

**The Experience of Living with Mesothelioma: A Meta-ethnographic Review and Synthesis of the  
Qualitative Literature.**

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## **The Experience of Living with Mesothelioma: A Meta-ethnographic Review and Synthesis of the Qualitative Literature.**

### **Abstract**

*Objective:* Mesothelioma is a life limiting cancer caused by previous exposure to asbestos. Due to the continued use of asbestos products internationally, the condition presents an increasing risk to global health with case numbers peaking in industrially developed nations. With the cancer reducing patient well-being, this study aimed to synthesise the qualitative findings of studies exploring the experiences of patients living with mesothelioma to generate new conceptual insights and guide therapeutic care.

*Method:* Thirteen databases were systematically searched: Academic Search Premier, BioMed Central, British Nursing Database, CINAHL Plus, Cochrane Library, Europe PubMed Central, MEDLINE, PsycARTICLES, PsycINFO, Science Direct, Scopus, Social Care Online, and Web of Science, between August and September 2020. Included articles were subject to quality appraisal using CASP checklists, and their respective findings analysed using a meta-ethnographic form of qualitative data synthesis.

*Results:* Twenty-two articles met the inclusion criteria, and the data synthesis produced three themes: (1) 'complex trauma'; (2) 'psycho-behavioural coping strategies'; and (3) 'external sources of support'. Combined, these themes form a novel conceptual framework and awareness of the patient experience that presents the lived trauma of disease alongside a patients coping processes and support pathways.

*Conclusion:* Robust therapeutic support is needed to address the psychosocial and existential burden shouldered by people with mesothelioma. Therapies which promote sentiments of acceptance, hope and benefit finding are proposed alongside initiatives that foster patient empowerment and meaning, and further promote patient choice in deciding end-of-life care. Recommendations for future research are also made.

**Keywords:** Mesothelioma; Cancer; Meta-ethnography; Qualitative; Synthesis

## Introduction

Mesothelioma is a cancer that primarily affects the lining of the lungs (visceral and parietal pleura) or abdomen (peritoneum), generally caused by previous asbestos exposure several decades prior to the onset of symptoms. Many industrially developed nations are now facing an unprecedented incidence of mesothelioma case numbers due to widespread industrial asbestos use through the 1950s-1980s (Novello et al., 2016). Moreover, the condition presents an increasing risk to global health because of the continued and often unregulated use of asbestos materials within industrially developing nations (Bibby et al., 2016; Delgermaa et al., 2011; Wickramatillake et al., 2019).

Due to its industrial and occupational origins, mesothelioma is significantly more common among men than women. Additionally, despite ongoing research efforts, the cancer is often difficult to treat using standard oncological methods (chemotherapy, radiotherapy, surgery etc.); as a result, mesothelioma typically features a poor prognosis wherein most people with the condition survive only 9-12 months after diagnosis, and just 10% of people live beyond 3 years (Bibby et al., 2016; Montanaro et al., 2009; Novello et al., 2016). Healthcare support thus seeks to control symptoms and extend life since the disease is rarely curable (NHS, 2019). Effective palliative care to help individuals and families manage the physical and psychosocial sequelae of disease is thus essential and recommended by national and international guidelines (Scherpereel et al., 2020; van Zandwijk et al., 2013; Woolhouse et al., 2018).

Mesothelioma bears a high symptom burden, with pronounced dyspnoea, pain, fatigue, and disturbed sleep greatly reducing patient well-being and quality-of-life (Kao et al., 2013; Nagamatsu et al., 2018; Nowak et al., 2004). Moreover, both patients and their carers report poignant feelings of hopelessness that important life goals can no longer be achieved, nor problems solved (Granieri et al., 2013).

While there is a profound need to help individuals cope with the distressing realities of mesothelioma, the current delivery of psychosocial support remains relatively under-developed and in much need of additional refinement (van Zandwijk et al., 2013). To this end, a systematic and contemporary review of the evidence would help researchers and clinicians identify salient care needs and produce tailored

therapeutic support. Previous reviews have used both quantitative and qualitative data to reveal the experiential shock of diagnosis and related feelings of despair and uncertainty, alongside the adverse changes to social roles, increasing sense of fatalism and use of avoidant coping, and iatrogenic distress (Bonafede et al., 2018; Moore et al., 2010). In addition, Ball et al (2016) identified elevated feelings of hopelessness in people living with mesothelioma -relative to people with other forms of lung cancer- as well as additional feelings of stress and unresolved anger toward former employers concerning the illness's industrial-occupational origins and legal proceedings. More recently, Sherbourne et al. (2020) reviewed the psychological impact of mesothelioma experienced by both individuals and their carers: concluding that peoples' emotional experiences are likely to fluctuate and be informed by the timing -and possible delays- of medical interventions and by their awareness of continuing illness progression throughout the mesothelioma journey. Additionally, Sherbourne et al. discuss the ubiquity of negative feelings across the illness narrative as well as the shared desires of patients and carers for good quality communication with healthcare providers.

Although existing reviews to date highlight some of the principal themes and issues of mesothelioma, there remains a substantive need to strengthen links between research and intervention development if an evidence-based approach to healthcare protocols and clinical practice is to be more fully realised (Guglielmucci et al., 2018a). Moreover, to the best of the authors' knowledge no review to date affords a dedicated synthesis of the qualitative literature on peoples' experiences of living with mesothelioma. Qualitative evidence syntheses are starting to be used more widely across healthcare related settings and are credited as a 'powerful' means for improving the relevance of guidelines by ensuring that the concerns of patient stakeholders are heard at all levels of the healthcare system (Downe et al., 2019). This paper therefore aims to provide a contemporary review and synthesis of the qualitative literature exploring the experiences of diagnosed individuals living with mesothelioma, and so asks the following research question: how do diagnosed individuals (patients) experience living with mesothelioma?

## **Method**

This review utilised Noblit and Hare's (1988) meta-ethnographic method for qualitative data synthesis. This approach to meta-ethnography is well-suited to conveying the illness experience of patients and allows a systematic means of combining qualitative evidence to develop conceptually innovative ideas that help clarify complex health issues and guide the design of services and decision-making practices (Cahill et al., 2018; Campbell et al., 2011). For these reasons, the method is one of the most frequently used and advocated methods for conducting a qualitative synthesis addressing health and social issues (France et al., 2019); and has been used previously to great effect to study cancer care and experiences (Bootsma et al., 2020; Quincey et al., 2016; Raque-Bogdan et al., 2019; Young et al., 2018).

## ***Search strategy***

A list of search terms was pooled from the authors' knowledge of the literature and supplemented by the addition of 'Medical Subject Heading' (MeSH) terms. Thirteen databases were searched: Academic Search Premier, BioMed Central, British Nursing Database, CINAHL Plus, Cochrane Library, Europe PubMed Central, MEDLINE, PsycARTICLES, PsycINFO, Science Direct, Scopus, Social Care Online, and Web of Science, over an 8-week period between August 1st and September 30th, 2020.

The Boolean search command read: *(Mesothelioma OR Asbestos\*) AND (Patient Experience\* OR View\* OR Perspective\*) AND (Qualitative OR Interview\*)*. If a journal provided the truncation function, indicated via asterisk, then this was used to simultaneously search for multiple word endings, such as 'Asbestos' or 'Asbestosis'. The literature search was further supplemented by checking the references of sourced articles for other related texts.

## ***Inclusion criteria***

Articles were required to have used a qualitative method to study the experiences of adult individuals, 18-years or older, diagnosed with mesothelioma. Articles that used mixed methods were also included if the qualitative data and findings could be clearly discerned from the quantitative data and findings.

For practical reasons, articles had to be written in English, and be published between January 1st, 2000 and July 1st, 2020—to help focus on contemporary studies. Conversely, articles were excluded if they did not provide qualitative data, or only provided duplicate data that was already reported elsewhere. Conference abstracts were also excluded, as were articles that focused on individuals' experiences of clinical trials and community interventions—instead of their experiences of living with mesothelioma. An article by Sweeney et al. (2009) was identified during the literature search and a decision made to include it in this synthesis. While not a research study, this article was published in an academic journal and presents an emotive and in-depth account of Sweeney's own experiences of being diagnosed and living with mesothelioma.

A decision was made to include the prior four mesothelioma review articles (cited in the Introduction) in the synthesis. While not a dedicated 'systematic review of reviews' (see for example Lau et al., 2016) this decision nonetheless allowed authors to include and synthesise previous reviewer commentaries around the subject, and further distinguish our own analysis and findings from that of earlier reviews. However, this required us to clearly differentiate the novel interpretations of previous review authors, as something 'new' and distinct from the studies they examined. This was achievable only by carefully unpicking reviewer commentary from individual study data and themes—this being a time-consuming and complex task (Smith et al., 2011).

### ***Screening***

After duplicates were removed, Author 1 screened papers by title and abstract in view of the inclusion criteria above. Remaining articles were then subjected to full-text review by Authors 1 and 2 with both authors independently assessing each article's relevance to the current synthesis, in terms of method, data and findings. Online meetings were held to allow both authors to discuss and resolve differences of opinion. The full screening process is visualised below via PRISMA flowchart (see Figure 1).

### ***Quality appraisal criteria***

To better understand the range and quality of the current research and evidence, checklists from the 'Critical Appraisal Skills Programme' ([CASP] 2018) were used. The *CASP Qualitative Studies Checklist* was used to assess individual research articles, and the *CASP Systematic Review Checklist* was used to assess the four review articles. Both checklists comprise ten questions that evaluate articles on various issues, such as the correct use of qualitative methodology, and handling of ethical issues.

Articles had to fulfil at least five of the ten respective criteria to be included in the synthesis, and this standard was met by all the articles appraised, though the Sweeney et al. (2009) text was not assessed, since it is neither a research study nor a literature review and was thus unsuited for review using CASP.

### ***Data extraction and synthesis***

The following information was tabulated to help provide a methodological overview of the literature: author(s) and year of publication; study location; number of participants- including gender, age range, and type of Mesothelioma; method of data collection and analysis (Table 1); and analytical themes (see Supplementary Table S2).

Data synthesis was done by hand using the iterative phases first outlined by Noblit and Hare (1988). Each article was printed and read repeatedly in order to enhance data immersion and analytical rigour. Particular attention was paid to the participants' verbatim accounts (first-order constructs), and to the analysis of these accounts by the original study authors (second-order constructs). Analytical themes were thus identified, and annotated line-by-line using colour highlighters and pens and organised into a themes table in view of the perceived similarities between excerpts. This was a systematic process that disaggregated article data and themes into its most constituent parts, while excluding data from non-patient sources (family, doctors etc.) to enable a singular focus on the patient experience.

The potential relationships between the various articles were then considered through 'reciprocal and refutational translations', to identify both their shared and dissimilar theoretical approaches, concepts and use of metaphors, in order to better situate and translate these articles in relation to one another

(see Noblit and Hare). Finally, after having read and analysed the articles at length, and assessed their reciprocal and refutational relationships, authors began synthesising the tabulated extracts of data by methodically combining excerpts from across the literature around shared concepts and themes while iteratively assessing if these lines of argument could be merged, or if they reflect thematically different aspects of the mesothelioma experience. This resulted in the production of three conceptually related themes that we present in the results section below. The analysis was conducted by Authors 1 and 2, and the synthesised themes reviewed and interrogated by Authors 3 and 5, resulting in minor changes.

## **Results**

### ***Study selection***

Initial searches identified 5,190 articles. Screening by title and abstract saw the removal of 5,159 texts. The remaining 31 articles were reviewed as full-texts and in view of the inclusion criteria. A further 14 studies were removed following this, and five articles were added after checking the references of the remaining texts for other related literature. This brought the final total to 22 articles (Figure 1).

### ***Study characteristics***

The study characteristics for each of the 22 included articles are shown in Table 1. Of the 18 research articles (excluding the four review articles): eight were conducted in the United Kingdom, four in Italy, three in Australia, two in Japan, and one in the United States. When participants' demographic details were reported, they often skewed toward males (often more than 75% of samples) and older groups, aged 60-80; only three studies reporting any participants younger than 55-years. Regarding the type of mesothelioma: 11 studies explored the experiences of individuals living with pleural mesothelioma, of which three studies also included people living with peritoneal mesothelioma. The other six studies did not specify the type of mesothelioma. In terms of the method of data collection: 10 studies used interviews and an additional two studies used interviews and focus groups, three studies used surveys, one study used clinical notes derived from a psychoanalytic therapy group, one study was a case study



combining both interviews, archived literature and local media reports, and one article presented an auto-ethnography of the lead author's own experiences living with mesothelioma.

### ***Quality appraisal***

A tabulated appraisal of the 17 studies (excluding Sweeney et al.) is shown in Supplementary Table S3, and appraisal of the four review articles is shown in Supplementary Table S4. Regarding the 17 studies, though there was some variance in the methodological quality of these articles, 10 studies scored well, fulfilling at least eight of the 10 criteria. Moreover, the majority of studies presented clear study aims, made appropriate use of a qualitative approach, and presented a suitable research design and strategy for recruitment. However, only six studies considered the researcher-participant relationship and its potential biasing impact on the participants' accounts. Likewise, only six studies adequately discussed their ethical processes, with most other articles simply stating that they had received ethical approval. Nevertheless, 13 studies presented robust analytical rigor together with a clear statement of findings and subsequent value to the research literature and practice.

Regarding the four review articles, these satisfied almost all appraisal criteria, with two review articles fulfilling all 10 criteria and two review articles fulfilling nine criteria—both because they did not assess the quality of previous studies.

### ***Study characteristics and quality appraisal: implications for the synthesis***

Whilst meta-ethnography affords a researcher the means to go beyond the findings of any single study through careful synthesis of the literature, it remains situated within the contexts and limitations of discrete studies and recognises this as implicating the resulting ethnography (Noblit and Hare, 1988). Indeed, the study characteristics and quality appraisal presented here highlight two important caveats for the current synthesis.

First, the prevalence of male and older participants across study samples means that this ethnography is likely to better reflect the lived experiences of these groups—rather than the lived experiences of

female individuals and younger groups living with mesothelioma. Likewise, the views and experiences of persons living with pleural mesothelioma are also likely to be better reflected by this ethnography due to the comparative wealth of research exploring this type of mesothelioma specifically.

Secondly, though much of the research to date demonstrates the correct use of qualitative methods, research design and recruitment, the researcher-participant relationship has been fairly unexamined; thus, any impact this may have had on the participants' accounts and their reporting may have gone unchecked during the synthesis process. However, we argue this would have been partially redressed by our synthesising findings from several studies, since this allowed us to compare and cross-examine study findings against one another to help offset the potential biases within individual accounts.

### ***Synthesis***

The synthesis of first-order and second-order constructs produced three interrelated themes, titled: (1) 'complex trauma'; (2) 'psycho-behavioural coping strategies'; and (3) 'external sources of support'.

These themes are individually presented below together with the quotations of individual participants (cited from the original study) to help illustrate thematic ideas. Quotations are indicated via italic font, line indentation and quotation marks. Synthesised articles are referenced via their assigned numbers that appear in Tables 1 and 2. This section concludes with a line of argument, wherein it is argued that the three themes presented can be conceptually combined to form a nascent conceptual framework (Figure 2) that adds to our understanding of the mesothelioma experience.

#### ***(1) Complex trauma***

This theme explores the multiple and often concurrent ways that mesothelioma diminishes a person's well-being, psychologically, socially and even existentially which we relate as a kind of complex trauma that inflicts deep and lasting psychosocial harm.

Even prior to the onset of disease, some individuals had already known about the causal link between asbestos and mesothelioma, inciting fears they may one day develop the disease due to prior asbestos

exposure—either at work or as the result of living in an asbestos-contaminated area (2,3,7,11,15,18). Individuals became especially fearful when they developed coughs or other similar chest ailments that might indicate the onset of mesothelioma (15). These fears were reinforced by former colleagues and community members developing and ultimately dying of the condition (7,11,15):

*“I’d always been aware that I might have it because me [sic] friends around me were going [dying] one by one...” (7)*

Therefore, when eventually a person received a diagnosis for mesothelioma, this may have felt like an awful confirmation of their worst fears. Indeed, the receiving of a diagnosis was often described as a profoundly distressing experience that left individuals in a deep state of shock and emotional disarray (3,5,7,8,9,12,15,16,18,20,22), intensified by a bleak and terminal prognosis (1,5,7,9,20):

*“There is no cure – it is a terminal disease. It is not like others [...] When you are diagnosed – you are diagnosed. There is no escaping it – no curing it.” (5)*

Once diagnosed, this bleak prognosis often induced chronic feelings of anxiety that appeared to stem from a general lack of certainty and definite information about disease progression and life expectancy (1,2,7,12,14,15,18,20,22); forcing many to live in a constant state of existential concern and ambiguity as they shoulder life living with a persistent and unknown threat to their very survival:

*“I don’t know whether the future will be a year or less, or whether it’ll be 6 or 8 years. I have no idea.” (22)*

These anxieties were often embedded amidst fears of future suffering and death (2,7,10,14,16,18,22); as individuals feared dying in pain (10,22), suffocating (7,22), or drowning due to the build-up of fluid in the lungs (7):

*“Fear is an ugly thing; yet, it is nevertheless something that makes us alert about the future. [...] after the diagnosis, I experienced deep terror: fear of physical pain.” (10)*

For many individuals, these fears were compounded by additional concerns about their family's future well-being and ability to manage should they die (11,12,18,19,22); moreover, many voiced fears that their partners and/or children may lack the necessary emotional and financial support to cope in their absence. Worse still, some individuals fretted because they may have unknowingly exposed others to asbestos and so placed them at-risk of developing mesothelioma as well (1,2,3,15,18):

*"Hoping it is not going to contaminate my wife she washed my clothes when I was working for the heating company and I had asbestos all over them." (1)*

Here then we begin to see how, for those living with mesothelioma, the onset of disease may present a multi-layered and complex trauma wherein the individual is beset by deep emotional and existential concern for themselves and others. These fears were often paired with feelings of frustration caused by the disabling effect of symptoms such as acute dyspnoea (1,7,14,16,22) and aches and pains (1,5,7), which restricted a person's ability to engage in meaningful activities at work or home and so prevented them living the 'normal' lives they wanted (1,2,5,7,11,12,13,16,22). Indeed, many resented feelings of weakness and dependency (2,5,11,12,13,16,22):

*"You can't clean the bathrooms, the kitchens, [...] the windows [...] It's just absurd! You physically can't. [...] now you always have to depend on others." (11)*

Additionally, for a number of individuals, social loss also appeared as a prominent part of their trauma, typified by feelings of stigmatisation and marginalisation by community groups and family (2,6,12,13); being either ostracised by peers, or separated from family members who felt "dirtied" by cancer (6). The continuing decline in physical health also left a number of people living increasingly isolated lives, since they felt unable to attend social gatherings or express their physical affection (1,2,16,22):

*"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..." (22)*

This theme therefore highlights the psychological, social, and existential burden shouldered by people living with mesothelioma; by inciting feelings of anticipatory anxiety and profound emotional despair, alongside recurrent fears of pain and death, as well as concern for family, frustration, and social loss. These psychosocial pains appear both deep and intertwined, as individuals fear both for the well-being of themselves and their family members, while resenting the loss of normalcy and their independence which in-turn increases the risk of social isolation and marginalisation. This, we argue, constitutes the complex psychosocial trauma of mesothelioma.

## ***(2) Psycho-behavioural coping strategies***

This theme explores the psychological and behavioural coping strategies individuals utilised in support of their well-being. These strategies seemed to help individuals reclaim a sense of psychological calm, individual autonomy, and personal meaning that alleviated in part the complex psychosocial trauma of living with mesothelioma.

Denial was most often reported among these strategies, and evidenced by individuals who consciously avoided thinking about mesothelioma due to the associated feelings of threat and anxiety this induced (1,3,11,12,17,18,21,22); with many seeming to dissociate from the illness to help engender a sense of psychological distance and emotional escape:

*“I didn't have the courage to face it. [...] I never wanted to face the problem because I knew what it could bring, and I preferred not to know too much.” (21)*

Conversely, other individuals found it greatly beneficial to better accept their diagnosis as a means to reorient their perspectives and think more positively (7,9,11,14,16,18,22). Here, individuals appeared to accept the inevitability of death -and of their illness- and thus strove to live in the present by readily embracing every opportunity to live life to the fullest:

*“You have to take life as it is [...] These things happen [...] if you stay there just feeling sorry for yourself you worsen everything. You have to be your own psychologist.” (11)*

This helped individuals retrain their thinking away from rumination and death toward positive thinking about life. Moreover, these individuals -by virtue of their increasing acceptance- appeared better able to find benefit in the potential opportunities still ahead of them and appreciate the lives they had lived (7,12,18,22):

*“You think ‘Why me?’ and then you think ‘Well why not me?’... one in three people have got it [cancer] so why not me? I’ve been perfectly healthy up to 55 so I’ve had 55, a lot of people don’t get that long.” (7)*

Novel constructions of hope were also evidenced as part of the coping process. These were typically short- and medium-term aspirations that remained grounded in the clinical realities of mesothelioma; recognising its incurable status yet remaining hopeful of living longer than expected, or of living long enough to see an upcoming family event (7,14,22). This provided individuals a flicker of optimism and something to aspire toward amidst the hardship of disease:

*“Like they say, the last thing that dies is hope, so you don’t wanna lose hope. There’s always hope and faith that the future’ll be there” (22)*

Still other individuals, in view of the physical and psychosocial difficulties presented by mesothelioma, construed their cancer journeys in warlike terms: positioning mesothelioma as an enemy that can be defeated via stoic resolve and effort (7,9,16). This helped reframe the adversity of illness as a challenge to be overcome, echoing the combative language seen in other cancer discourses:

*“I’m not going to roll over and play dead – that’s not me! So I’ll go down kicking and screaming until the living end!” (9)*

In addition to these psychological strategies, several distinctive forms of behavioural coping were also identified. These often appeared to help individuals reclaim a sense of control that had been otherwise diminished by the onset of mesothelioma. Moreover, individuals utilised dedicated exercise regimens, special diets, and alternative medicines to help enhance their perceived agency and control in fighting

the disease (1,3,7,18,22); thus, enabling them to adopt a more active role in their clinical journeys that helped ease feelings of anxiety:

*“Being well-informed and knowing my results eases my anxiety and gives me a sense of control.” (17)*

Individuals also sought to exercise their personal agency and coping by writing wills, pursuing financial compensation, agreeing end-of-life plans with care providers, and by retaining their household chores (3,7,14,22). Such strategies centred on personal autonomy and self-empowerment to lessen peoples’ health-related concerns. Still other individuals used more creative outlets to curate a sense of meaning in their illness experience, and give voice to other people affected by the disease (21):

*“Those who are sick because of asbestos continue to look for strategies to live... I started writing because we must not forget and to give meaning to this experience. Writing makes me remember and live.” (21)*

Consequently, this theme highlights an assortment of psychological and behavioural coping strategies used by people living with mesothelioma. Indeed, the multitude of these coping processes may reflect the intrinsic and profound difficulties of living with the complex psychosocial trauma of mesothelioma; this in-turn compelling many persons to rethink their thinking in order to reclaim a sense of positivity, hope, agency, and existential meaning. The diversity of these processes may also reflect the diversity of individuals and the idiosyncratic qualities of living and coping with the disease.

### **(3) External sources of support**

This theme examines peoples’ experiences of mesothelioma as it relates to the receipt and utilisation of external support. In doing so, this final theme further contextualises the mesothelioma experience in relation to informal and formal support pathways, and how these might advantage or disadvantage a person’s coping and broader lived experience.

Family and peer-based support were both often appreciated by individuals. In particular: family-based support was often credited to enhance an individuals' emotional coping by alleviating the build-up of negative emotions (5,11,14), whilst peer-based support appeared to afford patients the opportunity to compare notes and mutually explore with one another the emotional and practical nuances of living with mesothelioma (13,14,18,22):

*"There are times when you really do want to sit down and say, well this is really how I feel, perhaps with other people with mesothelioma, sharing support, you know." (13)*

Indeed, these social support mechanisms, whether enabled by family members or by peers living with mesothelioma, seemed to help many find emotional relief amidst the psychosocial trauma of disease (5,11,13,14,18,22). However, this was not always the case as some people chose to avoid peer-based support because in their experience it often involved patients trading distressing stories and statistics that reiterated the harsh realities of living with the illness (14,22):

*"There's a support group online, and they're very good except that can bring you down, too, because of so many people having so many problems." (22)*

Likewise, some found their family members' efforts to offer support to be overbearing and intrusive; and were irritated by their repeated attempts to discuss the individual's feelings (12):

*"He wants to stay close to me, but it's hard, very hard for me, because I've changed. I'm angry, mean, I do not bear anybody anymore, I don't want to see anybody." (12)*

Conversely, other people felt they could not discuss their feelings with family members who refused to talk about mesothelioma or its emotional consequences (6,9,21). This left them feeling increasingly isolated and intensified feelings of social loss:

*"I don't feel understood. Nobody wants to talk about emotions with me at home, but I cannot explain this to anybody. I am thinking negatively of life and especially my family." (21)*



The provision of informal social support -or lack thereof- thus appears important in understanding and contextualising the possible ways a person might both cope and experience living with mesothelioma.

Though increasing avenues for family-based and peer-based support were regularly seen as a positive, to help alleviate negative feelings, for some people this support was either undesirable or inaccessible; prompting some to actively engage and others to actively disengage from these support pathways.

Similarly, although an informed and patient-centred approach to healthcare support was highly valued and sought after by many (8,13,14,17,18,20,22), it could also be hard to navigate and left individuals feeling overwhelmed by the sheer number of medical personnel they met (7,14,15), whilst others felt disillusioned by a healthcare system that failed to address their existential concerns (19):

*“Where one meets the most senior clinical staff, one is left with a sense of technical competence, undermined [...] by a hesitation to be brave. Eye contact is avoided when one strays off the clinical map on to the metaphysical territory—I am a man devoid of hope—and circumlocution displaces a compassionate exploration of my worst fears.” (19)*

This data exemplifies the respective benefits and shortcomings of more formalised healthcare systems experienced by those living with mesothelioma; highlighting both the invaluable support they provide, while also acknowledging the possible complexities in their navigation, and relative inability to address an individual’s existential needs. Other formalised support structures are similarly discussed.

Information-based support that avoided complex medical terms was also greatly valued by individuals for helping them to understand the disease and its treatments and assume a more active role in clinical decision-making (17,22). Still, many felt underinformed and found it hard to access reliable resources (5,8,14,15), whilst others avoided information-based support entirely because -as with peer support- they felt it only served to amplify a negative message and reinforce feelings of despair (1,9,17):

*“Well I could go on the internet and the more you go on the internet, the more depressing it gets, so I shut that out the back of my mind, you know.” (9)*

Equally, among those eligible for financial compensation due to prior work-related asbestos exposure, some felt positive that payments would offer some degree of financial security to their surviving family (2,4,13). However, the financial claims process was often described as long and exhaustive with much form-filling and cross-examination which induced feelings of frustration and fatigue (2,4,7,11,13,18). Furthermore, several individuals felt conflicted and were hesitant to assign blame and make a financial claim against their former employers due to loyalties garnered through years of stable work and pay (2,3,7,12,15,16,18):

*"I loved my job and really I don't point any fingers at anybody I worked with." (15)*

This theme therefore helps clarify the ways by which people living with mesothelioma experience and engage with support. Various forms of social, healthcare, informational, and financial support often presented a major benefit to a person's well-being and capacity to cope with and manage the disease. However, their accessibility, adequacy and even desirability was contested by a number of individuals, thus revealing the limitations of these support pathways and some peoples' motivations to disengage from them.

### ***Line of argument synthesis***

The results and commentaries of the 22 articles were carefully studied and compared to allow authors to synthesis and produce three interpretive themes. It is argued that these themes combine to present a conceptual framework that helps contextualise our understanding of the mesothelioma experience by placing the complex trauma of disease alongside peoples' coping processes and support pathways. Moreover, each theme defines a conceptually distinct but interrelated aspect of the illness experience; with theme one clarifying the complex trauma of living with mesothelioma, theme two addressing the coping strategies that individuals used to alleviate this trauma, and theme three contextualising these experiences in view of broader support systems.

Figure 2 depicts this framework below by illustrating the three themes as interrelated constructs that are embedded within and influenced by one another. The concentric rounded rectangles each depict one of the three synthesised themes and houses their internal conceptual structure. The arcing arrows represent the bidirectional influence of these themes. Reading from the left, this figure illustrates the complex trauma of mesothelioma (theme one), peoples' intrapersonal coping strategies (theme two), and their external sources of formal and informal support (theme three).

[insert Figure 2 here]

Informed by this synthesis and novel framework it is possible to envision the mesothelioma experience as an interconnected process where we see the distinctive trauma of illness influencing an individual's psycho-behavioural coping and engagement with external support. For example, a person living with mesothelioma may feel deep emotional distress (theme one) and choose to avoid thinking about their diagnosis (theme two) and decline family- or peer-based support (theme three). Conversely, a person may find inspiration and meaning through creative projects and specific health practices (theme two) that ease feelings of existential doubt (theme one) and prompt the use of peer support (theme three).

## **Discussion**

This synthesis clarifies the lived experiences and coping processes of people living with mesothelioma, by way of three interrelated themes, labelled: complex trauma, psycho-behavioural coping strategies, and external sources of support. Together, these themes enable a more contextualised understanding of the illness experience that interconnects the acute trauma of disease and array of coping processes and support avenues that individuals used to help alleviate this pain.

Considering the findings further, the individuals' accounts often voiced deep and pervasive feelings of psychosocial trauma that permeated and defined much of their experiences living with mesothelioma. This aligns with survey data showing that mesothelioma patients have a lower quality of life compared to healthy controls (Granieri et al., 2013; Kao et al., 2013; Nagamatsu et al., 2018; Nowak et al., 2004).

Several factors are likely to contextualise and contribute toward the distress felt by individual patients, including the onset of physical symptoms that inhibit daily routine and social activity (Kao et al., 2013), intensive medical treatments that regularly present with unpleasant side-effects (Clayson et al., 2005), and an uncertain but dismal prognosis that induces feelings of mortality salience (Walker et al., 2019). Indeed, all these factors were cited by individuals across the synthesised literature, thus highlighting the need for robust and multifaceted therapies that address peoples' complex feelings of psychosocial distress and concern for family, in addition to their psycho-existential fears of death and dying.

Regarding their emotional well-being, individuals used several distinct psychological coping strategies -denial, acceptance, hope, and stoicism- to help ease their negative thoughts and feelings relating to mesothelioma. While such coping strategies may enhance patient well-being, they are often dissimilar to one another and thus vary in their efficacy to augment coping within a palliative cancer care setting (Nipp et al., 2016). In the current synthesis, although denial was most often cited across the literature, it was seldom discussed in positive terms by participants or study authors, and often seemed to afford only a fleeting respite from an otherwise depressing situation by refusing to think about it. By contrast discussions of acceptance, hope, and stoicism were often far more positive and implied better coping. Moreover, sentiments of hope (Olsson et al., 2011), resilience (Eicher et al., 2015), and benefit finding (Hong et al., 2021; Lin et al., 2021) have been shown to help people live with advanced forms of cancer, whereas denial is linked to poorer psychological outcomes (Nipp et al., 2016; Thompson et al., 2009), and may deter more adaptive forms of coping that inspire growth and psycho-emotional development (Vos and de Haes, 2006). Consequently, while individuals used various strategies across the literature to augment their well-being, these did not always appear equal, and efforts to cope whether through acceptance, hope, and/or stoicism, appeared far more beneficial to their long-term happiness.

Multiple behavioural coping strategies were also prominently discussed by individuals that seemed to enhance their sense of agency, either through diet and exercise, alternative medicine, will writing and planning of future care, or through artistic projects. These appeared to help individuals reclaim control

and find meaning in living with a condition that might otherwise leave them feeling helpless and bereft of purpose (Granieri et al., 2013). This therefore affirms the role of empowerment and meaning as an important element in understanding and supporting a person's psychospiritual well-being within the context of advanced cancer care (Lin and Bauer-Wu, 2003).

Whilst guidelines call for a comprehensive approach to clinical and therapeutic support to help people living with mesothelioma (Scherpereel et al., 2020; van Zandwijk et al., 2013), the synthesised findings also reveal a complex and nuanced engagement with external sources of informal and formal support. Moreover, no single support pathway -whether family and peer, healthcare, information, or financial- was universally praised, and while many people saw outside support as invaluable to their well-being, several individuals decried this support as either inaccessible, inadequate, or undesirable. This reflects the idiographic aspects of end-of-life care and need to work with individuals and their families to tailor support to peoples' physical, emotional, and spiritual needs (Ventura et al., 2014; Wenrich et al., 2003) and affirm patient choice and dignity in end-of-life care (Department of Health and Social Care, 2015). Lastly, our findings present a novel conceptual framework for an otherwise under-theorised condition. Though not an original aim of this review, the 'line of argument synthesis' and accompanying Figure 2 nevertheless conform with Jabareen's (2009) definition of a 'conceptual framework': in presenting an interpretive 'plane' for understanding the concepts and subtleties that underpin complex social issues. Much like the ARC framework for living with and beyond cancer (Le Boutillier et al., 2019), this nascent framework helps clarify peoples' experiences of adversity and change in living with cancer but extends a singular focus on mesothelioma for its especially difficult prognosis and impact on patient well-being. This framework also provides an opportunity to discuss these difficulties in view of larger social factors that implicate the design and rollout of therapeutic initiatives. These implications are discussed below.

### ***Implications for practice***

Robust and informed clinical support is essential if we are to meaningfully address the complex trauma of living with mesothelioma. Indeed, Guglielmucci et al. (2018a) call for a closer integration of research

and practice to help academics and clinicians develop care protocols that gain from an interdisciplinary evidence-base. To this end, the current paper presents a contextual synthesis and novel framework to help both researchers and clinicians perceive mesothelioma through the patient eye and think about suitable interventions that either help alleviate the experiential trauma of disease, enhance prominent psycho-behavioural coping strategies, or improve upon existing support systems.

Addressing psychological coping specifically, this paper recognises the utility of acceptance, hope, and stoicism for enhancing peoples' perceived well-being. Therapeutic initiatives are therefore advocated to help patients traverse the psychological and existential terrain conducive to these coping strategies. Acceptance-based therapy may be of a particular benefit in view of research linking acceptance with better psychological outcomes in palliative cancer patients (Nipp et al., 2016; Thompson et al., 2009). Such therapies would be complemented by initiatives that affirm patient empowerment and meaning, to help individuals reclaim a sense of agency and purpose in support of their psychospiritual well-being (Lin and Bauer-Wu, 2003).

This synthesis further stresses the difficulties around patient support and reiterates the need to tailor services where possible to better meet an individuals' contextual needs and preferences. Pursuing an open dialogue with patients and family members is hence recommended to identify urgent care needs and explore existing avenues for familial support—where they exist, and whether patients/relatives want to pursue them. Indeed, some individuals may wish to forgo any and all support (Lee et al., 2009), or accept assistance only in managing bodily symptoms and go without further psychosocial support. In either case, improving opportunities for patient choice not only adheres to policies of good practice (Department of Health and Social Care, 2015) but also reflects the subjective reality of death and dying that requires patient input and personalisation to enhance end-of-life care (Wenrich et al., 2003).

How medical information is written and presented requires further attention and flexibility in view of peoples' diverging relationships with informational resources. Though many pursued reliable sources of information, several individuals deliberately avoided any such support because it was seen as bleak

and upsetting. There is therefore a need to assess message framing throughout the healthcare journey -from early consultation through to diagnosis and beyond- to redress unduly negative messages that dissuade patient engagement with information and services.

### ***Strengths and limitations***

This is the first meta-ethnography to examine the experiences of individuals living with mesothelioma and presents a more contextual account of the patient, their coping strategies, and support structures. However, as stated before, because much of the literature to date focuses on the experiences of older men with pleural mesothelioma, the current synthesis is likely to better reflect the voices and concerns of these individuals—which leaves the voices of younger groups, women, and people living with other forms of mesothelioma comparatively unheard and unrepresented. In addition, while this synthesis is intended to help researchers and clinicians perceive and contextualise the mesothelioma experience, it makes no claim to data saturation, neither does it provide a definitive or prescriptive account of the innumerable ways a person may experience and therefore seek to cope with the disease. Instead, this synthesis and conceptual framework should be used judiciously as part of a person-centred approach, to help conceptualise the many interconnected aspects of mesothelioma trauma, coping and support, while also acknowledging and responding to the idiographic concerns of the individual.

### ***Future research***

Though the literature to date offers several rich and textured accounts that illustrate the use of various psychological coping strategies, the respective efficacy of these strategies for improving the well-being of people with mesothelioma is still unclear and in need of further study. Moreover, to the best of our knowledge, there is little literature (either quantitative or qualitative) specifically addressing individual coping strategies and psychotherapies for mesothelioma which inhibits a more informed approach to therapeutic practice. This line of research would likely be improved by efforts to see if the efficacy and use of different coping strategies and therapies changes over the illness trajectory, either as a function of disease progression and/or patient maturation.

Additionally, the research participant samples to date have often skewed toward older groups of men living pleural mesothelioma. Consequently, the voices of women and younger people remain relatively unheard and marginalised -both here and in the wider literature- as are the voices of individuals living with other distinctive forms of the illness, such as peritoneal, pericardial, and testicular mesothelioma. Future research is hence needed to help elucidate the experiences and support needs of these groups. Indeed, a greater awareness of how demographic and structural factors impact a person's experiences of the illness and healthcare is needed to improve our understanding of mesothelioma in view of larger societal factors.

Finally, although the literature to date presents a focussed analysis of patient experiences and coping, it often fails to study the contextual nuances of coping within broader social and family-based systems, despite evidence of intrafamilial exchanges exacerbating negative emotions and social withdrawal (Guglielmucci et al., 2018b). As a result, research findings often overlook the relational facets of coping as a collaborative process that is enacted by both the patient and their familial/social networks. Further research is therefore needed to help provide a contextual insight of how individuals and their relatives coproduce the coping process.

### ***Conclusion***

This synthesis outlines and visualises three interrelated themes that together clarify and contextualise the experiential trauma of living with mesothelioma alongside peoples' respective psycho-behavioural coping strategies and external support systems. In doing so, this synthesis presents a novel framework that is intended to help researchers and clinicians perceive mesothelioma through the patient eye and consider targeted clinical and therapeutic programmes that help individuals living with the condition. Further research is needed to help delineate the efficacy of respective therapies and coping strategies, and to further amplify those patient voices which have been overlooked within the literature to date. For practitioners, our findings reiterate the need to work with patients and families to tailor support where possible in seeking to empower patient autonomy and encourage adaptive forms of coping.



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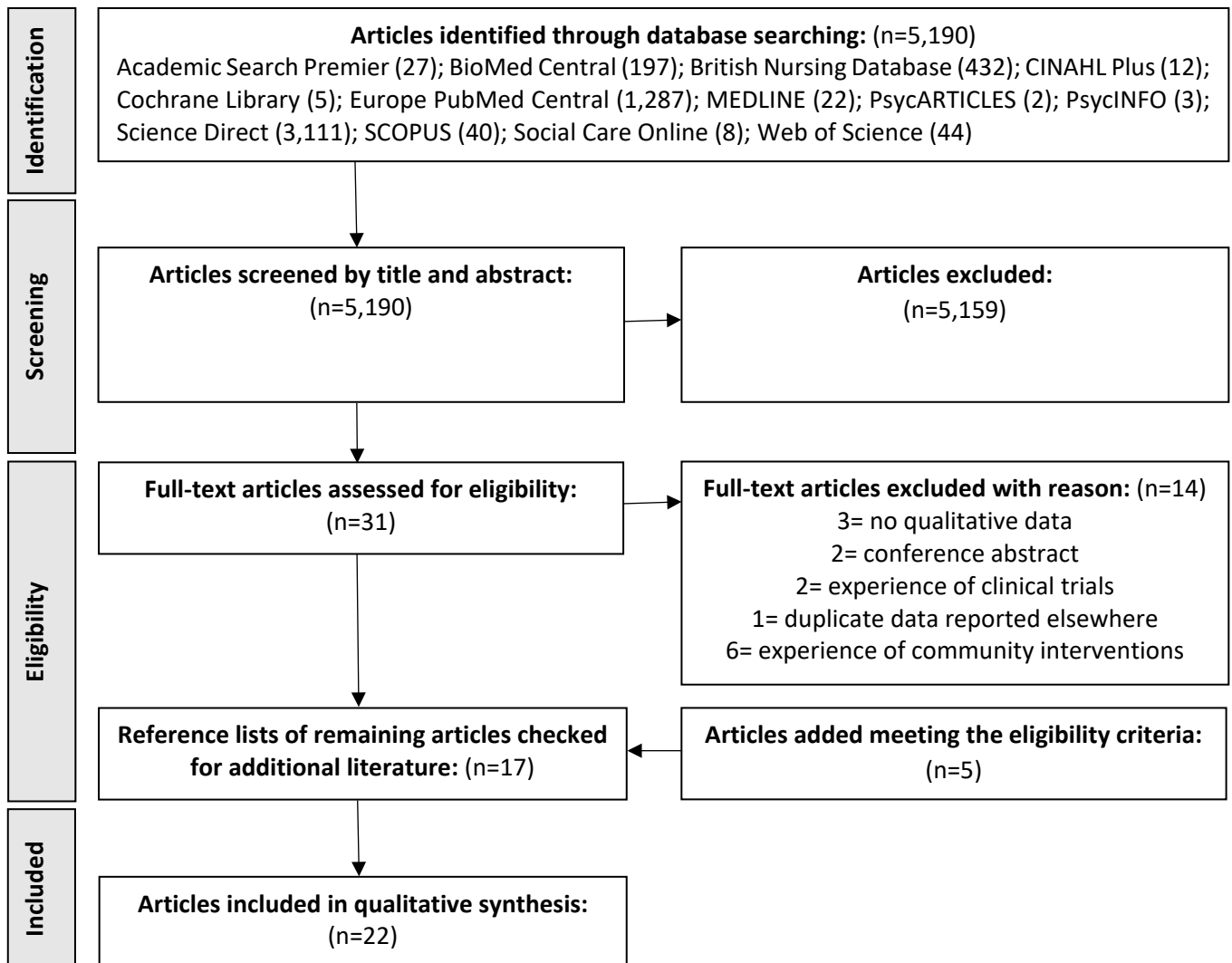
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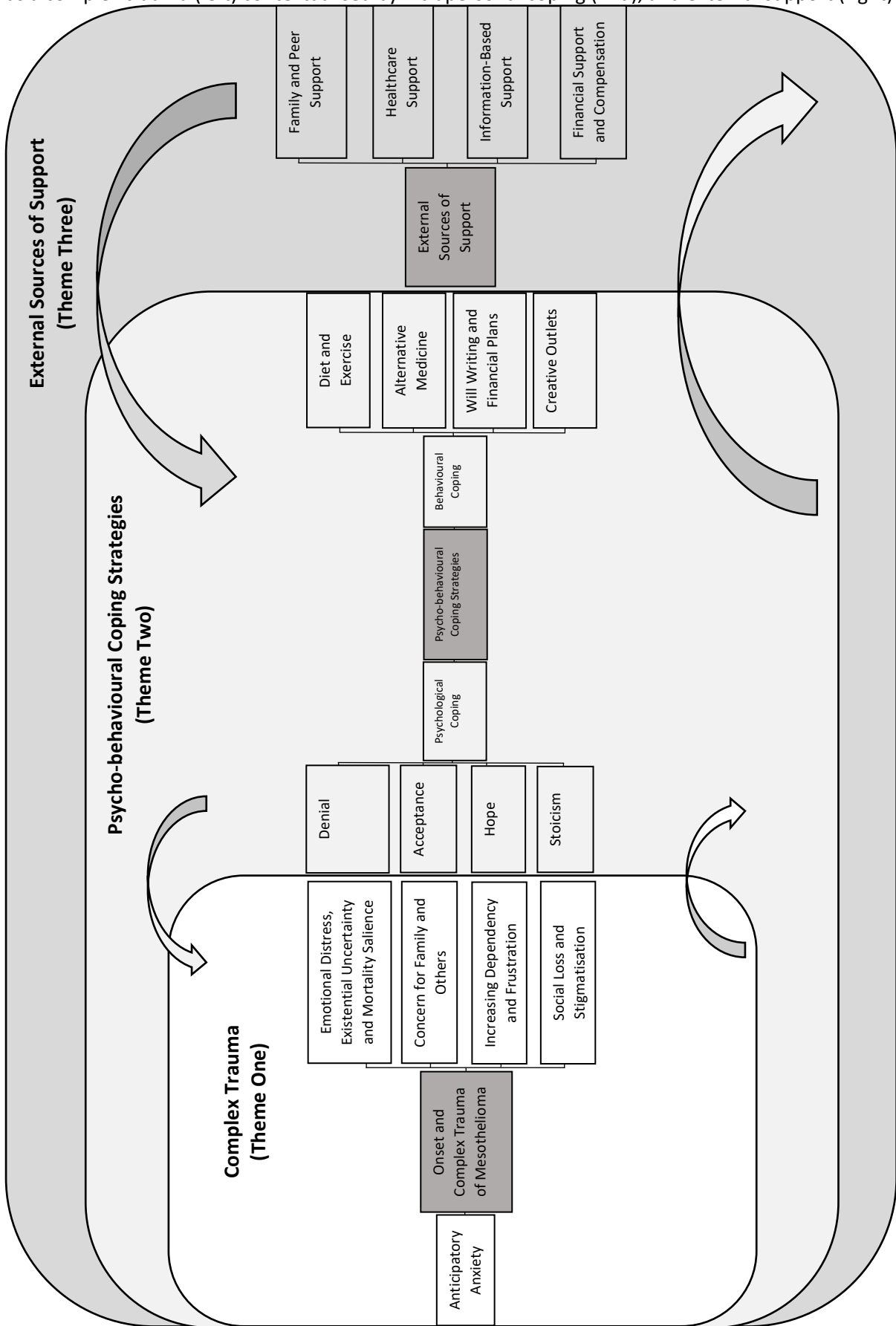
Young, B., Bedford, L., Kendrick, D., Vedhara, K., Robertson, J. F. R., & das Nair, R. (2018). Factors influencing the decision to attend screening for cancer in the UK: A meta-ethnography of qualitative research. *Journal of Public Health*, 40(2), 315–339. <https://doi.org/10.1093/pubmed/fox026>

Tables and Figures

Figure 1. PRISMA flowchart



**Figure 2.** Conceptual framework of themes and their connected roles in viewing the illness experience as a complex trauma (left) contextualised by intrapersonal coping (mid), and external support (right).



**Table 1.** Summary of included studies (*n* = 22).

<b>Author(s) and Year</b>	<b>1. Arber and Spencer (2013)</b>	<b>2. Ball et al. (2018)</b>	<b>3. Bonafede et al. (2018)</b>	<b>4. British Lung Foundation (2013)</b>	<b>5. Buultjens et al. (2018)</b>	<b>6. Chapple et al. (2004)</b>
<b>Country;</b>	UK; <i>n</i> = 10	Review Paper, <i>n</i> = 8 Studies	Review Paper, <i>n</i> = 7 Studies	UK; <i>n</i> = 31	Australia; <i>n</i> = 7	UK; <i>n</i> = 4
<b>Sample Size;</b>	Meso Patients; 8 Males, 2 Females;			Meso Patients; Unspecified Meso	Meso Patients; 6 Males, 1 Female;	Meso Patients; Unspecified Meso
<b>Age;</b>	Age Range: 56-82;				Age Range: 37-85;	
<b>Mesothelioma Type</b>	Pleural Meso				Unspecified Meso	
<b>Exclusions from Synthesis</b>	<i>n</i> = 9 Lung Cancer Studies with no Meso Patients	<i>n</i> = 14 Quantitative Studies, and Qualitative Studies looking at Asbestos Exposed Participants	<i>n</i> = 15 Relatives, 188 Bereaved Relatives	<i>n</i> = 19 Carers, Former Carers, and Patients with other Asbestos Related Illnesses	<i>n</i> = 41 Patients with Non-Mesothelioma Lung Cancer	
<b>Method of Data Collection</b>	Semi-structured Interviews (Face-to-Face)	Systematic Literature Review	Systematic Literature Review	Survey using 57 Closed Questions and Open Responses	Semi-structured Interviews (Face-to-Face) with Patients and their Carers	Semi-structured Interviews (Face-to-Face)
<b>Method of Data Analysis</b>	Grounded Theory	Meta Ethnography	Unspecified	Unspecified	Thematic Analysis	Unspecified

**Abbreviation.** Meso = Mesothelioma.



Table 1. Continued.

Author(s) and Year	7. Clayson et al. (2005)	8. Darlison et al. (2014)	9. Girgis et al. (2019)	10. Granieri (2016)	11. Guglielmucci et al. (2018b)	12. Guglielmucci et al. (2018a)
<b>Country;</b>	UK; n = 15	UK; n = 272	Australia; n = 8	Italy;	Italy; n = 10	Italy; n = 33
<b>Sample Size;</b>	Meso Patients;	Meso Patients;	Meso Patients;	Meso Patients	Meso Patients;	Meso Patients;
<b>Gender;</b>	13 Males;	Pleural & Peritoneal	6 Males;	n = Unspecified;	6 Males,	21 Males,
<b>Age;</b>	2 Females;		2 Females;	Pleural Meso	4 Females;	12 Females;
<b>Mesothelioma Type</b>	Age Range: 55-81; Pleural Meso		Age Range: 52-78; Unspecified Meso		Mean Age: 62; Pleural & Peritoneal	Mean Age: 64; Pleural & Peritoneal
<b>Exclusions from Synthesis</b>		n = 153 Relatives, 218 Bereaved Relatives	n = 6 Female Carers	Carers n = Unspecified	n = 9 Carers 2 Males, 7 Females	n = 28 Carers 6 Males, 22 Females
<b>Method of Data Collection</b>	Semi-structured Interviews (Face-to-Face)	Survey using 79 closed questions, and three open questions	Semi-structured Telephone Interviews and Focus Groups	Clinical Notes Derived from a Psychoanalytic Group	Semi-structured Interviews (Face-to-Face) with Patients and their Carers	Semi-structured Interviews (Face-to-Face) with Patients and their Carers
<b>Method of Data Analysis</b>	Grounded Theory	Unspecified	Thematic Analysis	Unspecified	Thematic Analysis	Thematic Analysis

Abbreviation. Meso = Mesothelioma.

Table 1. Continued.

Author(s) and Year	13. Hughes and Arber (2008)	14. Kasai and Hino (2018)	15. Lee et al. (2009)	16. Moore et al. (2010)	17. Nagamatsu et al. (2019)	18. Sherborne et al. (2020)
<b>Country;</b>	UK; n = 5	Japan; n = 5	Australia; n = 2	Review Paper, n = 5 Studies	Japan; n = 74	Review Paper, n = 15 Studies
<b>Sample Size;</b>	Meso Patients; 4 Males, 1 Female;	Meso Participants; 4 Males, 1 Female;	Meso Patients; Unspecified Meso		Meso Patients; 61 Males, 12 Females;	
<b>Age;</b>	Age Range: 54-76;	Age Range: 61-80;			Mean Age: 66;	
<b>Mesothelioma Type</b>	Pleural Meso	Pleural Meso			Pleural Meso	
<b>Exclusions from Synthesis</b>			n = 6 Carers, 5 Stakeholders	n = 8 Quantitative Studies		n = 2 Quantitative Studies
<b>Method of Data Collection</b>	Semi-structured Interviews (Face-to-Face)	Repeated Semi-structured Interviews (Face-to-Face)	Case Study of Semi-structured Interviews, and Analysis of Historical Literature and Media Reports	Literature Review	Survey using 72 Closed Questions, and 2 Open-ended Questions	Scoping Review
<b>Method of Data Analysis</b>	Phenomenological Analysis	Phenomenological Analysis	Constant Comparison Technique	Unspecified	Content Analysis	Thematic Analysis

Abbreviation. Meso = Mesothelioma.

Table 1. Continued.

Author(s) and Year	19. Sweeney et al. (2009)	20. Taylor et al. (2019)	21. Testoni et al. (2019)	22. Walker et al. (2019)
<b>Country;</b>	UK; <i>n</i> = 1	UK; <i>n</i> = 6	Italy;	USA; <i>n</i> = 7
<b>Sample Size;</b>	Male Meso	Meso Patients;	Meso Patients	Meso Patients;
<b>Gender;</b>	Patient;	3 Males,	<i>n</i> = Unspecified;	4 Males,
<b>Age;</b>	Pleural Meso	3 Females;	Unspecified Meso	3 Females;
<b>Mesothelioma Type</b>		Pleural Meso		Age Range: 58-79; Pleural Meso
<b>Exclusions from Synthesis</b>		<i>n</i> = 9 Carers, 16 Healthcare Professionals	<i>n</i> = 37 Relatives, and Unspecified Number of Non-Meso Patients	
<b>Method of Data Collection</b>	Auto-ethnography	Semi-structured Interviews, and Group Interviews	Semi-structured Interviews (Face-to-Face)	Semi-structured Interviews (Face-to-Face)
<b>Method of Data Analysis</b>		Framework Analysis	Unspecified	Phenomenological Analysis

Abbreviation. Meso = Mesothelioma.

**Online Only Supplementary Material for Research Paper:**

Understanding Peoples' Experiences of Mesothelioma using Qualitative Meta-Ethnography

**Research Paper Authored by:**

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**Research Paper Published in the American Psychological Association Journal:**

Health Psychology

**Contents:**

**Table S2:** Core themes from each of the included studies in the meta-ethnography

**Table S3:** Summary of the study quality appraisal (using the Critical Appraisal Skills Program Checklist)

**Table S4:** Summary of the review quality appraisal (using the Critical Appraisal Skills Program Checklist)

**Table S2.** Core themes from each of the included studies (*n* = 22).

1. Arber and Spencer (2013)	2. Ball et al. (2016)	3. Bonafede et al. (2018)	4. British Long foundation (2013)	5. Buultjens et al. (2018)	6. Chapple et al. (2004)	7. Clayton et al. (2005)	8. Darlison et al. (2014)
• Shock/Distress of Diagnosis	• Uncertain Prognosis	• Anticipatory Anxiety	• Diagnosis	• Shock/Distress of Diagnosis	• Stigmatisation	• Uncertain Prognosis	• Latrogenic Distress
• Psychological Coping- Denial	• Future Distress, Death	• Shock/Distress of Diagnosis	• Financial Compensation	• Concern for Family	• Shock/Distress of Diagnosis	• Shock/Distress of Diagnosis	• Shock/Distress of Diagnosis
• Behavioural Coping- health practices	• Concern for Family	• Concern for Family		• Informational Support		• Psychological Coping- Fatalism, Acceptance	• Healthcare Support
• Physical, Life-limiting Symptoms	• Physical, Life-limiting Symptoms	• Psychological Coping- Optimism, Denial		• Physical, Life-limiting Symptoms		• Behavioural Coping- Financial/care Arrangements, Health Practices	
• Social Support	• Stigmatisation			• Social Support		• Social Support	
• Latrogenic Distress	• Anticipatory Anxiety			• Financial Compensation		• Anticipatory Anxiety	
• Concern for Family	• Shock/Distress of Diagnosis					• Future Distress, Death	
	• Latrogenic Distress					• Physical, Life-limiting Symptoms	
						• Latrogenic Distress	
						• Financial Compensation	

Table S2. Continued.

9. Girgis et al. (2019)	10. Granieri (2016)	11. Guglielmiucci et al. (2018b)	12. Guglielmiucci et al. (2018a)	13. Hughes and Arber (2008)	14. Kasai et al. (2018)	15. Lee et al. (2009)	16. Moore et al. (2010)
• Shock/Distress of Diagnosis	• Shock/Distress of Diagnosis	• Shock/Distress of Diagnosis	• Anticipatory Anxiety	• Social Support	• Shock/Distress of Diagnosis	• Shock/Distress of Diagnosis	• Future Distress, Death
• Informational Support	• Future Distress, Death	• Concern for Family	• Concern for Family	• Healthcare Support	• Future Distress, Death	• Uncertain Prognosis	• Shock/Distress of Diagnosis
• Psychological Coping-Resilience	• Inability to Disclose Diagnosis	• Physical, Life-limiting Symptoms	• Physical, Life-limiting Symptoms	• Physical, Life-limiting Symptoms	• Psychological Coping-Acceptance	• Concern for Family	• Physical, Life-limiting Symptoms
	• Social Support	• Psychological Coping- Denial, Acceptance	• Psychological Coping- Presentism, Acceptance	• Financial Compensation	• Iatrogenic Distress	• Financial Compensation	• Psychological Coping- Resilience
		• Stigmatisation	• Financial Compensation	• Iatrogenic Distress	• Informational Support	• Anticipatory Anxiety	• Changing Social Roles
		• Social Support	• Social Support	• Healthcare Support	• Healthcare Support	• Social Support	• Iatrogenic Distress
			• Iatrogenic Distress			• Iatrogenic Distress	• Healthcare Support
						• Informational Support	

Table S2. Continued.

	17. Nagamatsu et al. (2019)	18. Sherborne et al. (2020)	19. Sweeney et al. (2009)	20. Taylor et al. (2019)	21. Testoni et al. (2019)	22. Walker et al. (2019)
•Healthcare Support		•Anticipatory Anxiety	•Shock/Distress of Diagnosis	•Shock/Distress of Diagnosis	•Social Support	•Uncertain Prognosis
•Informational Support		•Uncertain Prognosis	•Informational Support	•Healthcare Support	•Behavioural Coping- Writing	•Shock/Distress of Diagnosis
•Iatrogenic Distress		•Shock/Distress of Diagnosis	•Iatrogenic Distress	•Iatrogenic Distress	•Psychological Coping- Denial, Acceptance	•Physical, Life-limiting Symptoms
	•Psychological Coping- Denial, Acceptance, Resilience	•Concern for Family			•Physical, Life-limiting Symptoms	•Psychological Coping- Optimism, Acceptance
	•Future Distress, Death					•Future Distress, Death
	•Healthcare Support					•Social Support
	•Informational Support					•Concern for Family
						•Behavioural Coping- Health Practices
						•Healthcare Support

**Table S3.** Summary of Study Quality Appraisal

Study	Critical Appraisal Skills Programme (CASP)—Qualitative Checklist										Total Criteria Fulfilled*
	Aims Stated Clearly	Suitable use of Qualitative Methodology	Suitable Research Design	Suitable Recruitment Strategy	Suitable Data Collection Method	Considered Researcher- Participant Relationship	Ethical Issues Suitably Handled	Ample Rigor of Data Analysis	Findings Stated Clearly	Value to Research, Policy & Practice	
Arber and Spencer (2013)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	8
British Lung Foundation Foundation (2013)	Yes	Yes	Yes	Unclear	Yes	No	No	No	Yes	Yes	6
Buultjens et al. (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Chapple et al. (2004)	Yes	Yes	Unclear	Yes	Yes	No	No	Yes	Yes	Yes	7
Clayson et al. (2005)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Darlison et al. (2014)	Yes	Yes	Unclear	Yes	Yes	No	No	No	Yes	Yes	6

\* Criteria fulfilled if reviewer answered Yes to the question presented by CASP (e.g., Was there a clear statement of the aims of the research?)  
Total Criteria Fulfilled score range: 0-10, with a higher score denoting higher research quality.



**Table S3.** Continued

Study	Critical Appraisal Skills Programme (CASP)—Qualitative Checklist										Total Criteria Fulfilled*
	Aims Stated Clearly	Suitable use of Qualitative Methodology	Suitable Research Design	Suitable Recruitment Strategy	Suitable Data Collection Method	Considered Researcher- Participant Relationship	Ethical Issues Suitably Handled	Ample Rigor of Data Analysis	Findings Stated Clearly	Value to Research, Policy & Practice	
Girgis et al. (2019)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Granieri (2016)	Yes	Unclear	Yes	Yes	Yes	Yes	No	No	No	Unclear	5
Guglielmucci et al. (2018b)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	8
Guglielmucci et al. (2018a)	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	7
Hughes and Arber (2008)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	8
Kasai and Hino (2018)	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	9

\* Criteria fulfilled if reviewer answered Yes to the question presented by CASP (e.g., Was there a clear statement of the aims of the research?)  
Total Criteria Fulfilled score range: 0-10, with a higher score denoting higher research quality.

**Table S3.** Continued

Study	Critical Appraisal Skills Programme (CASP)—Qualitative Checklist										Total Criteria Fulfilled*
	Aims Stated Clearly	Suitable use of Qualitative Methodology	Suitable Research Design	Suitable Recruitment Strategy	Suitable Data Collection Method	Considered Researcher- Participant Relationship	Ethical Issues Suitably Handled	Ample Rigor of Data Analysis	Findings Stated Clearly	Value to Research, Policy & Practice	
Lee et al. (2009)	Yes	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	Yes	7
Nagamatsu et al. (2019)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Taylor et al. (2019)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	8
Testoni et al. (2019)	No	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	Yes	7
Walker et al. (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10

\* Criteria fulfilled if reviewer answered Yes to the question presented by CASP (e.g., Was there a clear statement of the aims of the research?)  
Total Criteria Fulfilled score range: 0-10, with a higher score denoting higher research quality.

**Table S4.** Summary of Review Quality Appraisal

Review	Critical Appraisal Skills Programme (CASP)—Review Checklist										Total Criteria Fulfilled*
	Was the Review Clearly Focussed	Do Authors seek the Right Type of Papers	Were Relevant Studies Included	Does the Review Adequately Assess Study Quality	Was it Appropriate to Combine Study Findings	Are the Review Findings Presented Clearly	Are the Review Findings Precise	Can the Results be Applied to the Local Population	Were all Important Outcomes Considered	Are the Benefits Worth the Harms and Costs	
Ball et al. (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Bonafede et al. (2018)	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	9
Moore et al. (2010)	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	9
Sherborne et al. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10

\* Criteria fulfilled if reviewer answered Yes to the question presented by CASP (e.g., Did the review address a clearly focused question?)  
Total Criteria Fulfilled score range: 0-10, with a higher score denoting higher review quality.