Mesothelioma palliative care needs: supporting patients and families with new research-based resources

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Mesothelioma is a rare cancer without cure, with 2400 deaths per year in the UK (Cancer Research UK, 2023). Most cases arise from occupational exposure to asbestos, and the time-lag between exposure and development of mesothelioma means that incidence rates peak in old age. The 2016–2018 statistics on mesothelioma show that the incidence is higher in males, with around 2200 new cases per year, compared to 470 in females (Cancer Research UK, 2023). Treatment options are limited and prognosis poor, with 1- and 3-year survival rates being 40% and 10%, respectively (Royal College of Physicians, 2018). Patients living with mesothelioma have palliative care needs from diagnosis onwards, with a high symptom burden of fatigue, dyspnoea, pain, weight loss, anxiety and low mood (Hoon et al, 2021). To address these needs, patients and their families require both well-coordinated care from healthcare professionals, and a willingness to engage with palliative care. Community and specialist nurses are key to achieving this ambition (Walshe, 2020; Harrison et al, 2022).

Abstract

Background: Mesothelioma is a rare cancer without cure. Clinical guidelines recommend the timely provision of palliative/supportive care; however, a new study identified barriers to achieving this ambition. **Objective**: The study aimed to explore palliative care needs and the role of Mesothelioma Clinical Nurse Specialists (MCNSs); and to develop resources to address study findings. **Methods**: The mixed-methods study included a literature review, focus groups, interviews and surveys. **Results**: The study highlighted the important role of the MCNSs in palliative care and the need to: address disjointed care; improve support for families; and explain the benefits of palliative care for patients/families. A co-production approach developed an animation for patients/families to demystify palliative care and explain the benefits of early-stage engagement; and an infographic targeted at community and primary care professionals. Recommendations for community nursing practice are described.

Keywords: Mesothelioma • palliative care • community nursing • patients and families

Palliative care needs in mesothelioma

Mesothelioma clinical guidelines recommend the timely provision of palliative and supportive care (British Thoracic Society Standards of Care Committee, 2007; Scherpereel et al, 2010). Both generalist and specialist palliative care are needed (dependent upon individual needs), with both elements offering different but complementary care (Gardiner et al, 2022a). Specialist palliative care (SPC) is provided by healthcare professionals with specialist training or expertise; generalist palliative care is provided by health or social care professionals who do not have specialist training, but who still provide palliative care as a part of their role, such as community nurses (Shipman et al, 2008). However, there is a paucity of evidence on the most effective way to provide both specialist and generalist palliative care for mesothelioma (Brims et al, 2019; Harrison et al, 2021).

A recent research project by the Mesothelioma UK Research Centre set out to explore the views of mesothelioma patients on palliative care, and the palliative care role of mesothelioma clinical nurse specialists (MCNSs) (Gardiner et al, 2022c). MCNSs are funded by the charity Mesothelioma UK, and a UK network provides specialist care for patients and families. The mixed-methods study included: a literature review, focus groups and interviews with 16 MCNSs, a survey of 23 MCNSs, and secondary analysis of a national mesothelioma patient experience survey conducted by Mesothelioma UK (510 responses).

Findings

The literature review identified key elements required to address palliative care needs in mesothelioma: organisation and coordination of services; management of care needs, especially due to the high symptom burden (and symptoms that can be difficult to palliate); communication and information needs for both patients and families; and the importance of considering whole family palliative care needs (Harrison et al, 2021). Needs may be complicated by legal processes being undertaken by the patient, who may be seeking compensation for asbestos exposure within the workplace. This legal aspect adds an additional pressure to patients and their families. The review identified an overarching theme of uncertainty, for patients and families living with the pain of not knowing how, and when, the end of life will occur.

The focus groups and interviews with MCNSs (Gardiner et al, 2022a) found that they are highly skilled and play a key role in providing generalist palliative care and coordinating care; this is achieved via joint working with both specialist palliative care services and community services. However, the processes for ensuring a timely referral to specialist palliative care were inconsistent and dependent upon effective team working with community colleagues. Additional barriers to care were identified, including a reluctance by some patients and families to engage with palliative care due to negative associations with end of life, and misconceptions that early-stage engagement was not appropriate.

The survey of MCNSs found a high proportion of respondents perceived that they play a role in palliative care, and the whole sample had received training or education and were confident in providing care (Gardiner et al, 2022b). Secondary analysis of the patient survey (the 2019 Mesothelioma Outcomes, Research and Experience survey) found that one-fifth of patient respondents (21%; n=104) reported receiving support from a community palliative care nurse; the majority reported that support at home had not been needed (63%; n=315) (Gardiner et al, 2022b). When asked if they had received support in relation to planning end-of-life care, the majority reported that this was not applicable (73%; n=365), or they did not wish to discuss it (7%; n=33).

The key recommendations from the research are: the importance of valuing the role of the MCNS in palliative care, as this is central to supporting patients and their families; addressing disjointed and uncoordinated care; streamlining referral routes; the need to explain the benefits of palliative care for patients and families, as well as challenge any misconceptions; and the need for better support for families (Gardiner et al, 2022a). The research underlined how important it is that people with mesothelioma and their families have access to palliative care from diagnosis, to ensure that needs are addressed, and plans made at an early stage.

New resources

Researchers from the Mesothelioma UK Research Centre, together with the charity Mesothelioma UK, stakeholders from healthcare professionals, and members of the public, set out to develop new resources to address findings from the palliative care study. Working with a creative design company, the resources aim to encourage early-stage engagement with palliative care and to signpost healthcare professionals to sources of information to ensure smooth transitions to palliative care, and address care needs.

A co-production approach was utilised with stakeholders including clinicians, researchers and patients/carers. This ensured that the resources addressed the aims and the perspectives of all key stakeholders groups. The perspectives of patients and families were key to this and ensured that the resources were both meaningful and appropriate. This was confirmed when the resources were presented at several patient and family events and audiences spontaneously applauded.

The first resource is a short animation. It is aimed at patients/families and sets out to demystify palliative care, address misconceptions, and highlight the benefits of early-stage engagement. The animation is freely available on the Mesothelioma UK (MUK) palliative care webpages in both the patient and healthcare professionals' sections (MUK, 2022a). It can be used as a tool to open and set the tone for positive conversations with patients about palliative care or as a resource for patients/families. The animation has been presented at patient and family events, and has been well received as a means of normalising the use of palliative care within mesothelioma.

The second resource is an infographic, and it is freely available on the MUK website (MUK, 2022a). It was developed to counter possible information gaps about mesothelioma, given the rarity of the condition. The one page infographic is targeted at community and primary care professionals and provides a short-cut to information about palliative care needs, and signposts to sources of help. The healthcare professionals in the development team wanted to ensure that all professionals providing care for mesothelioma patients/families feel comfortable in seeking advice.

Our dissemination and impact plan sought to collect evidence of impact for mesothelioma nurses, patients and their families. Whilst we are at an early stage of collecting evidence of impact, we have received feedback from patients/families that the animation has changed their thinking and understanding of palliative care and this has enabled them to feel more at ease. We have also received feedback from MCNSs who have used the animation as a tool within their practice around talking about palliative care, and have found it useful. The animation has also been shared on the websites of various patient and health professional organisation websites, and is included in a mesothelioma patient app.

Recommendations for community nursing practice

Mesothelioma is a rare condition; many community nurses may never care for a patient. It is therefore expected that when patients are encountered, they will require education on the condition and how best to provide care. The downloadable infographic provides an information resource to share with colleagues, and signposts to specialist support.

Mesothelioma patients, carers and health professionals can access the MUK support line (via telephone and email), which provides specialist knowledge and support (MUK, 2022b). MCNSs can be contacted directly for clinical information and advice. A general information line provides

Key points

- Mesothelioma is a rare cancer with palliative care needs for both patients and families from diagnosis onwards
- Palliative care works best when introduced at an early stage so that plans are in place in advance of need
- Timely provision of palliative care is best achieved through collaborative working
- New research-based resources are available for mesothelioma palliative care
- The infographic provides key information about mesothelioma palliative care needs for healthcare professionals and signposts to sources of help
- The 3-minute animation demystifies palliative care for patients and families and can be used as a resource for signposting patients, or as a tool to open conversations with patients and families.

CPD reflective questions

- When a condition is rare, such as mesothelioma, where can you signpost patients to, and where can you get information and advice?
- How will you incorporate the animation into your practice around introducing patients to palliative care, and what are the key points that should be emphasized?
- How would you work collaboratively to ensure that patients have both their generalist and specialist palliative care needs addressed in a timely way?

information on benefits, compensation, and support groups, among other things. Patients not currently receiving support from MCNSs can be flagged with MUK, to see what support can be offered. MUK also provides information about clinical trials for mesothelioma.

There are currently 34 MCNSs. Mesothelioma UK aims to provide MCNS cover across the UK; for example, in England, aiming to provide one or two nurses per Cancer Alliance (depending on the population size). MCNSs are accessible both via local networks or the support line.

The research found that palliative care worked best when patients and families were informed about this holistic approach at an early stage to ensure that benefits are accrued through their journey, and they are receptive and amenable to any later referrals to specialist palliative care (Gardiner et al, 2022a). Community nurses can play a key role in communicating the purpose, role, and benefits of palliative care for both patients and families. We know from the research that the potential barriers to accepting palliative care are around fears due to negative associations with end of life, concerns that accepting palliative care could mean that active treatment has ended, and a lack of awareness of the nature and benefits of palliative care (Gardiner et al, 2022a). Information sharing about palliative care is best undertaken by healthcare professionals as part of a trusted therapeutic relationship with patients and families. Community nurses can play a central role in communication (Seymour et al, 2010), as part of a collaborative approach. Conversations can be difficult, especially if this includes questions about prognosis. Mesothelioma clinical nurse specialists can provide advice when planning conversations, and in signposting to sources of support.

Timely and seamless palliative care is achieved through excellent team working; community nurses are central to realising this ambition. MCNSs are key agents within the multidisciplinary care team, providing a dual role, both as sources of advice and information, and in taking a lead role in decision-making in referrals to specialist palliative care. Referral routes to specialist palliative care vary, and it is essential that delays are avoided, especially as mesothelioma patients may undergo a sudden and rapid deterioration (Gardiner et al, 2022a). It is also known that symptom control in mesothelioma can be difficult, and specialist input is vital to ensure optimum care (Harrison et al, 2021).

A key aspect of palliative care support for families is ensuring that they are informed prior to the death of their loved one that a coroner's inquest/procurator fiscal investigation may be necessary. Mesothelioma is classified as an unnatural cause of death, and the coroner/procurator fiscal must be informed. The inquest/investigation can be a difficult experience for families (Harrison et al, 2022), and bereavement support is needed.

Conclusion

Mesothelioma patients and their families have palliative care needs from diagnosis onwards (Harrison et al, 2021; Harrison et al, 2022; Gardiner et al, 2022a; 2022b). Community nurses can play a vital collaborative role in ensuring that optimum care is provided. The new research-based resources provide useful tools in achieving the ambition of early conversations with patients and families to overcome barriers to acceptance and timely referral to specialist palliative care (Gardiner et al, 2022a). Family palliative care needs continue into bereavement, and ongoing support is valued (Harrison et al, 2022). **BJCN**

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