
Understanding the role of Mesothelioma UK clinical nurse specialists in meeting the palliative care needs of patients and families: a mixed methods study

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Research summary

Patients with mesothelioma and their families have palliative care needs throughout their illness.

There is evidence that specialist palliative care can improve the quality of life of patients with other health conditions, and reduce health system costs and resource utilisation. However, a study in the UK and Australia found that early, specialist palliative care for patients with malignant pleural mesothelioma did not have any additional benefits on quality of life over usual care. This might be explained by differences in care systems, as patients in the UK and Australia may already have their palliative care needs met by current care arrangements.

This could mean that patients with mesothelioma may have their palliative care needs met by generalist palliative care providers, and that specialist palliative care input is not required in the early stages of the illness.

In the UK, Mesothelioma UK clinical nurse specialists (MCNSs) are key providers of generalist palliative care who play an important role in supporting patients, which may reduce the need for early specialist palliative care. The aim of this study was, firstly to explore the palliative care needs of people with mesothelioma and their families, and secondly to explore the role of MCNSs in supporting patients with palliative care needs.

Specialist palliative care is provided by health/allied health professionals with specialist/accredited training in palliative care, working on a specialist palliative care team e.g. Macmillan nurses.

Generalist palliative care is provided to patients as a part of standard care by any healthcare professional who is not part of a specialist team e.g. GPs.

Palliative care is used in mesothelioma to enable patients to feel as well as possible, by managing symptoms such as breathlessness or pain. Palliative care also provides psychological, social, and spiritual support for people with mesothelioma and their families.

Palliative care is beneficial at all stages of mesothelioma, right from the beginning of the illness to the end of life, and bereavement.

Methods

The study used a mixed methods design: -

- (i) A systematic review of published international evidence on palliative care needs in mesothelioma (Harrison et al 2021).
- (ii) Analysis of pre-existing research data from the National Mesothelioma Outcomes, Research and Experience (MORE) Survey in 2019, completed by 510 patients.
- (iii) An online survey of 23 Mesothelioma UK CNSs exploring delivery of palliative care.
- (iv) Focus groups and individual interviews with 16 Mesothelioma UK CNSs to explore their role in palliative care provision, and barriers and opportunities to achieving good palliative care.
- (v) Following data collection and analysis, a workshop with nine experts in palliative care and mesothelioma, developed recommendations.

Results

1

Patients with mesothelioma have significant palliative care needs, from diagnosis onwards. These include management of symptoms (physical, psychological, emotional, and social), information and communication needs.

2

The family carers of people with mesothelioma also have palliative care needs, including during bereavement. Their needs often differ to those of the patient, particularly around information needs and 'what lies ahead'.

3

Mesothelioma UK CNSs are highly skilled at providing palliative care, the majority have received training or education in palliative care. Mesothelioma UK CNS's role in providing palliative care is likely to contribute to a reduced need for early specialist palliative care.

4

There is an important distinction between 'specialist' palliative care and 'generalist' palliative care. Mesothelioma UK CNSs provide the majority of generalist palliative care and some specialist palliative care. They play a key role in supporting patients' early palliative care needs. They work closely with, and refer to, specialist palliative care to manage greater needs.

5

Good partnership working between Mesothelioma UK CNSs and specialist palliative care is crucial to ensuring patients receive seamless care. Referral pathways from Mesothelioma UK CNSs to specialist palliative care are variable and may need improving.

6

A co-ordinated approach to a patient's care is crucial. Patients and their families appreciate a single point of contact to avoid 'falling through the gaps' between services, especially at the end of life.

7

Patients with mesothelioma and their families can be reluctant to accept palliative care due to negative associations with the term 'palliative' For some, palliative care is wrongly associated only with dying, rather than care which helps patients and their families to live as well as possible with mesothelioma.

8

COVID-19 has presented significant challenges both to patients with mesothelioma and the healthcare professionals that support them. The limitations of virtual communication should be acknowledged.

These findings have important implications for palliative care provision in mesothelioma. A range of recommendations have been developed for clinical practice including:

- Valuing the Mesothelioma UK CNS role in palliative care, which is central to supporting patients
- Addressing disjointed and un-coordinated care
- Explaining the benefits of palliative care for patients and their families, and challenging any misconceptions
- Better supporting family carers.

Conclusion

This study provides valuable insights into palliative care needs in mesothelioma, and how these needs can be met.

Increasing the profile and visibility of Mesothelioma UK CNSs, and recognising their expertise in palliative care, will help ensure that all health care professionals caring for mesothelioma patients can make contact with the Mesothelioma UK CNS workforce. Improvements in collaborative working between Mesothelioma UK CNSs and other providers of palliative care may also improve outcomes for patients and families. Our research found that referral pathways to specialist palliative care can be inconsistent. Organisational change may be required to avoid delays and improve efficiency.

Disjointed and un-coordinated care is one of the most challenging issues for patients. Open conversations between health professionals and patients about the challenges of achieving co-ordinated care may help to manage patients' expectations. Establishing a 'gold standard' care pathway incorporating palliative care, may be useful as a benchmark to aim towards.

Negative perceptions of the term 'palliative care' can discourage patients and their families from accepting this care. It's important not to avoid using the term 'palliative care', rather to ensure that it is explained correctly. It should be introduced as early as is appropriate into patient and carer conversations, emphasising its important role in improving quality of life.

Support for family caregivers is important, and carers should be signposted to support groups that meet their needs, for example Mesothelioma UK carer support groups. Practical information for carers on providing support at the end of life, and what to do after a person dies, may also be helpful.

The recommendations from this study will inform changes to clinical practice, future research, and policy which will improve the experience of patients with mesothelioma and their families at all stages of living with the conditions.

“By chance my work had involved visiting a hospice and I understood that palliative care was not just about the final days, but about helping people to live well and manage their symptoms. This meant that when palliative care was mentioned by the nurse I welcomed it” (Family carer)