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

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- Objectives

In order to effectively provide support and care for individuals and families living with mesothelioma, we need to understand their experiences and priorities. This evidence review draws together existing research on the experience of living with mesothelioma. The purpose of this review was to identify what is known about the experience of people living with mesothelioma, from the perspective of patients and their carers.

- Methods

The review protocol is registered on PROSPERO (CRD42020204726).

Systematic searches were conducted across Medline, PsycInfo, Scopus and the Cumulative Index to Nursing and Allied Health Literature. Google Scholar was also searched. The inclusion criteria stipulated that studies were peer-reviewed, reported on the experience of living with mesothelioma from the perspective of patients and informal carers, were written in English, and were published between December 2008 and October 2020. The quality of the included studies was assessed using the Mixed-Methods Appraisal Tool. Data were extracted and a narrative synthesis was developed.

- Results

Twenty-five studies were identified that met the inclusion criteria. Twelve of the studies utilized qualitative methods, 12 utilized quantitative methods and one used mixed-methods. Findings were divided into eight areas: experience of diagnosis; physical impact of mesothelioma; psychological impact of mesothelioma; impact on informal carers, carers and relationships; self-management; health care professionals and systems; treatment and trials; and asbestos exposure and

compensation. In addition to literature focusing on the devastating physical and psychological impact of a diagnosis of mesothelioma, there is a growing body of evidence showing that quality of life and well-being in a broader sense are also impacted by a diagnosis of mesothelioma. Complex emotions regarding exposure to asbestos were reported. Not only anger and a sense of injustice, but also guilt and responsibility for potentially having exposed their family members to asbestos. The experiences of informal carers are increasingly being recognised as important. However, little research focused on the experiences of carers.

Professionals that were compassionate, honest and supportive positively influenced patient experience. Continuity, coordinated care and good communication between treatment centres were reported as important in the literature. Specialist nurses and good GP support were key to coordinated and individualised care. Non-healthcare professionals such as Asbestos Support Groups and legal professionals were also reported as valuable sources of support.

Challenges relating to trial participation included difficulties in assimilating information about the trial process, and understanding of randomisation and clinical equipoise. Motivations for taking part in trials included wanting to exhaust all treatment options, the possibility of enhanced care, and altruism. Travel time to trial centres, expenses for travel, and accommodation were reported as barriers to trial participation.

- Conclusion

Over the past 12 years the volume of mesothelioma patient and carer experience research has grown. This has contributed to our understanding of the complex needs and experiences of mesothelioma patients and their carers. However, this review has identified several gaps in current evidence. Recommendations for further research are provided. The findings from the current review will inform a research prioritisation exercise that is being conducted by the Mesothelioma UK Research Centre in 2021.