



This is a repository copy of *Patients' and informal carers' experience of living with mesothelioma: A systematic rapid review and synthesis of the literature*.

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/184820/>

Version: Accepted Version

Article:

Ejegi-Memeh, S. orcid.org/0000-0002-9241-300X, Sherborne, V., Harrison, M. orcid.org/0000-0001-9874-921X et al. (4 more authors) (2022) Patients' and informal carers' experience of living with mesothelioma: A systematic rapid review and synthesis of the literature. *European Journal of Oncology Nursing*, 58. 102122. ISSN 1532-2122

<https://doi.org/10.1016/j.ejon.2022.102122>

Article available under the terms of the CC-BY-NC-ND licence (<https://creativecommons.org/licenses/by-nc-nd/4.0/>).

Reuse

This article is distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs (CC BY-NC-ND) licence. This licence only allows you to download this work and share it with others as long as you credit the authors, but you can't change the article in any way or use it commercially. More information and the full terms of the licence here: <https://creativecommons.org/licenses/>

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk
<https://eprints.whiterose.ac.uk/>

Title: Patients' and informal carers' experience of living with mesothelioma: A systematic rapid review and synthesis of the literature

Authors

Stephanie Ejegi-Memeh (corresponding author) RN, PhD

University of Sheffield
Division of Nursing and Midwifery
Health Sciences School
Barber House
3 Clarkehouse Road
Sheffield S10 2LA
s.ejegi-memeh@sheffield.ac.uk
@EjegiMemeh

Virginia Sherborne MA, PhD

University of Sheffield
Division of Nursing and Midwifery
Health Sciences School
Barber House
3 Clarkehouse Road
Sheffield S10 2LA
hvsherborne1@sheffield.ac.uk

Madeline Harrison PhD

University of Sheffield
Division of Nursing and Midwifery
Health Sciences School
Barber House Annex
3 Clarkehouse Road
Sheffield S10 2LA
madeleine.harrison@sheffield.ac.uk

Bethany Taylor PhD

University of Sheffield
Health Sciences School
Barber House Annex
3 Clarkehouse Road
Sheffield S10 2LA

btaylor3@sheffield.ac.uk

Michaela Senek PhD

University of Sheffield
Division of Nursing and Midwifery

Health Sciences School
Barber House Annex
3 Clarkehouse Road
Sheffield S10 2LA
m.senek@sheffield.ac.uk

Angela Tod RN, MSc, MmedSci, PhD

University of Sheffield
Health Sciences School
Barber House Annex
3 Clarkehouse Road
Sheffield S10 2LA

a.tod@sheffield.ac.uk

Clare Gardiner PhD

University of Sheffield
Division of Nursing and Midwifery
Health Sciences School
Barber House Annex
3 Clarkehouse Road
Sheffield S10 2LA
c.gardiner@sheffield.ac.uk

Data Availability Statement

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

Conflict of Interest statement for all authors

No conflict of interest to declare for any author

Funding statements

This project was funded by Mesothelioma UK as part of a portfolio of research conducted by the Mesothelioma UK Research Centre – Sheffield (MUKRC-S). The MUKRC-S is an alliance between the Mesothelioma UK and the University of Sheffield. The views expressed are those of the author(s), and not necessarily those of Mesothelioma UK or University of Sheffield.

Ethical approval statement

Ethical approval was not required for the study.

Patients' and informal carers' experience of living with mesothelioma: A systematic rapid review and synthesis of the literature

Abstract

Purpose

Mesothelioma is a rare and incurable cancer linked to asbestos exposure. It primarily affects the pleura. This systematic rapid review aimed to identify what is known about the experience of living with mesothelioma, from the perspective of patients and their informal carers.

Methods

Medline, PsycInfo, Scopus and the Cumulative Index to Nursing and Allied Health Literature were searched for empirical studies published between December 2008 and October 2020. Google Scholar was searched. The inclusion criteria stated that studies were peer-reviewed, reported the experience of living with mesothelioma from the perspective of patients and carers and written in English. The Mixed-Methods Appraisal Tool was used to assess quality. The review protocol is registered on PROSPERO (CRD42020204726).

Results

Twenty-five studies met the inclusion criteria. Following data extraction, a narrative synthesis identified three themes: the impact on the individual; the impact on informal carers and relationships; and interactions with professionals and systems. The physical and psychological symptom burden of mesothelioma on patients' lives was reported as high. Both the qualitative and quantitative literature highlighted that patients and carers may have different needs throughout the mesothelioma journey. Differences included psychological experiences and preferences regarding the timing of information and support provision. Patients and carers expected their health care professionals to be knowledgeable about mesothelioma or refer to those who were. Health care professionals that were compassionate, honest and supportive also positively influenced the experience of patients and carers living with mesothelioma. A lack of communication or misinformation was damaging to the patient-healthcare professional relationship. Continuity of care, coordinated care and good communication between treatment centres were widely reported as important in the literature. Fragmented care was identified as detrimental to the patient experience, increasing anxiety in patients. However, relationships with professionals were not only important in terms of co-ordinating care. There was also evidence that good relationships with healthcare professionals were beneficial to coping with the mesothelioma diagnosis.

Conclusion

The volume of mesothelioma experience research has grown over the past decade. This has led to our growing understanding of the complex needs and experiences of mesothelioma patients and carers. However, this review identified several evidence gaps.

Key words

1. Introduction

Mesothelioma is an incurable and rare cancer which primarily affects the pleura. It less commonly affects the peritoneum, pericardium and testicular vaginal tunica. It is usually caused by asbestos exposure, often decades prior to diagnosis. With approximately 2700 new cases diagnosed each year, the UK has the highest incidence of mesothelioma in the world (Cancer Research UK, 2020). The prognosis is poor and mesothelioma is associated with a range of life-limiting, debilitating disease-related symptoms including pain, breathlessness, cough, lethargy and sweating (Mercadante et al., 2016; Royal College of Physicians, 2020). While mesothelioma is incurable, various treatments exist. Chemotherapy, radiotherapy and, more recently, immunotherapy are the main treatments used to slow down disease progression, control symptoms and improve quality of life (QOL) for those living with mesothelioma (Bibby and Maskell, 2018; NICE Guidelines, 2020). Clinical trials which aim to find better treatments for mesothelioma are increasing in number, but mesothelioma survival rates remain low (Cantini et al., 2020). Despite the poor prognosis there is considerable potential to improve the patient and carer experience of living with mesothelioma, through the provision of appropriate care and support.

The cause of mesothelioma, the high symptom burden and the poor outlook for patients has led to a consensus that this patient population face unique challenges compared to other cancers (Ball et al., 2016; Bates et al., 2017). Recognition of these challenges has led to growth in research exploring the patient experience of mesothelioma (Darlison et al., 2014; Moore et al., 2015; Taylor et al., 2019). Patient experience research is recognised as influential over the design and delivery of healthcare services, as well as identifying issues of most importance to patients and carers (Lee, 2019; Lees, 2011; Wolf et al., 2014) and can positively influence patient outcomes in the absence of any curative treatment options.

There has been growing acknowledgement of the significant impact a diagnosis of mesothelioma can have on the psychological and social well-being of not only patients, but also their carers (Girgis et al., 2019; Sherborne et al., 2020). Literature reviews have been conducted into the psychological effects of mesothelioma on patients and their carers (Ball et al., 2016; Bonafede et al., 2018; Sherborne et al., 2020) and the palliative care needs of patients living with mesothelioma (Harrison et al., 2021). These reviews provide much needed insight into specific needs of patients and carers. However, research gaps remain and a review with a broader objective has the potential to complement more specific reviews and highlight gaps in the patient and carer literature.

A selective literature review conducted by Moore et al. (2010) explored the patient and carer experience of living with mesothelioma. They found a limited evidence based exploring the experience of living with mesothelioma. All papers were published in the USA, UK, Canada and Australia and focused on the impact of mesothelioma on patients' and carers' physical, emotional and social experiences. Their findings also focused on positive and negative interactions with healthcare systems. One key finding of note was that carers reported receiving little information and support from health care professionals. Since Moore et al.'s review (2010) the international body of

patient experience literature has increased (Bonafede et al., 2020; Dooley et al., 2010; Nagamatsu et al., 2018). Furthermore, a wide range of new treatments, care configurations and support options for mesothelioma have emerged over the last ten years. This is coupled with various changes to health policy, service provision and organisation which have profoundly altered the care that people living with mesothelioma receive (e.g. (Hampshire Asbestos Support Group, 2022; Mesothelioma UK, 2022)). Therefore, we present an updated literature review of research conducted over the past ten years and identify research gaps that remain. This systematic rapid review aimed to identify what is known about the experience of living with mesothelioma, from the perspective of patients and their informal carers.

2. Methods

A systematic rapid review was conducted in order to address the review aim (Grant and Booth, 2009; Plüddemann et al., 2018). The purpose of the review was to contribute towards a Research Prioritisation Exercise which began in January 2021. Therefore, a time limit of two months was set on the review process. According to Schünemann & Moja (2015), this shortened review period justifies the use of a systematic rapid review methodology. In order to expedite the review process only literature published since the date of the previous literature review (December 2008) was included. According to Plüddemann et al., (2018) an update of a previous review and strict time limit are two ways of shortening the full systematic rapid review process. Within systematic rapid reviews, components of the review process are often simplified in order to speed up the review process (Tricco et al., 2015). The review protocol is registered on PROSPERO: (CRD42020204726). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist was used as the reporting guideline (Moher et al., 2014).

2.1 Search strategy

Peer-reviewed qualitative, quantitative and mixed-methods studies published in English between December 2008-October 2020 were included in the review. The electronic databases searched were MEDLINE, CINAHL, PsycINFO and Scopus. Google Scholar was also searched. Key search terms related to people living with mesothelioma (Mesothelioma, patient, carer, family member, informal carer, caregiver, family care*); and lived experience (experience, perception, QOL, psychological, emotional, physical, social, support, care, needs, coping, distress, hope). Medical Subject Headings (MeSH) terms were used. See Table 1 for the search strategy to identify studies from electronic databases.

2.2 Selection process

Titles and abstracts were screened by one reviewer (SEM) according to the inclusion and exclusion criteria (Table 2 – Inclusion and exclusion criteria). A second reviewer (MH), independently screened ten percent of titles and abstracts to ensure the inclusion and exclusion criteria were being consistently applied and to reduce risk of bias (Plüddemann et al., 2018). Fifty-seven full-text articles were assessed for inclusion by two independent reviewers (SEM and either VS/MH/BT/MS/CG/AT). Disagreements at the title and abstract and full-text stage were resolved by discussions until a consensus was reached.

2.3 Data extraction and synthesis

A data extraction form was used to extract and collate findings in Microsoft Excel. The data fields included publication details (author, year); country; research aim; study design/methods; study population; main characteristics of included patients/carers: proportion with mesothelioma, time since diagnosis, age, gender; key findings presented; and limitations (see Table 3 – Summary of included papers). A narrative synthesis methodology was used to develop themes (Plüddemann et al., 2018). Data were synthesised in a tabular and then textual form (Grant and Booth, 2009). All authors contributed to the synthesis process.

2.4 Quality appraisal

The Mixed-Methods Appraisal Tool (MMAT) was used to appraise the methodological quality of all included studies (Hong et al., 2018). The MMAT assesses the methodological quality of five types of study design. It uses two screening questions to determine whether the study is empirical and then five quality criteria. One advantage of the MMAT is that all studies could be appraised using one tool improving the possibility for comparison. For the current review, while we appraised the quality of the papers, this did not influence the weighting attributed to each in the findings section. As this is a rapid review of an under-researched area, inclusion of a paper in the review was not determined by methodological quality. Use of a traditional scoring method is discouraged when using the MMAT (Hong et al., 2018), so an overall score for each paper is not presented. However, the appraisal has informed the narrative description of the studies and informed the weighting placed on the findings of the different studies in Table 3 and the Results section. All studies were appraised by SEM. According to Plüddemann et al. (2018) in rapid systematic reviews, it is sufficient to have a single reviewer at the critical assessment stage. However, to reduce bias, a random selection of ten percent of the included studies were assessed by a second reviewer, VS. Disagreements were resolved through discussions until a consensus was reached.

3. Results

The search retrieved a total of 874 papers and 25 met the inclusion criteria. The PRISMA flow diagram in Figure 1 illustrates the article selection process.

Twenty-five full-text articles were included in the review. The included studies were qualitative (n=12), quantitative (n=12) or used mixed-methods (n=1). The majority of studies were conducted in the UK (n=8), or Italy (n=6). Only one study came from a country (Brazil) not classified as 'high income'. Sample sizes ranged from five patients in two of the qualitative studies (Girgis et al., 2019; Kasai and Hino, 2018) to 392 in a national survey undertaken in the UK (Saunders et al., 2015). Eleven studies reported the experience of carers, as well as of patients (Bonafede et al., 2020; Borgogno et al., 2015; Darlison et al., 2014; Girgis et al., 2019; Granieri et al., 2013; Guglielmucci et al., 2018b, 2018a; Moore et al., 2015; Padilha Baran et al., 2019; Taylor et al., 2019; Warby et al., 2019). Of these, one included data only collected from carers (Padilha Baran et al., 2019). Nineteen studies included the experience of living with pleural mesothelioma; and four of living with peritoneal mesothelioma (Darlison et al., 2014;

Guglielmucci et al., 2018a, 2018b; Padilha Baran et al., 2019). An additional two studies did not state the type of mesothelioma (Moore et al., 2015; Taylor et al., 2019).

The main findings from the rapid review are grouped under three themes: the impact on the individual; the impact on informal carers and relationships; and interactions with professionals and systems.

3.1 The impact on the individual

The physical and psychological symptom burden of mesothelioma on patients' lives was reported as high (Dooley et al., 2010; Mercadante et al., 2016; Walker et al., 2019). The most common symptoms reported in the literature included shortness of breath, pain, fatigue, insomnia, disturbed sleep and sweating (Arber and Spencer, 2013; Darlison et al., 2014; Kasai and Hino, 2018; Mercadante et al., 2016; Nagamatsu et al., 2018; Walker et al., 2019; Williams et al., 2018). More recently, cough has been reported as a clinical problem experienced by up to 39% of participants in one study (Mercadante et al., 2016). Decreased appetite, decreased food intake and weight loss were also reported as common symptoms (Mercadante et al., 2016; Walker et al., 2019). Jeffery (2019) reported that patient malnourishment led to increased fatigue and lower quality of life. The difficulty of controlling physical symptoms was reported as challenging and sometimes embarrassing for patients (Arber and Spencer, 2013; Nagamatsu et al., 2018). The literature is beginning to make links between the physical symptoms and the impact of these symptoms on patients' lives, with severe physical symptoms often triggering a psychological reaction, leading to stress, anger and anxiety (Dooley et al., 2010).

Other psychological symptoms reported included depression and decreased well-being (Dooley et al., 2010; Mercadante et al., 2016; Walker et al., 2019). Borgogno et al. (2015) reported emotional numbing typical of traumatic stress, and in their recent quantitative study, Bonafede et al. (2020) found posttraumatic symptoms in 11% of patients. However, given the recognition of the psychological burden of mesothelioma, there appears to be low availability or uptake of psychological support. In terms of psychological interventions, Bonafede et al. (2020) reported that low percentages of patients received psychological counselling (13%) and psychiatric medication, e.g., antidepressants, antipsychotics, anxiolytics, (20%). Individual psychotherapy had been recommended to only 8% of participants, whereas group psychotherapy had been recommended to 46%. This discrepancy between high level of psychological symptoms and low levels of psychological interventions perhaps suggests unmet psychological needs in those living with mesothelioma.

The onset of symptoms, particularly breathlessness (Wood et al., 2013), was reported as extremely distressing. Symptoms such as breathlessness often generated anxiety and reminded participants of their health condition. This led to concerns about what would happen to their families after their death (Dooley et al., 2010). Wood et al.'s (2013) evaluation of non-pharmacological breathlessness management highlighted the important role that simple interventions (e.g. fans, relaxation exercises) can play in coping with symptoms.

Patient participants employed various techniques to cope with the physical and psychological effects of mesothelioma. These included non-pharmacological

interventions, using psychological and practical strategies, and turning to religion and spirituality (Bonafede et al., 2020; Padilha Baran et al., 2019; Walker et al., 2019). Positive effects of coping mechanisms were reported (Walker et al. 2019). These included hope, optimism and a greater appreciation for daily routines. The availability of clinical trials also provided a source of hope for some (Guglielmucci et al., 2018b; Padilha Baran et al., 2019).

Both the qualitative and the quantitative literature showed patients found complementary therapies useful for symptom alleviation (Padilha Baran et al., 2019; Warby et al., 2019). One study reported that complementary therapies were used by 23% of patients (Warby et al., 2019). Avoidance, discounting of statistics and considering one's situation to be unique were also found to be ways of coping with mesothelioma (Girgis et al., 2019). The range of coping strategies identified in the literature highlight patients' need to be considered individuals.

The literature reported complex emotions that individuals exposed to asbestos and subsequently diagnosed with mesothelioma may experience. Participants experienced shame and guilt around exposure to asbestos and now living with mesothelioma. These feelings were reported as difficult to discuss, particularly with family members (Borgogno et al., 2015; Guglielmucci et al., 2018a). Participants also felt anger and a sense of injustice around the occupational nature of exposure (Borgogno et al., 2015; Guglielmucci et al., 2018a):

"I want to understand why if you go to work, you will die" (Borgogno et al., 2015, p. 421)

The literature also reported patients' feelings of guilt and responsibility for exposure and having potentially exposed their loved ones to asbestos (Guglielmucci et al., 2018b, 2018a; Kasai and Hino, 2018).

3.2 The impact on informal carers and relationships

Most of the literature focused on the patient experience of living with mesothelioma. However, eleven studies reported the experience of informal carers, as well as that of patients (Bonafede et al., 2020; Borgogno et al., 2015; Darlison et al., 2014; Girgis et al., 2019; Granieri et al., 2013; Guglielmucci, Bonafede, et al., 2018; Guglielmucci, Franzoi, et al., 2018; Moore et al., 2015; Padilha Baran et al., 2019; Taylor et al., 2019; Warby et al., 2019). Of these, one included data only collected from family carers (Padilha Baran et al., 2019).

Both the qualitative and quantitative literature highlighted that patients and carers may have different needs throughout the mesothelioma journey. Differences included psychological experiences (Bonafede et al., 2020) and preferences regarding the timing of information and support provision (Girgis et al., 2019). More often, however, caregivers' experiences were included primarily for the purpose of accessing the patient experience rather than to understand the carers' experience on its own terms (Padilha Baran et al., 2019; Warby et al., 2019). However, a qualitative study by Girgis et al. (2019) dedicates two themes to the devastating social, practical and emotional impact on carers. This reflects a growing recognition of the separate needs of carers (Girgis et al., 2019).

In a 2020 study, carers reported high levels of depression and scored significantly higher than patients for traumatic symptoms (Bonafede et al., 2020). The authors suggest survivors' guilt and the emotional load of caring may be reasons for carers' significantly worse trauma score. There was evidence that carers sometimes hid their own emotional turmoil to protect other family members. This negatively impacted upon their own emotional wellbeing (Girgis et al., 2019).

Bereaved carers found support groups to be a useful space for expressing emotions, working through the loss and acquiring a new sense of identity after the death of their carers (Borgogno et al., 2015). One paper reported individualised support was beneficial for carers (Girgis et al., 2019). There was evidence that women sought social support more readily than men (Bonafede et al., 2018). Bereaved caregivers reported they would have found it helpful to have received grief counselling (39%), or had a post-death consultation with a medical specialist (25%) or palliative care specialist (23%) (Warby et al., 2019). This perhaps reflects a need for increased care and support for carers both before, and after, the death of the person with mesothelioma.

Challenges to patient and caregiver relationships included the uncertainty around how patient symptoms would develop and changes in patient personality and physical ability (Guglielmucci et al., 2018a, 2018b). The literature also reported that some patients struggled to have open conversations about their condition as the thought of worsening of symptoms and death was frightening (Bonafede et al., 2020; Dooley et al., 2010; Guglielmucci et al., 2018b, 2018a; Wood et al., 2013). Making practical plans for death such as putting their legal affairs in order, so that their families were financially secure enabled participants to prepare themselves and their families for their death (Dooley et al., 2010; Kasai and Hino, 2018; Warby et al., 2019). This suggests that, while discussions around death may be challenging, practical actions may be easier for patients to consider. However, patient inhibition regarding discussions of death may make it challenging to ensure carers can adequately prepare for the patients' death.

Positive impacts on patients' and carers' relationships were also reported. Patients experienced a heightened appreciation of their friendships and family relationships (Nagamatsu et al., 2018; Walker et al., 2019). However, changes in intimate relationships were reported as difficult for patients to accept:

“You know I get hugs, but very careful ones because he doesn't want to touch the area that's so sore. He is very affectionate, but the old warm cuddling is not there, and that saddens me a lot...” (Walker et al., 2019, p. 6)

3.3 Interactions with professionals and systems

Interactions with health and legal professionals and services influenced experiences of living with mesothelioma. At diagnosis these interactions were one distinct area of focus, with four studies discussing factors that facilitated good communication at that time. These included the news being broken in a private environment (Taylor et al., 2019), not being rushed (Taylor et al., 2019; Walker et al., 2019) and information being communicated in a sensitive yet understandable way (Darlison et al., 2014; Nagamatsu et al., 2019; Taylor et al., 2019).

Continuing after diagnosis, professionals that were compassionate, honest and supportive positively influenced the experience of patients and carers living with mesothelioma (Moore et al., 2015; Nagamatsu et al., 2019; Walker et al., 2019). Poor communication, a lack of communication or misinformation was damaging to the patient-healthcare professional relationship (Nagamatsu et al., 2019; Walker et al., 2019). Continuity of care, coordinated care and good communication between treatment centres were widely reported as important in the literature (Arber and Spencer, 2013; Nagamatsu et al., 2019; Taylor et al., 2019; Walker et al., 2019; Wood et al., 2013). Fragmented care was identified as detrimental to the patient experience, increasing anxiety in patients (Warnock et al., 2019). However, relationships with professionals were not only important in terms of co-ordinating care. There was also evidence that relationships with HCPs were beneficial to coping (Girgis et al., 2019; Walker et al., 2019).

Patients expected their HCPs to be knowledgeable about mesothelioma or refer to those who were (Moore et al., 2015; Nagamatsu et al., 2019; Walker et al., 2019). Getting the timeliness and balance of mesothelioma information right appeared challenging. First, this was due to patients and carers having differing information needs (discussed above) (Girgis et al., 2019; Nagamatsu et al., 2019). Second, some patients and carers may prefer to avoid negative information to maintain hope (Girgis et al., 2019):

'Health professionals need to be less negative and insensitive towards the diagnosis/prognosis. We all know that mesothelioma has no known cure and is terminal, but it is sometimes the last thing the patient needs rammed down their throats. We all want to live in hope!' (Darlison et al., 2014, p. 18)

Non-healthcare professional support reported as valuable included visits from Asbestos Support Groups and palliative care teams (Arber and Spencer, 2013). Nagamatsu et al. (Nagamatsu et al., 2019, 2018) found that in Japan 46% of their participants received palliative care. In contrast, in an Australian study, Warby et al. (2019) found that 31% of patients and 81% of carers received palliative care.

One study of pain highlighted a discrepancy between the patient experience and healthcare professionals' assessment (Salminen et al., 2013). Their findings showed a significant disparity with 64% of mesothelioma patients reporting they experienced pain "quite a bit" or "very much". However, physicians assessed that only 41% of the participants did so ($p=0.039$). This disparity highlights that patient experience and healthcare professionals' assessment of that experience may not always align. The study findings highlight the importance of ensuring that patient pain (and other symptoms) is not underestimated by healthcare professionals, and also the contribution that studies comparing patient experience and healthcare professionals' assessment can make to knowledge.

Challenges faced by patients and carers included difficulties in understanding who was in charge of the patient's care (Arber and Spencer, 2013) and infrequent appointments (Darlison et al., 2014). The value of well-coordinated, multidisciplinary working was reported by several studies (Darlison et al., 2014; Moore et al., 2015; Nagamatsu et al., 2019). Nagamatsu et al. (2019) suggested the development of

country-wide specialized care systems would be beneficial for patient care. Specialist nurses and good General Practitioner support were reported as key to coordinated and individualised care (Darlison et al., 2014; Taylor et al., 2019; Walker et al., 2019). Professional support reported as valuable from non-healthcare professionals included Asbestos Support Groups (Arber and Spencer, 2013) and legal professionals.

The qualitative sub-study conducted by Williams et al. (2018) differentiated between symptoms that could be attributed to mesothelioma and those attributed to *treatment* for mesothelioma. Participants reported that both mesothelioma and treatment for mesothelioma led to pain, fatigue and shortness of breath. Nausea, vomiting, trouble remembering things and poor sleep quality were some of the symptoms attributed to treatment rather than the mesothelioma itself.

Kasai & Hino (2018) reported that the wishes of carers influenced treatment decisions. In addition to the influence of carers, there is some evidence of patients considering longevity and QOL (Darlison et al., 2014; Nagamatsu et al., 2019). One paper reported some patients prioritised pain-relief and dying at home over active treatment:

“I do not want to suffer from heavy treatment. Just relieve my pain and let me stay at home until the last day.” (Nagamatsu et al., 2019, p. 4)

Warnock et al. (2019) conducted the most comprehensive study of the experience of trial participation from the perspective of patients living with mesothelioma. Challenges for patients regarding trials included difficulties in assimilating information about the trial process, understanding of randomisation and of clinical equipoise. Motivations for wanting to participate in clinical trials included wanting to exhaust all treatment options, the possibility of enhanced care and altruism. Travel time to trial centres, expenses for travel and hotel accommodation were reported as barriers to participation. In contrast, Darlison et al. (2014) found 86% of participants were willing to travel for diagnostic procedures. This suggests differences between patient willingness to travel for a trial (in which there is no guarantee you are receiving an intervention of therapeutic value) and travelling for diagnostic reasons.

4. Discussion

4.1 Discussion of findings

This rapid review draws together the evidence base regarding the experience of living with mesothelioma from the perspective of patients and informal carers. A similarly broad review was conducted by Moore et al. (2010). Their main findings were grouped as the physical impact, emotional effects, social consequence, and experience of care. Our findings show a broader range of patient experience research has been conducted since that time, with topics spanning experience of psychological impact, diagnosis, treatment, trials and compensation (Girgis et al., 2019; Nagamatsu et al., 2018; Taylor et al., 2019; Warnock et al., 2019). However, the evidence base is limited, and several gaps remain.

Moore et al.'s 2010 review reports a significant physical and psychological impact on patients and carers. However, research included in the first and second theme of this review highlights the impact physical symptoms, such as malnourishment and fatigue, can have on patients' quality of life and psychological well-being (Jeffery et al., 2019;

Walker et al., 2019). A greater understanding of the impact that physical symptoms can have on the QOL and mental health of those living with mesothelioma is required. Further research is required on how interventions, for example, focused on nutrition, exercise and mental health, may be beneficial for patients and carers living with mesothelioma.

In recent years, literature reviews have been conducted into the psychological impact of mesothelioma on those diagnosed (Ball et al., 2016; Bonafede et al., 2018; Sherborne et al., 2020). Their findings showed patients experience psychological distress and despair. These findings have also been reflected in the first and second theme of our findings. However, our findings also showed some limited reporting of the sources of hope, and coping techniques for patients and carers to alleviate their psychological burden of living with mesothelioma. The literature is beginning to suggest ways in which patients, carers and professionals manage both the physical and psychological symptoms of mesothelioma (Sherborne et al., 2020; Wood et al., 2013). Further research evaluating interventions that can alleviate physical and psychological symptoms of mesothelioma would be of value. Furthermore, given the small number of studies focused on the psychological experience of the carer, additional exploration into this area would be beneficial.

The literature contained in the third theme reflected a growing acknowledgement of the role that legal and support group professionals play in access to compensation. The potential for some patients to access compensation is another aspect of mesothelioma which sets it apart from other cancers, and the impact of seeking compensation has only recently been explored. Ball et al., (2016) highlight that pursuing compensation may provide a sense of justice and financial security. Our review findings support this, but also show that little is known about the patient experience of seeking compensation. Many of those living with mesothelioma have been exposed to asbestos whilst working. Further research is required on the process of seeking compensation and occupational history taking.

The third theme shows the role of HCPs, particularly nurses, is important to providing individualised, well-coordinated and high-quality care for patients and families. We also noted the complexities of the role HCPs are required to fulfil. Moore et al. (2015) highlighted the importance of not taking hope away from patients by providing too much information, indicating the importance of an individualised, tailored approach to information provision. This could be complex for HCPs for two reasons. First, providing the appropriate amount of information in a timely fashion for patients is difficult as it requires time, skill and expertise in mesothelioma. Second, as evidenced in the second theme, patients and carers may require differing amounts and/or types of information. HCPs need to feel secure and confident in the type and volume of information they provide. A relationship-centred care approach may be advantageous to explore in future research (Dewar and Nolan, 2013; Nolan et al., 2004).

While mesothelioma survival remains poor, a growing number of clinical trials are available for mesothelioma patients (Bibby and Maskell, 2018; Kotova et al., 2015; NICE Guidelines, 2020). The National Mesothelioma Audit (2020) recommends that “Fit patients should be offered referral to specialist centres if they wish, for consideration of systemic treatment within clinical trials” (pg. 16). However there is little evidence on the experience of clinical trials for mesothelioma despite trial

participation being common. As the availability of trials grows, there are an increasing number of people living with mesothelioma navigating experiences of and decisions around trial participation.

However, there is little research describing patient experience of clinical trial participation, despite trial participation now being common (Warnock et al., 2019). Neither is there much research exploring the factors influencing patient decisions regarding treatment and trial engagement. Ensuring patients have access to accurate information, as well as making sure they understand that information, is therefore essential. Our review shows research is needed on access to clinical trials, exploring how patients make decisions about participating, their understandings of trials and their experiences of participating. This information would ensure HCPs can adequately support patients and carers who are considering participating in trials.

We make three methodological suggestions for future patient and carer experience research. Through combining the evidence from qualitative, quantitative and mixed method studies, our findings showed potential for developing patient experience studies using mixed methods. Mixed methods have been recognised as useful for exploring and representing the patient and carer experience from multiple angles (Lees, 2011) and yet they are underutilised in mesothelioma research. Our second suggestion is for increased patient and public involvement in research. Increased involvement of patients and carers in the development of research priorities will ensure research is focused on issues with the most impact on their lives, and that subsequent interventions and resources developed are appropriate and user-friendly (Tsianakas et al., 2012; Warnock et al., 2019). Creative, co-production methods of collecting and interpreting data may become more important when working more closely with patients and carers. Finally, longitudinal studies which map the mesothelioma journey over time may be advantageous for understanding patient and carer needs at different points across the mesothelioma journey and changing needs over time.

4.2 Implications for practice

Through their role in assisting patients to navigate complicated medical systems and to access appropriate care, specialist nurses and general practitioners are important for patients and carer experience (Darlison et al., 2014; Davey and Henshall, 2021). Furthermore, the growing number of treatment and trial options suggests that patients require additional information and support in making decisions around the treatment and trials available. A recent study by Henshall et al. (2021) conducted in the United Kingdom found variation in the level of information provided to patients about clinical trials, as well as how to access local support groups. Patients and their families depend upon the information provided by their health care professionals. First, there is a need to ensure that health care professionals are equipped with the most up to date information. In reality, given the heavy workload of most health care professionals remaining up to date on frequent changes may be challenging. However, the COVID-19 pandemic has increased the amount of online support available to patients and informal carers. Signposting patients and carers to reliable and up to date online sources of information is one way to promote more equitable access to high quality treatment, trials and support information.

4.3 Limitations

As with any literature review, there is always the risk that some literature may have been overlooked. However, the team consisted of several members who have experience of conducting systematic review. Additionally, the systematic process of

data searching and management should ensure all relevant literature has been included. A second limitation is that a limited evidence base from low- and middle-income countries suggests our findings may have less relevance for these countries. Only one study in this review was conducted in a non-high income country, Brazil (Upper-middle). Given that several low/middle income countries continue to import asbestos, their populations will continue to be exposed to relatively high levels of asbestos. Therefore, research into those living with mesothelioma in low/middle income countries is required.

5. Conclusions

This review provides valuable insight into the impact and burden of mesothelioma on both patient and their informal carers living with mesothelioma. Patients and carers continue to experience devastating physical, psychological and economic effects. The treatment options for mesothelioma remain limited. Therefore, improving the patient and carer experience of living with mesothelioma remain a vital tools the best way to improve patient outcomes. We now know that health care professionals and systems have a profound impact on the patient and carer experience. Armed with this knowledge there is great potential to continue developing training and organising systems in ways which patients and their carers report as beneficial for their care.

References

- Arber, A., Spencer, L., 2013. "It's all bad news": the first 3 months following a diagnosis of malignant pleural mesothelioma. *Psychooncology*. 22, 1528–33. <https://doi.org/10.1002/pon.3162>
- Ball, H., Moore, S., Leary, A., 2016. A systematic literature review comparing the psychological care needs of patients with mesothelioma and advanced lung cancer. *Eur. J. Oncol. Nurs.* 25, 62–7. <https://doi.org/10.1016/J.EJON.2016.09.007>
- Bates, G.E., Mostel, J.L., Hesdorffer, M., 2017. Mesothelioma survivorship: challenges in delivering quality care. *Expert Rev. Qual. life cancer care* 2, 177–180. <https://doi.org/10.1080/23809000.2017.1345308>
- Bibby, A.C., Maskell, N.A., 2018. Current treatments and trials in malignant pleural mesothelioma. *Clin. Respir. J.* 12, 2161–2169. <https://doi.org/10.1111/crj.12938>
- Bonafede, M., Ghelli, M., Corfiati, M., Rosa, V., Guglielmucci, F., Granieri, A., Branchi, C., Iavicoli, S., Marinaccio, A., 2018. The psychological distress and care needs of mesothelioma patients and asbestos-exposed subjects: A systematic review of published studies. *Am. J. Ind. Med.* 61, 400–412. <https://doi.org/10.1002/ajim.22831>
- Bonafede, M., Granieri, A., Binazzi, A., Mensi, C., Grosso, F., Santoro, G., Franzoi, I.G., Marinaccio, A., Guglielmucci, F., 2020. Psychological distress after a diagnosis of malignant mesothelioma in a group of patients and caregivers at the national priority contaminated site of casale monferrato. *Int. J. Environ. Res. Public Health* 17, 1–15. <https://doi.org/10.3390/ijerph17124353>
- Borgogno, F.V., Franzoi, I.G., Barbasio, C.P., Guglielmucci, F., Granieri, A., 2015.

Massive trauma in a community exposed to asbestos: Thinking and dissociation among the inhabitants of Casale Monferrato. *Br. J. Psychother.* 31, 419–432. <https://doi.org/10.1111/bjp.12170>

Cancer Research UK, 2020. Mesothelioma statistics | Cancer Research UK [WWW Document]. *Cancer Res. UK*. URL <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/mesothelioma> (accessed 10.31.19).

Cantini, L., Hassan, R., Sterman, D.H., Aerts, J.G.J.V., 2020. Emerging Treatments for Malignant Pleural Mesothelioma: Where Are We Heading? *Front. Oncol.* <https://doi.org/10.3389/fonc.2020.00343>

Darlison, L., Mckinley, D., Moore, S., 2014. Findings from the National Mesothelioma Experience Survey. *Cancer Nurs. Pract.* 13, 32–38. <https://doi.org/10.7748/cnp2014.04.13.3.32.e1063>

Davey, Z., Henshall, C., 2021. Improving mesothelioma follow-up care in the UK: a qualitative study to build a multidisciplinary pyramid of care approach. *BMJ Open* 11, 48394. <https://doi.org/10.1136/bmjopen-2020-048394>

Dewar, B., Nolan, M., 2013. Caring about caring: Developing a model to implement compassionate relationship centred care in an older people care setting. *Int. J. Nurs. Stud.* 50, 1247–1258. <https://doi.org/10.1016/j.ijnurstu.2013.01.008>

Dooley, J.J., Wilson, J.P., Anderson, V.A., 2010. Stress and depression of facing death: Investigation of psychological symptoms in patients with mesothelioma. *Aust. J. Psychol.* 62, 160–168. <https://doi.org/10.1080/00049530903510757>

Girgis, S., Smith, A., Lambert, S., Waller, A., Girgis, A., 2019. “It sort of hit me like a baseball bat between the eyes”: a qualitative study of the psychosocial experiences of mesothelioma patients and carers. *Support. care cancer* 27, 631–8. <https://doi.org/10.1007/s00520-018-4357-0>

Granieri, A., Tamburello, S., Tamburello, A., Casale, S., Cont, C., Guglielmucci, F., Innamorati, M., 2013. Quality of life and personality traits in patients with malignant pleural mesothelioma and their first-degree caregivers. *Neuropsychiatr. Dis. Treat.* 9, 1193–1202. <https://doi.org/10.2147/NDT.S48965>

Grant, M.J., Booth, A., 2009. A typology of reviews: an analysis of 14 review types and associated methodologies. *Heal. Inf. Libr. J.* 26, 91–108. <https://doi.org/10.1111/j.1471-1842.2009.00848.x>

Guglielmucci, F., Bonafede, M., Franzoi, I., Granieri, A., 2018a. Research and malignant mesothelioma: lines of action for clinical psychology. *Ann Ist Super Sanità* 54, 363–372. <https://doi.org/10.4415/ANN>

Guglielmucci, F., Franzoi, I.G., Bonafede, M., Borgogno, F. V., Grosso, F., Granieri, A., 2018b. “The less i think about it, the better i feel”: A thematic analysis of the subjective experience of Malignant Mesothelioma patients and their caregivers. *Front. Psychol.* 9. <https://doi.org/10.3389/fpsyg.2018.00205>

Harrison, M., Gardiner, C., Taylor, B., Ejegi-Memeh, S., Darlison, L., 2021. Understanding the palliative care needs and experiences of people with mesothelioma and their family carers: An integrative systematic review. *Palliat.*

Med. 026921632110073. <https://doi.org/10.1177/02692163211007379>

- HASAG Asbestos Disease Support, 2022. HASAG Asbestos Disease Support [WWW Document]. URL <https://hasag.co.uk/> (accessed 1.31.22).
- Henshall, C., Davey, Z., Walthall, H., Ball, H., Shahidi, M., Park, J., Rahman, N., 2021. Recommendations for improving follow-up care for patients with mesothelioma: a qualitative study comprising documentary analysis, interviews and consultation meetings. *BMJ Open* 11. <https://doi.org/10.1136/bmjopen-2020-040679>
- Hong, Q., Gonzalez-Reyes, A., Pluye, P., 2018. Improving the usefulness of a tool for appraising the quality of qualitative, quantitative and mixed methods studies, the Mixed Methods Appraisal Tool (MMAT). *J. Eval. Clin. Pract.* 24, 459–467. <https://doi.org/10.1111/jep.12884>
- Jeffery, E., Lee, Y.C.G., Newton, R.U., Lyons-Wall, P., McVeigh, J., Nowak, A.K., Cheah, H.M., Nguyen, B., Fitzgerald, D.B., Creaney, J., Straker, L., Peddle-McIntyre, C.J., 2019. Body composition and nutritional status in malignant pleural mesothelioma: implications for activity levels and quality of life. *Eur. J. Clin. Nutr.* 73, 1412–1421. <https://doi.org/10.1038/s41430-019-0418-9>
- Kasai, Y., Hino, O., 2018. Psychological Transition Characteristics of Patients Diagnosed with Asbestos-Related Mesothelioma. *Juntendo Med. J.* 64, 114–121. <https://doi.org/10.14789/jmj.2018.64.jmj17-0a09>
- Kotova, S., Wong, R.M., Cameron, R.B., 2015. New and emerging therapeutic options for malignant pleural mesothelioma: Review of early clinical trials. *Cancer Manag. Res.* 7, 51–63. <https://doi.org/10.2147/CMAR.S72814>
- Lee, D., 2019. A model for designing healthcare service based on the patient experience. *Int. J. Healthc. Manag.* 12, 180–188. <https://doi.org/10.1080/20479700.2017.1359956>
- Lees, C., 2011. Measuring the patient experience. *Nurse Res.* 19, 25–28. <https://doi.org/10.7748/nr2011.10.19.1.25.c8768>
- Mercadante, S., Degiovanni, D., Casuccio, A., 2016. Symptom burden in mesothelioma patients admitted to home palliative care. *Curr. Med. Res. Opin.* 32, 1985–1988. <https://doi.org/10.1080/03007995.2016.1226165>
- Mesothelioma UK, 2022. Mesothelioma UK [WWW Document]. URL <https://www.mesothelioma.uk.com/> (accessed 1.31.22).
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G., 2014. PRISMA 2009 Checklist. *Ann. Intern. Med.* 151, 264–269.
- Moore, S., Darlison, L., Mckinley, D., 2015. The experience of care for people affected by mesothelioma. *Cancer Nurs. Pract.* 14, 14–20. <https://doi.org/10.7748/cnp.14.2.14.e1170>
- Moore, S., Darlison L, S., Tod A, M., 2010. Living with mesothelioma. A literature review. *Eur. J. Cancer Care (Engl).* 19, 458–468. <https://doi.org/10.1111/j.1365-2354.2009.01162.x> European
- Nagamatsu, Y., Oze, I., Aoe, K., Hotta, K., Kato, K., Nakagawa, J., Hara, K.,

- Kishimoto, T., Fujimoto, N., 2019. Physician requests by patients with malignant pleural mesothelioma in Japan. *BMC Cancer* 19, 1–7. <https://doi.org/10.1186/s12885-019-5591-7>
- Nagamatsu, Y., Oze, I., Aoe, K., Hotta, K., Kato, K., Nakagawa, J., Hara, K., Kishimoto, T., Fujimoto, N., 2018. Quality of life of survivors of malignant pleural mesothelioma in Japan: A cross sectional study. *BMC Cancer* 18, 1–7. <https://doi.org/10.1186/s12885-018-4293-x>
- NICE Guidelines, 2020. NHS England interim treatment options during the COVID-19 pandemic (last updated 9 November 2020). *Natl. Inst. Heal. Care Excell.* 1–6.
- Nolan, M.R., Davies, S., Brown, J., Keady, J., Nolan, J., 2004. Beyond “person-centred” care: a new vision for gerontological nursing. *J. Clin. Nurs.* 13, 45–53. <https://doi.org/10.1111/j.1365-2702.2004.00926.x>
- Padilha Baran, F.D., Alves Das Mercês, N.N., Mansano Sarquis, L.M., Martins Da Rosa, L., Mensi, C., Brey, C., 2019. Therapeutic itinerary revealed by the family members of individuals with mesothelioma: Multiple case studies. *Texto e Context. Enferm.* 28, 1–15. <https://doi.org/10.1590/1980-265X-TCE-2017-0571>
- Plüddemann, A., Aronson, J.K., Onakpoya, I., Heneghan, C., Mahtani, K.R., 2018. Redefining rapid reviews: a flexible framework for restricted systematic reviews. *BMJ evidence-based Med.* 23, 201–203. <https://doi.org/10.1136/bmjebm-2018-110990>
- Royal College of Physicians, 2020. National Mesothelioma Audit report 2020 (for the audit period 2016–18) [WWW Document]. *R. Coll. Physicians.* URL <https://www.rcplondon.ac.uk/projects/outputs/national-mesothelioma-audit-report-2020-audit-period-2016-18> (accessed 4.12.20).
- Salminen, E.K., Silvoniemi, M., Syrjänen, K., Kaasa, S., Kloke, M., Klepstad, P., 2013. Opioids in pain management of mesothelioma and lung cancer patients. *Acta Oncol. (Madr).* 52, 30–37. <https://doi.org/10.3109/0284186X.2012.725944>
- Saunders, C.L., Abel, G.A., Lyratzopoulos, G., 2015. Inequalities in reported cancer patient experience by socio-demographic characteristic and cancer site: Evidence from respondents to the English cancer patient experience survey. *Eur. J. Cancer Care (Engl).* 24, 85–98. <https://doi.org/10.1111/ecc.12267>
- Schünemann, H.J., Moja, L., 2015. Reviews: Rapid! Rapid! Rapid!.and systematic. *Syst. Rev.* 4, 1–3. <https://doi.org/10.1186/2046-4053-4-4/PEER-REVIEW>
- Sherborne, V., Seymour, J., Taylor, B., Tod, A., 2020. What are the psychological effects of mesothelioma on patients and their carers? A scoping review. *Psychooncology.* pon.5454. <https://doi.org/10.1002/pon.5454>
- Taylor, B., Warnock, C., Tod, A., 2019. Communication of a mesothelioma diagnosis: Developing recommendations to improve the patient experience. *BMJ Open Respiratory Res.* 6, 1–10. <https://doi.org/10.1136/bmjresp-2019-000413>
- Tricco, A.C., Antony, J., Zarin, W., Striffler, L., Ghassemi, M., Ivory, J., Perrier, L., Hutton, B., Moher, D., Straus, S.E., 2015. A scoping review of rapid review

methods. *BMC Med.* 13, 1–15. <https://doi.org/10.1186/S12916-015-0465-6/TABLES/6>

Tsianakas, V., Robert, G., Maben, J., Richardson, A., Dale, C., Wiseman, T., 2012. Implementing patient-centred cancer care: Using experience-based co-design to improve patient experience in breast and lung cancer services. *Support. Care Cancer* 20, 2639–2647. <https://doi.org/10.1007/s00520-012-1470-3>

Walker, S.L., Crist, J.D., Shea, K., Holland, S., Cacchione, P.Z., 2019. The Lived Experience of Persons With Malignant Pleural Mesothelioma in the United States. *Cancer Nurs. Publish Ah*, 1–9. <https://doi.org/10.1097/ncc.0000000000000770>

Warby, A., Dhillon, H.M., Kao, S., Vardy, J.L., 2019. A survey of patient and caregiver experience with malignant pleural mesothelioma. *Support. Care Cancer* 4675–4686. <https://doi.org/10.1007/s00520-019-04760-x>

Warnock, C., Lord, K., Taylor, B., Tod, A., 2019. Patient experiences of participation in a radical thoracic surgical trial: findings from the Mesothelioma and Radical Surgery Trial 2 (MARS 2). *Trials* 20, 598. <https://doi.org/10.1186/s13063-019-3692-x>

Williams, L.A., Whisenant, M.S., Mendoza, T.R., Haq, S., Keating, K.N., Cuffel, B., Cleeland, C.S., 2018. Modification of existing patient-reported outcome measures: qualitative development of the MD Anderson Symptom Inventory for malignant pleural mesothelioma (MDASI-MPM). *Qual. Life Res.* 27, 3229–3241. <https://doi.org/10.1007/s11136-018-1982-5>

Wolf, J.A., Marshburn, D., LaVela, S.L., DrPH, V., 2014. Defining patient experience. *Patient Exp. J.* 1, 7–19. <https://doi.org/10.35680/2372-0247.1004>

Wood, H., Connors, S., Dogan, S., Peel, T., 2013. Individual experiences and impacts of a physiotherapist-led, non-pharmacological breathlessness programme for patients with intrathoracic malignancy: A qualitative study. *Palliat. Med.* 27, 499–507. <https://doi.org/10.1177/0269216312464093>

Table 1 Search strategy to identify studies from electronic databases

Research Question	What do we know about the experience of living with mesothelioma, from the perspective of patients and their family carers?
Population	Mesothelioma patients (pleural and peritoneal) and their families <ul style="list-style-type: none"> • Search terms: Mesothelioma, patient, carer, family member, informal carer, caregiver, family care*
Intervention	<ul style="list-style-type: none"> • N/A
Outcome	Lived experience <ul style="list-style-type: none"> • Search terms: experience, perception, quality of life, psychological, emotional, physical, social, support, care, needs, coping, distress, hope
Comparator	N/A
Study designs	All primary research
Publication types	Journal articles
Date of publication	December 2008 onwards
Language	English language only
Other limits	Adults only

Table 2 – Inclusion and exclusion criteria

Inclusion	Exclusion
Primary research including Qualitative/quantitative/mixed-methods studies	Literature reviews, editorials, opinion pieces, letters
Focus on the experience of living with mesothelioma (physical, psychological, emotional, social aspects of symptoms/treatment, care needs, impact on family carer etc);	Focus on Quality of Life measures as part of clinical trials, clinical outcomes, epidemiology, biology or intervention development.
Perspective of patient or family/informal carer	Results not separated by cancer type
Published from December 2008 to October 2020	
Involving adult (over 18 years) humans	
In English	

Table 3 Summary of included papers

Author, Year, Country	Study Aim	Study design and methodology	Population, setting and sample size	Key findings
Arber and Spencer. (2013) UK	To explore patient's experience during the first 3 months following a diagnosis of malignant pleural mesothelioma (MPM)	Qualitative Grounded theory approach.	MPM patients from two acute trusts in the South of England. N=10	<p>Uncertainty led to emotional, physical and psychosocial distress during the first three months following diagnosis.</p> <p>Strategies for ameliorating distress included complementary and alternative medicine, dietary changes, visits from Asbestos Support Groups and referral to palliative care.</p> <p>Continuity of care also helped ameliorate some of patients' uncertainty</p>
Bonafede et al. (2020) Italy	To examine the emotional impact after the diagnosis of malignant mesothelioma in a group of patients and familial caregivers in a National Priority Contaminated Site (NPCS).	Quantitative Cross-sectional questionnaire.	MPM patients and carers recruited from a medical database of a Mesothelioma Unit in Casale Monferrato, Italy. Patients N= 108 Carers N=94	<p>Low percentages of patients received psychological counselling (13%) and psychiatric medication (20%). Individual psychotherapy was recommended to 8% of participants. Group psychotherapy was recommended to 46%.</p>

				<p>Patients "suppress" (do not think about or verbalise negative emotions) more than carers (linked with some not wanting to attend support groups perhaps)</p> <p>Carers were more traumatised than patients, experienced survivors guilt and women carers were more depressed and traumatised.</p>
Borgogno et al. (2015) Italy	To present the experience of the first multifamily group in Casale Monferrato	Qualitative Observational. No specific methodology identified.	MPM patients, informal carers (including bereaved family carers) and health care professionals. Data were collected around a multifamily group intervention in Casale Monferrato, Italy. N=approximately 50	<p>Anger at asbestos exposure. This particularly found in a families with multiple exposures.</p> <p>Providing support for the whole family, not just the patient was reported as important</p> <p>Patient and carer loneliness/feeling isolated from community after a diagnosis of mesothelioma. Support groups were reported as important to alleviating loneliness</p>
Darlison et al. (2014) UK	To give people with mesothelioma, their families and carers, and those bereaved by the disease, an opportunity to	Quantitative. Cross-sectional survey.	Mesothelioma patients and carers recruited via Mesothelioma UK, the National Lung	Primary care practitioners may need more training in recognising the symptoms of mesothelioma

	comment on their specific experiences of healthcare provision and to provide evidence for how services may be improved.		<p>Cancer Forum for Nurses, British Thoracic Oncology Group, Asbestos Victims Support Groups Forum UK and Mesothelioma Warriors on Facebook.</p> <p>Patients <i>N</i>=272 Family members <i>N</i>=153 Bereaved family members <i>N</i>=218</p>	<p>Most participants (86%) were willing to travel for diagnostic procedures.</p> <p>Most participants (66%) did not receive information about clinical trials</p> <p>Most participants (88%) were provided with a named specialist nurse or key worker.</p> <p>Differences between the experience of those living with peritoneal mesothelioma and pleural mesothelioma were highlighted.</p> <p>Equitable access to specialist care, team communication, accuracy of information and end of life care were highlighted as areas requiring further improvement in practice.</p>
Dooley et al. (2010) Australia	To investigate stress and depression symptoms in men living with mesothelioma	Quantitative. Cross-sectional survey.	<p>Mesothelioma patients recruited via a lawsuit filed against their employer</p> <p><i>N</i>=49</p>	Significant levels of depression, stress, anger and general psychological impairment

				<p>Symptom severity predicted traumatic stress reactions</p> <p>Difficulties in interpersonal relationships were linked to intrusive thoughts of death and dying</p> <p>The financial burden of providing care was mentioned</p>
<p>Girgis et al. (2019) Australia</p>	<p>To explore the experiences of patients suffering from mesothelioma and their carers and their perceptions of how their needs may be addressed.</p>	<p>Qualitative. Thematic analysis.</p>	<p>Mesothelioma patients and carers recruited from three tertiary hospitals in Sydney, Australia.</p> <p>Individual interviews Patients <i>N</i>=5 Carers <i>N</i>=3</p> <p>Focus groups Patients <i>N</i>=3 Carers <i>N</i>=3</p>	<p>Stress and anger at the point of diagnosis was reported as particularly difficult</p> <p>Difficulties around the timeliness and accuracy of mesothelioma information was reported as problematic</p> <p>Carers sometimes hid their own emotional turmoil to protect other family members.</p> <p>Carers and patients may have different needs to each other, at different times</p>
<p>Granieri et al (2013) Italy</p>	<p>To evaluate the quality of life and personality traits in</p>	<p>Quantitative. Cross-sectional study.</p>	<p>MPM patients, first degree relatives and healthy controls</p>	<p>Compared to healthy controls, carers were more likely to report the</p>

	patients with MPM and their first-degree caregivers		recruited via non-profit organisations in Casale Monferrato and Monfalcone, Italy. Patients <i>N</i> =27 First degree relatives <i>N</i> =55 Healthy controls <i>N</i> =40	presence of fears that inhibit normal activities (negative thinking). Carers were also more likely to have poorer physical health. Compared to healthy controls, patients were also more likely to have poorer physical health.
Guglielmucci, Franzoi et al. (2018) Italy	To investigate the subjective impact of malignant mesothelioma diagnosis on both patients and caregivers	Qualitative. Thematic analysis.	Mesothelioma patients and caregivers recruited via one National Health Center. Patients <i>N</i> =33 Caregivers <i>N</i> =28	Participants reported challenges around accepting new physical limitations. Both patients and carers expressed difficulties in discussing mesothelioma and the future but wanting to find better ways of discussing death and the future with family members. The need for support for family members was highlighted. Carers reported changes to their family member's personality.
Guglielmucci, Bonafede et al. (2018) Italy	To investigate the lived experience of both MPM patients and their caregivers, providing an in-depth comprehension of	Qualitative. Thematic analysis.	Mesothelioma patients and caregivers recruited via one National Health Center.	Participants experienced but found it challenging to verbalise emotions such as shame, guilt and blame. Communication between

	the psychological sequelae of the disease.		Patients <i>N</i> =10 Caregivers <i>N</i> =9	family members could be challenging People outside of the family but living a similar experience provided emotional support and understanding Challenges around seeking compensation were discussed
Jeffery et al. (2019) Australia	To determine the prevalence of presarcopenia and malnutrition in malignant mesothelioma patients and investigate if activity levels and quality of life differed according to body composition and nutritional status.	Quantitative. Cross-sectional study	MPM patients recruited via a tertiary specialist pleural disease and medical oncology clinic in Western Australia. <i>N</i> =61	Patients who are of average or overweight can be malnourished. Malnourishment can lead to lower quality of life
Kasai and Hino (2018) Japan	To explore malignant pleural mesothelioma patients' experiences of post-diagnostic psychological transition.	Qualitative. Longitudinal phenomenological hermeneutical study. Semi-structured interviews conducted up to 13 times with each participant (4-13 times).	MPM patients recruited via their physicians. <i>N</i> =5	Initial shock of diagnosis Participants reported anger as well as guilt around their asbestos exposure. Participants reported challenges around obtaining sufficient information, and to making decisions around treatment and trials. Family members

				wishes were important when making treatment decisions. Practical plans were made for death
Lyratzopoulos et al. (2012) UK	To examine variation in the number of pre-referral consultations with a general practitioner between patients with different cancers and sociodemographic characteristics.	Quantitative. Cross-sectional survey.	Mesothelioma patients recruited via a National cancer survey. Surveys were sent by post N=275	28% of participants with mesothelioma had three or more pre-referral GP consultations No age related statistical differences were found.
Mercadante et al. (2016) Italy	The aim of this study was to examine the epidemiological characteristics and symptom burden of mesothelioma patients when admitted to home palliative care.	Quantitative. Chart review	Mesothelioma patients admitted to the home palliative care program of Casale Monferrato. N= 56	Clinical problems experienced included pain, weakness, depression, dyspnoea, decreased intake and decreased wellbeing Cough experienced by 39% of participants
Moore et al. (2015) UK	To give people the opportunity to comment on their personal experience of care and provide evidence for further service development plans.	Quantitative. Thematic content analysis of three free text responses from a cross-sectional survey	Mesothelioma patients and carers recruited via Mesothelioma UK, the National Lung Cancer Forum for Nurses, M-NAT, British Thoracic Oncology Group, Asbestos Victims Support Groups Forum Uk and	Results focused on the importance of compassionate care, information and communication, and competent care. Participants reported feeling like mesothelioma is not prioritised in regards to other cancers.

			<p>Mesothelioma Warriors on Facebook.</p> <p>Patients <i>N</i>=272 Family members <i>N</i>=153 Bereaved family members <i>N</i>=218</p>	
Nagamatsu et al. (2018) Japan	The aims of this study were to investigate the quality of life of survivors of malignant mesothelioma in Japan and to determine the factors that correlate with their quality of life.	Quantitative. Cross-sectional survey.	<p>MPM patients recruited via invitation to 422 cancer hospitals in the Japanese Ministry of Health and Welfare.</p> <p><i>N</i>=133</p>	<p>Fatigue and dyspnoea were commonly reported symptoms. Symptoms were often overlapping and difficult to control</p> <p>Familial relationships were correlated with quality of life.</p> <p>Long term survival and poor performance scores were linked to poorer quality of life.</p> <p>46% of their participants received palliative care</p>
Nagamatsu et al. (2019) Japan	The aim is to determine the needs of patients within the health services by quantifying the requests to their physicians and qualitatively analyzing their answers to two open-ended	Mixed-methods. Content analysis of two open-ended questions contained in a cross-sectional survey	<p>MPM patients recruited via invitation to 422 cancer hospitals in the Japanese Ministry of Health and Welfare.</p>	<p>Understandable explanations to meet patients needs – participants wanted to know the cause of the symptoms, prognosis and have a treatment plan.</p>

	questions regarding these requests.		N=73	<p>Participants wanted patient-centred treatment that balanced treatment with quality of life</p> <p>Receiving compassionate care from healthcare professionals was reported as important</p>
Padilha et al. (2019) Brazil	<p>To describe the therapeutic itinerary revealed by the relatives of individuals with mesothelioma</p> <p>To understand the path taken by the individuals in the search for health care</p>	<p>Qualitative.</p> <p>Multiple case study</p> <p>Sixteen case studies. Data from six family members presented.</p>	<p>Family members of mesothelioma patients recruited via medical records.</p> <p>N=6</p>	<p>Participants discussed self-treatment used before seeking professional help-seeking</p> <p>Challenges of navigating healthcare systems, both to receive a diagnosis and whilst living with mesothelioma</p> <p>The role of religion in providing hope was discussed</p> <p>Changes in family dynamics were discussed</p>
Salminen et al. (2013) Finland	The aim of this study was to compare the outcomes of pain treatment with opioids among mesothelioma and lung cancer patients treated for palliation and assess	<p>Quantitative.</p> <p>Nested case-control study.</p>	<p>Mesothelioma and lung cancer patients who were enrolled in a larger European wider study (EPOS).</p> <p>Mesothelioma N=22 Lung Cancer N=88</p>	Moderate to severe pain was associated with younger age, sleeplessness and persistence of breakthrough pain

	factors which confound to optimal treatment.			Patients experience of pain was worse than the HCPs assessment of the pain. Disparity: 64% to 41%
Saunders et al. (2015) UK	To analyze data from the English Cancer Patient Experience Survey 2011/2012 to explore variation in the experience of care between patients with cancer for all survey questions.	Quantitative. Survey including 392 mesothelioma cases	Mesothelioma patients recruited via a National cancer survey. Surveys were sent by post N=392	Compared to other cancers patients with mesothelioma reported positive experiences of information about financial support.
Taylor et al. (2019) UK	To understand the experience of communicating a diagnosis of MPM from the perspective of patients, family carers and health professionals.	Qualitative. Framework analysis	MPM patients and carers recruited via Mesothelioma UK. Patient N=6 Family carers N=9	All findings from this study focus on the diagnostic pathway Shock, devastation and uncertainty Importance of continuity and accessibility of healthcare professionals Importance of the way in which information is communicated "warm, inclusive, respectful and participatory" manner Multidisciplinary team working The role of Asbestos Support Groups in terms of

				benefits, compensation and legal claims
Walker et al. (2019) USA	To explore the lived experience of MPM in the United States and identify unmet patient needs.	Qualitative. Descriptive phenomenological study	MPM patients recruited via a large northeastern United States university medical center with a dedicated interprofessional MPM program. <i>N=7</i>	Uncertainty and worries about the future Challenges in adapting to the new norm Value in relationships. This included family relationships, peer relationships and relationships with health care professionals
Warby et al. (2019) Australia	To document the experience of malignant mesothelioma patients and their caregivers	Quantitative. Cross-sectional survey	MPM patients and caregivers recruited via of an invitation letter to the icare Dust Diseases Care to all registered MPM patients. Patients <i>N=78</i> Caregivers <i>N=106</i>	First symptoms included shortness of breath, cough, pain, and fever. Carers reported wanting more information regarding the disease trajectory and what to expect when caring for someone living with mesothelioma. Bereaved caregivers reported they would have found it helpful to have received grief counselling (39%), or had a post-death consultation with a medical specialist (25%) or palliative care specialist (23%)

				<p>Complementary therapies were used by 23% of patients</p> <p>Doctors were the main source of compensation information.</p>
Warnock et al. (2019) UK	To generate insights into the patient experience of recruitment, consent and randomisation along with the influences and motivations underlying their decisions.	<p>Qualitative</p> <p>Nested longitudinal framework approach. Semi-structured interviews conducted at four different time points before, during and after clinical trial participation</p>	<p>MPM patients recruited via the MARS 2 trial.</p> <p>N=15</p>	<p>Participants expressed challenges in assimilating trial information</p> <p>Decisions around joining trials were also challenging for patients. Obstacles to joining trials were discussed</p> <p>Experiences of trials showed anxiety around randomisation and disappointment if unable to have the intervention</p> <p>The importance of feeling supported throughout the trial process was discussed</p>
Williams et al. (2018) USA	To modify the MD Anderson Symptom Inventory for patients with malignant pleural mesothelioma and create a fit-for-purpose symptom-burden measure	<p>Qualitative</p> <p>Descriptive analysis</p>	MPM patients recruited via outpatient clinics at The University of Texas MD Anderson Cancer Center.	<p>This study reported differences between mesothelioma symptoms and treatment symptoms.</p> <p>Their findings highlight the impact of symptoms on people's lives. Most</p>

			N=20	common interference were listed as: general activity, mood, work, relationships, and enjoyment of life.
Wood et al. (2012) UK	To evaluate how patients with intrathoracic malignancy (lung cancer or pleural mesothelioma) undergoing the nonpharmacological breathlessness management programmes benefited from the programme, using a qualitative methodology	Qualitative. Interpretative phenomenological analysis of interviews with 6 patients	MPM via recruitment to the non-pharmacological breathlessness programmes for lung cancer patients. N=6	The findings report on the impact of breathlessness on quality of life Patients may not know that non-pharmacological help is available for breathlessness Carers play an important role in supporting the learning of new techniques The importance of health care professional approach (compassionate care and communication) was also discussed