



A systematic literature review comparing the psychological care needs of patients with mesothelioma and advanced lung cancer



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ABSTRACT

Purpose: Psychological distress which adversely affects a person's experience of cancer has been shown to be highly prevalent in patients with mesothelioma. Historically, the assumption has been made that the evidence guiding the supportive care needs for lung cancer is relevant to those with mesothelioma. The objective of the study was to evaluate if the psychological care needs differ between patients with pleural mesothelioma and those with advanced lung cancer.

Methods: A search of MEDLINE, CINAHL, PsycARTICLES, Psychology and Behavioural Sciences Collection, PsycINFO databases, grey literature and the Cochrane Library of Systematic Reviews identified 17 studies meeting a predefined inclusion criteria. These were critically appraised for quality. Data relating to psychological experiences was extracted which was then synthesised narratively and through a process of meta ethnography.

Results: Common themes identified across the studies created 10 key concepts. These were uncertainty, normality, hope/hopelessness, stigma/blame/guilt, family/carer concern, physical symptoms, experience of diagnosis, iatrogenic distress, financial/legal and death and dying. Key similarities and differences were identified between the mesothelioma and lung cancer evidence.

Conclusions: There is limited research exploring the lived experiences of those with mesothelioma and lung cancer, with the majority of them having methodological and/or reporting concerns compromising the conclusions made. However, reoccurring themes in the evidence were found suggesting a number of areas where the psychological experience of mesothelioma differs from that of advanced lung cancer. These findings warrant further research to explore further and if proven, the need for the provision of specialist mesothelioma care services is affirmed.

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1. Background

Malignant pleural mesothelioma is a rare cancer arising from the lining of the lung (pleura); usually as a result of previous exposure to asbestos some 20–50 years previously. It is a uniformly fatal diagnosis (Kazan-Allen, 2005; Steele and Klabasta, 2005; Szlosarek et al., 2008) and its incidence is increasing worldwide. In Great Britain the total number of recorded deaths has risen from 153 in 1968 to 2347 in 2010, and is expected to peak in this decade (Health and Safety Executive, 2012).

Pleural mesothelioma is often a rapidly progressive disease with a median survival of 6–12 months from diagnosis (Curran et al., 1998; Edwards et al., 2000; O'Byrne et al., 2004). Patients characteristically present with advanced disease and symptoms include breathlessness, chest wall pain, weight loss, sweating and fatigue (Pistolesi and Rusthoven, 2004; Cordes and Brueggen, 2003). The severity of symptoms often increases as the disease progresses and may prove difficult to palliate (Cordes and Brueggen, 2003; Chapman et al., 2005; Clayson et al., 2005). These factors commonly associated with mesothelioma may help to explain the high levels of psychological sequelae reported in individuals living with the disease, including anxiety, depression, anger, fear, isolation and hopelessness (Lebovits et al., 1983; Clayson, 2003; Cordes and Brueggen, 2003; Chapman et al., 2005; Hughes and Arber,

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2008; Arber and Spencer, 2012).

The effects of psychological distress in cancer have been well-researched. It can greatly increase the risk of developing depression and anxiety states, as well as impacting negatively on overall quality of life, marital and family relationships, compliance with treatment and even survival (Faller et al., 1997; Colleoni et al., 2000; Prieto et al., 2002; Akechi et al., 2006; Greer et al., 2008). Given the palliative nature of treatment for pleural mesothelioma and the inherent need to optimise quality of life for individuals with the disease, an understanding of the factors that may impact on psychological wellbeing and the introduction of appropriate interventions to ameliorate them are crucial.

Until recently, distinct services for pleural mesothelioma have not been developed resulting in variable approaches to treatment and care (Department of Health, 2007; Moore and Darlison, 2011). Historically, services for mesothelioma have been provided by the existing infrastructure in place for lung cancer with assumptions being made that the care needs of individuals with either disease are the same. However, increasingly health care professionals and advocacy groups are lobbying for distinct services for individuals affected by mesothelioma in recognition that some of their care needs may be unique to their particular situation (Darlison, 2008).

In light of the above, this paper presents the findings of a recent study that systematically examined the literature in an attempt to evaluate whether the psychological needs of individuals with pleural mesothelioma differ from those of individuals with advanced lung cancer.

2. Aim

The study aimed to answer the following research question: Are the psychological needs of individuals diagnosed with pleural mesothelioma the same as those diagnosed with advanced lung cancer?

3. Objectives

The objectives were to:

- Identify papers which explore the impact of pleural mesothelioma and advanced lung cancer on psychological wellbeing.
- Identify factors that are reported to cause psychological distress in individuals with mesothelioma and advanced lung cancer.
- Compare and contrast the similarities and differences of these factors between the two disease populations.
- Identify the clinical implications of the findings in respect to needed services for patients with mesothelioma.

4. Method

A systematic literature review was chosen to address the research question as it is a method that not only identifies and makes sense of the available evidence but also helps to map out areas of uncertainty and identify where further research is needed (Petticrew and Roberts, 2006). In order to identify relevant papers for review, an electronic search of the databases MEDLINE, CINAHL, PsycARTICLES, Psychology and Behavioural Sciences Collection, PsychINFO (all accessed through EBSCO Host) and the Cochrane Library of Systematic Reviews was undertaken. 'Grey literature' was also identified and relevant reference lists searched for further papers. Studies meeting predefined inclusion and exclusion criterion (Table 1) were read and critically appraised for quality using the Critical Appraisal Skills Programme (CASP) checklist for appraising qualitative research (CASP, 2013) (Box 1).

Each study was then awarded a grade of A, B or C where:

- 'A' denotes the study is well conducted and reported, and there are no concerns.
- 'B' denotes some concerns relating to the way the study was conducted and/or reported but which are not severe enough to reduce the validity of the findings.
- 'C' denotes serious concerns about the study design, conduct and/or reporting which result in the findings not being deemed valid (London South Bank University, 2013).

Box 1

CASP qualitative checklist (CASP, 2013).

- Was there a clear statement of the aims of the research?
- Is a qualitative methodology appropriate?
- Was the research design appropriate to the aims of the study?
- Was the recruitment strategy appropriate to the aims of the study?
- Was the data collected in a way that addressed the research issue?
- Has the relationship between the researcher and participants been adequately considered?
- Have ethical issues been taken into consideration?
- Was the data analysis process sufficiently rigorous?
- Is there a clear statement of findings?
- How valuable is the research?

Table 1

Inclusion and exclusion criteria for selecting papers.

	Inclusion criteria	Exclusion criteria
Type of study	<ul style="list-style-type: none"> • Qualitative studies which explore experience. • Mixed method studies if qualitative aspects are presented in relation to experience. • English language. 	<ul style="list-style-type: none"> • Studies such as controlled trials and cohort studies which produce empirical explanations as opposed to experience. • Case studies, review documents, commentaries and personal opinion pieces. • Non-English language.
Clinical population and diagnosis	<ul style="list-style-type: none"> • All adults aged 18 and over with pleural mesothelioma or advanced lung cancer (i.e. lung cancer that is inoperable or not amenable to radical treatment). 	<ul style="list-style-type: none"> • Patients with lung cancer who have had a surgical resection or completed treatment with curative/radical intent. • Patients with primary mesothelioma in another site e.g. peritoneum.
Severity of disease	<ul style="list-style-type: none"> • Disease where all treatments would be given with palliative intent. 	<ul style="list-style-type: none"> • Early stage disease where treatments would be given with curative intent.
Outcomes	<ul style="list-style-type: none"> • Psychological issues, feelings, experience, views, perceptions, distress. 	<ul style="list-style-type: none"> • Psychological outcomes assessed by quantitative tools such as quality of life scales.

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