narrative analysis	To explore patients' lived experiences	Patients reported frustration and loss of faith in medical physicians due to a delayed or missed diagnosis; acceptance of reduced treatment options and outcomes; physical deterioration from the disease and treatment, breathlessness, panic, frailty, vulnerability, uncertainty, and loss of control; fear of becoming a burden; awareness of mortality.	71.79
Schellekens et al., 2017, The Netherlands ⁵¹	63 lung cancer patients (2 mesothelioma, sex and age not specified) and 44 partners	RCT—assigned to intervention or usual care	To examine the effectiveness of additional group-based mindfulness-based stress reduction intervention over usual care in reducing patient and/or partner psychological distress	At baseline, 22 patients (35%) reported clinically heightened anxiety and depression.	74.36
Schofield et al., 2013, Australia ⁵²	108 lung cancer patients (6 mesothelioma, sex	RCT—assigned to intervention or usual care	To test the effectiveness of a tailored supportive	At baseline, average composite anxiety and depression score was in the mild range.	79.49

	and age not specified) and 44 partners		care intervention for patients		
Schook et al., 2014, Netherlands ⁵⁷	5 lung cancer patients (0 mesothelioma) and 20 caregivers (3 of mesothelioma patients)	Semi-structured telephone interviews, thematic analysis	To explore reasons why lung cancer patients and caregivers search the Internet for information rather than consulting with their own specialist	The Internet was a regular source of information on lung cancer, especially at certain times like the start of a new treatment or the development of new symptoms, and for advice about managing emotions and daily life. They sought information to complement specialist advice, connect with fellow sufferers, and keep concerns from each other. and because Some felt vulnerable and ashamed, and caregivers didn't want to burden specialists with questions about their own concerns and needs.	74.36
Sinclair et al., 2017, Australia ⁴¹	149 chronic, severe respiratory disease patients (number with mesothelioma and their sex and age not specified)	Partial RCT—assigned to intervention or usual care	To test whether a systematic nurse-led advanced care planning intervention increases advanced care planning in patients	At baseline, participants most commonly reported problems with mobility and reductions in usual activity, following by pain and discomfort, anxiety and depression, and personal care issues. Just under half reported breathlessness and about one-third were eligible for long-term oxygen therapy.	76.92
Ugalde et al., 2012, Australia ⁵³	108 lung cancer patients (6 mesothelioma, sex and age not specified)	Cross-sectional survey using baseline RCT data	To determine patients' unmet need and psychological distress at the start of treatment	Patients reported an average of 17 unmet needs. Psychological/emotional needs were the top 4 of the top 15 unmet needs. These were dealing with concerns about your family's fears and worries, dealing with feeling dependent on others, coping with frustration of not being able to do things you used to, and coping with fears about physical deterioration. 7 of the 15 needs regarded medical communication (i.e., timeliness, fullness, and clarity of information). 31.5% had clinical/subclinical anxiety and 19.4% had clinical/subclinical depression. Number of unmet needs was correlation with higher anxiety and depression scores.	69.23

Note. COPD=chronic obstructive pulmonary disease; RCT=randomized controlled trial.