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MESOTHELIOMA UK

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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Abbreviations

CNS	Clinical Nurse Specialist
GP	General Practitioner
MCNS	Mesothelioma Clinical Nurse Specialist
MORE survey	Mesothelioma Outcomes, Research and Experiences survey
MPM	Malignant Pleural Mesothelioma
PC	Palliative Care
SPC	Specialist Palliative Care

Executive summary

Introduction

Patients with mesothelioma and their families have palliative care needs throughout the relatively short trajectory of their illness. There is evidence that specialist palliative care can improve the quality of life of patients with palliative care needs in other conditions, and at the same time reduce health system costs and resource utilization. However, a randomised controlled trial in the UK and Australia found that early routine specialist palliative care for patients with malignant pleural mesothelioma did not have any additional impacts on quality of life over standard care (Brims 2019). One reason for this finding may relate to differences in care systems, with patients in the UK and Australia potentially having their palliative care needs met by current care configurations. Specifically, patients with mesothelioma may have their palliative care needs met by generalist palliative care providers, meaning specialist palliative care input is not required early in the trajectory. Specialist palliative care is defined as health and allied health professionals with specialist or accredited training in palliative care delivery, who work as part of a specialist palliative care team. Generalist palliative care is defined as care provided to those with life limiting illness as an integral part of standard clinical practice, by any healthcare professional who is not part of a specialist palliative care team. In the UK, Mesothelioma UK clinical nurse specialists 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 twofold, firstly to explore the palliative care needs of people with mesothelioma and their families, and secondly to explore the role of Mesothelioma UK Clinical Nurse Specialists (MCNS's) in supporting patients with palliative care needs.

Methods

The study used a mixed methods design involving two workstreams. Workstream one comprised analysis of existing literature and previously collected data including: (i) a systematic review of published international evidence on palliative care needs in mesothelioma; (ii) secondary analysis of existing research data from the National Mesothelioma Outcomes, Research and Experience (MORE) Survey in 2019, completed by 510 patients. Workstream two involved a cross sectional study of Mesothelioma UK clinical nurse specialists using quantitative and qualitative data collection methods, specifically: (iv) an on-line survey of 23 MCNS's exploring delivery of palliative care and; (v) focus groups and individual interviews with 16 MCNS's to explore their role in palliative care provision, and barriers and facilitators to achieving good palliative care. Following data collection and analysis, a workshop was convened with nine experts in palliative care and mesothelioma, and a series of recommendations were developed and subsequently refined.

Results

Eight key findings were generated from the research and are presented here:

- 1) Patients with mesothelioma have significant palliative care needs, from the point of diagnosis. 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 after bereavement. Their needs often differ to those of the patient, particularly around information provision and 'what lies ahead'.

- 3) Mesothelioma UK clinical nurse specialists 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 CNS's 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 complex cases.
- 5) Good partnership working between Mesothelioma UK CNS's and specialist palliative care is crucial to ensuring patients receive seamless care. Referral pathways from Mesothelioma UK CNS's to specialist palliative care are variable and may need streamlining.
- 6) A co-ordinated approach to a patients 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 preconceptions about the term 'palliative'. Societal perceptions, stigma and fear of death may contribute to negative impressions of palliative care.
- 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 significant 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; challenging negative perceptions of palliative care and; better supporting family carers. Recommendations for future research and for policymakers and funders have also been developed.

Conclusion

This study provides valuable insights into palliative care needs in mesothelioma, and the role of Mesothelioma UK clinical nurse specialists and others in meeting these palliative care needs. Patients with mesothelioma and their families have significant palliative care needs throughout the course of their illness. Mesothelioma UK CNS's play a crucial role in supporting patients and families palliative care needs, and are highly skilled in providing this care. There is an important distinction between specialist and generalist palliative care in mesothelioma, with each playing a crucial role. Good partnership working between Mesothelioma UK CNS's, other generalist palliative care providers and specialist palliative care is crucial to ensure patients receive co-ordinated and seamless care. Challenges to good palliative care in mesothelioma include misunderstandings of the term 'palliative care' and reluctance amongst patients and families to engage with this care, in addition to the huge disruptions and challenges brought about by the COVID-19 pandemic. The recommendations from this study will inform changes to clinical practice, future research and policy which will impact on the experience of patients with mesothelioma and their families at the end of life.

Abstract

Patients with mesothelioma and their families have palliative care needs throughout the relatively short trajectory of their illness. In the UK, Mesothelioma UK clinical nurse specialists are key providers of generalist palliative care who play an important role in supporting patients with palliative care needs. The aim of this study is to explore the palliative care needs of people with mesothelioma and their families, and to explore the role of Mesothelioma UK Clinical Nurse Specialists (MCNS's) in supporting patients with palliative care needs.

The study used a mixed methods design involving two workstreams. Workstream one comprised analysis of existing literature and previously collected data. Workstream two involved a cross sectional study of MCNS's using quantitative and qualitative data collection methods. Eight key findings were generated from the research: (1) Patients with mesothelioma have significant palliative care needs, from early in the disease trajectory; (2) Family carers of people with mesothelioma also have palliative care needs, including after bereavement; (3) MCNS's are highly skilled at providing palliative care, the majority have received training or education in palliative care; (4) There is an important distinction between 'specialist' palliative care and 'generalist' palliative care. MCNS's often provide the majority of generalist palliative care, but work with/refer to specialist palliative care to manage complex cases; (5) Good partnership working between MCNS's and specialist palliative care is crucial to ensure patients receive seamless care; (6) A co-ordinated approach to a patients care is crucial, patients and their families appreciate a single point of contact to avoid 'falling through the gaps'; (7) Patients with mesothelioma and their families can be reluctant to accept palliative care due to preconceptions about the term 'palliative'; (8) COVID-19 has presented significant challenges both to patients with mesothelioma and the healthcare professionals that support them.

This study provides valuable insights into palliative care needs in mesothelioma, and the role of Mesothelioma UK clinical nurse specialists and others in meeting these palliative care needs. A range of recommendations have been developed for practice, further research and policy which focus on acknowledging and supporting the MCNS role in palliative care provision, integrated working with specialist palliative care and identifying/supporting patient and family needs in a timely way. These recommendations will inform changes to clinical practice, future research and policy which will impact on the experience of patients with mesothelioma and their families at the end of life.

Outputs

Journal articles:

Harrison M, Gardiner C, Taylor B, Ejegi-Memeh S, Darlison L. Understanding the palliative care needs and experiences of people with mesothelioma and their family carers: An integrative systematic review. *Palliative Medicine*. 2021;35(6):1039-1051. doi:10.1177/02692163211007379

Harrison M, Darlison L, Gardiner C. A qualitative study exploring the experiences of end of life care for patients with mesothelioma from the perspective of bereaved family caregivers in the UK. *Journal of Palliative Care* (under review)

Conferences:

Harrison et al. An Integrative Systematic Review Exploring the Palliative Care Needs of Patients With Mesothelioma and Their Carers (oral) iMIG 2021.

Gardiner C, Harrison M. Palliative care provision in mesothelioma: perspectives of clinical nurse specialists. (poster) BTOG 2021

Gardiner C, Harrison M. An Integrative Systematic Review Exploring the Palliative Care Needs of Patients With Mesothelioma and Their Carers. (poster) European Association of Palliative Care conference 2021

Gardiner C, Harrison M, Tod A. Palliative care provision in mesothelioma: perspectives of Mesothelioma UK Clinical Nurse Specialists. (poster) NCRI On-line Conference 2021.

Other outputs:

Gardiner C. The role of mesothelioma UK clinical nurse specialists in palliative care needs. *Mesothelioma Matters Magazine*. Spring 2020

Darlison L, Gardiner C, Henshall C, Tod A. Making Mesothelioma Patient Research Happen – The UK Experience. *IASLC Newsletter* 2020.

Introduction

Mesothelioma is a rare, incurable cancer with a high symptom burden (Moore et al., 2009). Approximately 2700 people in the UK receive a diagnosis of mesothelioma each year (CRUK, 2021). Most cases of the disease are caused by preventable asbestos exposure, which usually occurs in the workplace resulting in mesothelioma being classified as an industrial disease (Suzuki et al., 2005; Noonan, 2017). People with mesothelioma experience a range of debilitating symptoms including pain, breathlessness, cough, fatigue, sweating and weight loss, as well as anxiety and low mood (Hoon 2021). Mesothelioma typically progresses rapidly and the majority of people with the disease will die within a year of diagnosis (CRUK, 2021). Consequently, people with mesothelioma and their families have palliative care needs throughout the relatively short trajectory of their illness, from diagnosis to the end of life (Tinkler et al, 2017).

Compared with other cancers, the palliative care needs of people with mesothelioma are particularly challenging to manage due to the complexity of the disease and the occupational causes (Zhang et al., 2015, Kirkham 2011). The British Thoracic Society and the European Respiratory Society highlight the importance of palliative care provision to manage the symptoms of mesothelioma and the need to offer emotional, psychological and spiritual support (Wiggins et al., 2007; Scherpereel et al., 2010). A guideline for supportive and palliative care for patients with lung cancer and mesothelioma has also been developed by the National Lung Cancer Forum for Nurses (Richardson 2013).

There is evidence that specialist palliative care improves the quality of life of patients with palliative care needs across a range of conditions, and at the same time reduces health system costs and resource utilization (Temel et al., 2010). However, a recent multicentre randomised controlled trial in the UK and Australia (the RESPECT trial) has shown that early routine specialist palliative care for patients recently diagnosed with malignant pleural mesothelioma does not have any additional impacts on quality of life over standard care (Brims, 2019). One reason for this finding may relate to differences in care systems, with patients in the UK and Australia potentially having their palliative care needs met by current care configurations. In the UK, an important but under researched innovation in patient care in this field is the introduction of the Mesothelioma UK clinical nurse specialist.

In the UK, clinical nurse specialists (CNSs) play a prominent role in supporting patients with palliative care needs, even if they do not have the term 'palliative care' in their job description or role title (Salamanca-Balen et al., 2018). CNSs have been found to demonstrate high levels of skill in managing complex conditions that give rise to palliative care needs (Seymour et al., 2002; Stilos & Daines, 2013). They positively influence patients' outcomes by providing care which improves communication, information provision and coordination of care (Corner et al., 2003; Knowles, 2007).

There is some evidence of the crucial role of CNSs in supporting patients and their families across the mesothelioma journey. One study showed that the continuity provided by a CNS has the potential to improve the quality of the diagnosis experience for mesothelioma patients and their families (Warnock et al., 2018). Further qualitative research has reported that the CNS facilitates communication within the multidisciplinary team and the relationship that the CNS develops with the mesothelioma patient and family members can help with anticipating communication needs across the diagnostic pathway (Taylor 2019).

The charity Mesothelioma UK¹ is dedicated to providing specialist mesothelioma information, support and education, and to improving care and treatment for all UK mesothelioma patients and their carers. One of the strategic aims of the charity is to ensure that specialist mesothelioma

¹ <https://www.mesothelioma.uk.com/>

nursing is available to all patients in need, by provision of funds for Mesothelioma UK CNSs (MCNS's). There are currently over 30 such nurses in post, regionally based throughout the UK. This is the first research study to explore the role of MCNSs in meeting the palliative care needs of mesothelioma patients and their families.

Research aims

- To understand how Mesothelioma UK clinical nurse specialists work to meet the palliative care needs of their patients.
- To describe the characteristics, needs, experiences and outcomes of patients with mesothelioma and their carers who receive Mesothelioma UK clinical nurse specialists care.
- To describe barriers and facilitators to palliative care in mesothelioma, from the perspectives of patients, carers and Mesothelioma UK clinical nurse specialists.
- To make recommendations to optimise palliative care delivery by Mesothelioma UK clinical nurse specialists.

Research questions

- What are the palliative care needs of patients with mesothelioma?
- What palliative care interventions are employed by Mesothelioma UK clinical nurse specialists?
- What is the range of service configurations relating to Mesothelioma UK clinical nurse specialist care?
- What skills and attributes do Mesothelioma UK clinical nurse specialists employ in the delivery of palliative care?
- What palliative care support and development needs do Mesothelioma UK clinical nurse specialists identify?
- What barriers and facilitators to palliative care are experienced by Mesothelioma UK nurses, patients and carers?
- What is the role of Mesothelioma UK clinical nurse specialists in supporting, empowering and advocating for patients with mesothelioma?

Chapter 1: Understanding the palliative care needs and experiences of people with mesothelioma and their family carers: An integrative systematic review

This chapter is published in full: Harrison M, Gardiner C, Taylor B, Ejegi-Memeh S, Darlison L. Understanding the palliative care needs and experiences of people with mesothelioma and their family carers: An integrative systematic review. *Palliative Medicine*. 2021;35(6):1039-1051. doi:10.1177/02692163211007379

Introduction

A better understanding of the palliative care needs and experiences of people with mesothelioma and their family carers is needed in order to inform decisions on what services need to be in place, who should provide them and at what time they should be offered. Compared with other cancers, mesothelioma poses unique complexities in terms of palliative care needs due to the rarity of the disease, the rapidity of decline (Zhang 2015) and the industrial nature of the disease, which is associated with the need for a legal inquiry by a coroner and protracted compensation claims processes (Kirkham 2011). In order to explore the existing evidence base about palliative care needs in mesothelioma we conducted a systematic review of published literature. The aim of this systematic integrative review was to identify and synthesise existing evidence on the palliative care needs and experiences of people with mesothelioma and their family carers and describe how their needs are being addressed.

Methods

Literature review question

What are the palliative care needs and experiences of people with mesothelioma and their family carers?

Design

An integrative systematic review methodology was employed to enable the inclusion of findings from a diverse range of methodologies (i.e. qualitative and quantitative) in this under researched topic. The review followed the procedures outlined in the Centre for Reviews and Dissemination (CRD) guidance. The review protocol is registered in PROSPERO: CRD42020190115. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) was used as the reporting guideline.

Search strategy

Electronic searches were undertaken using the following databases: MEDLINE, CINAHL, PsycINFO and the Cochrane Library. Core search terms included: mesothelioma and palliative care or end of life care or terminal care or supportive care or hospice. The search was limited to include papers published from 01 January 2000 to 10 May 2020. The terms were adapted for each database and MeSH terms were used, where possible. The reference lists of included papers were searched for potentially relevant articles.

Once duplicates had been removed, the title and abstract of all identified records were screened according to the inclusion and exclusion criteria shown in table 1 by one reviewer (MH); whilst a second reviewer (CG) independently screened ten percent of records to ensure the inclusion and exclusion criteria were being applied with good agreement. Full-text review was carried by two independent reviewers (MH and one other). Decisions were documented in separate databases and disagreements were resolved by consensus.

Inclusion criteria	Exclusion criteria
Empirical research studies (any research design) or comprehensive reviews including information about the palliative care needs* and experiences of people with mesothelioma and their family carers	Not focused on people with mesothelioma/ data from people with mesothelioma not presented separately
	No reference to the palliative care needs* or experiences of patients and families
	Conference proceedings/discussion articles/ commentary/ letters/ book chapters without a comprehensive literature review
	Published in a language other than English

Table 1. Inclusion and exclusion criteria (Palliative care need was defined as the capacity to benefit from palliative care)*

Data extraction, analysis and synthesis

The process of extracting and synthesising the data followed the integrative method described by Whitemore and Knafl (2005) which allows for the synthesis of findings from a diverse range of designs (qualitative, quantitative and reviews). Data reduction and extraction were conducted by one reviewer (MH) using a pre-defined pro forma, including the following: author(s); year of publication; country where study was conducted; study design; population; setting; sample; characteristics of included patients (age, sex, time since diagnosis); patients' palliative care needs and who identified them; family carers' palliative care needs and who identified them; and how palliative care needs were being addressed.

Quality appraisal

All studies included in the analysis were assessed for methodological quality. Each assessment was carried out by two independent reviewers (MH and one other). Where disagreements arose they were discussed and resolved through consensus. The Mixed Methods Appraisal Tool (MMAT) was used to appraise primary research. To appraise reviews, the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Systematic Reviews and Research Syntheses was used. The appraisal informed a narrative description of study quality and the weight placed on the findings of different studies in the data synthesis.

Results

A total of 508 articles were initially retrieved and 14 met the inclusion criteria.

Study characteristics

Table 2 shows a summary of the characteristics of the included studies along with a summary of the main findings relevant to this review. The included studies used a variety of different methodologies: quantitative (n=8), qualitative (n=5) and review (n=1). The majority of studies were conducted in the UK (n=6) or Australia (n=5), with others from Japan (n=2), Italy (n=1), and the United States (n=1).

Methodological quality

Overall, the methodological quality of the included studies was moderate to high. The qualitative studies included were generally of high methodological quality, but there was a lack of information about sampling strategies and little justification of sample size. The quantitative descriptive studies sometimes failed to ensure the sample was representative of the target population. The only randomised controlled trial was methodologically sound, but it was not possible to blind participants or the research team to group allocation due to the nature of the palliative care intervention. One of the quantitative non-randomised studies was methodologically sound, but the other attempted to evaluate effectiveness without a control group and did not account for any confounding factors. The only systematic review to be included in the review lacked a clear search strategy.

Main findings and key themes

The synthesis highlighted one cross cutting theme of 'uncertainty' and five themes within this: (1) organisation and co-ordination of services, (2) communication and information needs, (3) management of care needs and high symptom burden, (4) consideration of the impact of seeking compensation, and (5) family carer needs. Each of the five themes will be described in turn.

1) Organisation and co-ordination of services

The cross-cutting theme of uncertainty was described in relation to the diagnosis, prognosis and progression of mesothelioma across a number of qualitative studies (Arber 2013, Clayson 2005, Walker 2019) and a qualitative review (Ball 2016). This uncertainty and loss of control was compounded when patients also did not know who was co-ordinating their care. Care was described as fragmented and uncoordinated, with patients 'bewildered' by various doctors and patients left feeling that they were navigating the system on their own (Lee 2009). In addition, patients not receiving active anticancer therapy reported feeling abandoned by the system (Hughes 2008). Communication between hospital and community services was criticised in qualitative studies and a survey found communication between healthcare professionals was perceived to be variable, with 25% of patients stating that their health professionals talked to each other occasionally or hardly ever (Warby 2019). Studies have highlighted the need for people with mesothelioma to receive a co-ordinated, team-based approach to palliative care, whilst recognising that they need a named point of contact to provide some certainty about who is in charge of their care.

When describing the organisation of palliative care services for people with mesothelioma, studies often lacked clarity in terms of what they meant by palliative care, with few studies making a clear distinction between generalist and specialist palliative care (Brims 2019). However, the language used, such as 'referral' or 'access' to palliative care, demonstrate an underlying assumption, from authors and patient participants, that palliative care is provided by a separate, specialist team rather than by existing members of the patients clinical team. A number of articles made recommendations about the availability of palliative care suggesting early, timely, or more equitable access is needed. Routine early referral of patients with mesothelioma to specialist palliative care was evaluated in a randomised controlled trial, which found that it was not effective at improving

quality of life or mood in patients with good performance status compared with standard care (Brims 2019). Other studies recommending early referral to (specialist) palliative care provided this suggestion on the basis of qualitative reports of patients having to independently seek out a palliative care referral (Arber 2013, Hughes 2008) and poor pain management prior to referral (Mercadante 2016). Additionally, lack of palliative care input was found to be associated with patients expressing more suggestions for improvements in their medical care and increased likelihood of receiving chemotherapy in the last month of life (which represents poor oncology practice) (Kao 2013). However, it is important to note that in this review the need for early referral was not expressed directly by patients or clearly indicated by the findings. A recent survey conducted in Australia found that, of the patients who had not received palliative care, none felt that it could have helped them, whereas 13% of carers thought it would have been helpful (Warby 2019). Offering a palliative care referral at the time of diagnosis when patients felt overwhelmed with new information was perceived to be distressing in two qualitative studies (Hughes 2008, Clayson 2005).

In contrast, a more recent qualitative study shifts the emphasis from specialist palliative care referral to the role that nursing staff can play in providing supportive care (a term often used synonymously with palliative care) (Walker 2019). Nurses are recommended to support patients with malignant pleural mesothelioma to find meaning in their lives and encourage strategies for adapting to a “new norm”, as well as promoting control through healthy lifestyle choices, autonomous decision making and spiritual practices. This is consistent with a suggestion from another study that supportive care could be provided via an early opportunity for a home visit with a clinical nurse specialist or specialist palliative care nurse (Arber 2013). Where patients described the palliative care they had received, it was viewed as beneficial as it provided an opportunity to discuss their anxieties and help them to feel more prepared.

2) *Communication and information needs*

Most of the articles included in the review (n=9) described difficulties in accessing information to enable people with mesothelioma to make informed treatment decisions and/or poor communication practices between healthcare professionals and patients. The information and communication needs highlighted were described in relation to patients’ whole care experience, including palliative care, but not necessarily specifically about palliative care. Studies highlighted difficulties accessing reliable and accurate information (Lee 2009), and clear, understandable explanations (Walker 2019, Nagamatsu 2019). Patients also wanted to have an opportunity to express their illness story and valued the opportunity to be listened to by a healthcare professional; demonstrating the importance of two-way communication. Two studies highlighted the importance of developing relationships with other people with mesothelioma and a need to share their experiences with others in a similar position, where this was not available (Hughes 2008, Walker 2019).

The need for open and frank communication when conveying information about the curability, prognosis and progression of the disease was highlighted across multiple studies. In one survey, 35% of patients would have liked more information about what to expect from their disease, whilst 58% of carers would have liked more information about what to expect in caring for someone with malignant pleural mesothelioma (Warby 2019). A survey in Japan, found that whilst most participants (n=17) wanted clear and complete information about their disease and its prognosis, a smaller number (n=5) wanted the information to be delivered in a more indirect or vague manner (Nagamatsu 2014). These differences highlight the importance of a personalised approach to communication and information provision, which was also recommended in a recent qualitative

study (Nagamatsu 2019). In the same study, patients highlighted that they would like more information about how and when death might occur. The lack of clear information exacerbated feelings of uncertainty.

Information provision was perceived to be the role of healthcare professionals with one article describing the importance of staff being knowledgeable about mesothelioma and dedicated to its treatment (Nagamatsu 2019). Walker et al (2019) emphasise the key role that nursing staff play in communication by assessing information needs and providing personalised education. One article described an evaluation of an educational program on palliative care for patients with malignant pleural mesothelioma for nurses in Japan (Nagamatsu 2014). Nurse participants were highly satisfied with the program and its handbook and the evaluation suggested that the training reduced perceived difficulties experienced by nurses caring for people with mesothelioma. Quotes highlighted a desire to learn more about communicating with dying patients; lack of resources about how to provide palliative care for people with mesothelioma; and concerns around health care professional's knowledge of how to control symptoms and what medicines to prescribe.

3) Management of care needs and high symptom burden

The high symptom burden experienced by people with mesothelioma was widely described across the included articles. Mercadante and colleagues (2016) observed that patients had a consistently high physical and psychological symptom burden with patients scoring a mean sum of 37.7/100 on the Edmonton Symptom Assessment System at admission to home palliative care. A high prevalence of pain, weakness, poor appetite, poor well-being and dyspnea were noted. Three quarters of patients had pain (18 moderate, 2 severe) on admission despite having received high doses of opioids; pain was found to be associated with the amount of oral morphine delivered and dyspnea. Patients earlier in the disease trajectory expressed fears of uncontrolled pain, shortness of breath/suffocation and the process of dying, whereas those interviewed later in the trajectory redefined the meaning of their symptoms as the disease developed. The heavy symptom burden provided a constant reminder of disease progression and health status. The poor prognosis related to mesothelioma caused a dilemma for patients about whether to initiate and/or continue treatment given the limited gains offered and the considerable side effects associated with treatment. An observational study conducted in a single UK centre found 33% of people with mesothelioma chose active symptom control; the primary reasons for declining anti-cancer treatment were concerns over side effects, the modest survival benefit and previous negative chemotherapy experiences (Bibby 2017). Those choosing active symptom control were older (mean age 74 vs 68), had a poorer performance status and were more often female (24% vs 11%). Open and frank communication between physician and patient about when to cease chemotherapy was recommended, as it was found that patients who received chemotherapy at the end of life had shorter survival compared to those who did not. Furthermore, there was a non-significant trend for patients to die in their usual residence if they did not receive chemotherapy in the last month of life (Kao 2013).

Uncertainty and lack of control resulting from the incurable nature of the disease, lack of clarity around disease progression and when death would occur was perceived to be a primary cause of the emotional and psychosocial distress associated with mesothelioma. This was illustrated by descriptions of the diagnosis as a "death sentence" and narratives of existential distress relating to "loss of control not only of the body, but also of one's life" (Arber 2013). A qualitative review identified a theme of hopelessness across three mesothelioma studies due to the incurable nature of the disease and limited prognosis, whereas other studies noted acceptance of the terminal nature of the illness and hope for a cure or short/long term survival. Psychological symptoms described

included depression, anxiety and traumatic stress symptoms. Coping strategies employed by people with mesothelioma included: 'taking life one day at a time'; engaging with spiritual or religious rituals and support; focusing on making the best use of time left; and exploring fears and anxieties with a health care professional. Furthermore, some articles described patients employing practical strategies such as putting their financial affairs in order to make the future more predictable, or to reduce the burden on family (Ball 2016, Clayson 2005, Walker 2019).

4) Consideration of the impact of seeking compensation

As a disease commonly caused by occupational exposure to asbestos, most people with mesothelioma are eligible for compensation. An Australian survey, that included a compensation scheme as a source of recruitment, found that 97% of participants sought compensation and most participants had learned compensation might be an option from a doctor (62%) (Warby 2019). For one patient, who received information about seeking compensation at the time of diagnosis, it was perceived that this was too early as they were overwhelmed by information at that time. The main reasons described for seeking compensation were to 'leave their family financially secure' (67%), for 'justice' (59%) and because they 'needed money to help with treatment costs' (30%) (Warby 2019). As an industrial disease, one study found that patients wanted their doctors to view them as a victim of asbestos, whereas another described the dilemma of whether to seek compensation from a longstanding employer to whom they felt significant loyalty. Several qualitative studies described how the additional burden of seeking compensation aggravated an already difficult situation. The terminal nature of the diagnosis meant that what limited time the patient had left had to be spent meeting lawyers, completing forms and finding relevant documents and evidence of asbestos exposure (Ball 2016). Furthermore, due to the high symptom burden of the disease it was described that seeking compensation had to be a joint effort between the patient and carer, as there are times when the patient was too unwell to pursue the claim. Moreover, whether or not they would actually receive the compensation was another source of uncertainty.

5) Family carer needs

The needs of family carers were described in four of the included papers (Warby 2019, Brims 2019, Lee 2009, Hughes 2008). The only randomised controlled trial included in the review identified that routine early referral to specialist palliative care significantly improved carer satisfaction compared to usual care (Brims 2019). Specifically there was increased satisfaction reported with the emotional support provided to family members by the specialist palliative care team, as well as other items related to how the carer perceived care was provided to the patient in terms of: attention to symptoms, management of symptoms, response to symptom changes and emotional support. A survey identified that 31% of carers would have liked clearer information about malignant pleural mesothelioma (Warby 2019) and a qualitative study highlighted the need for information around intimacy as symptoms progressed (Hughes 20087). Moreover, family carers would have liked the opportunity to talk to a healthcare professional by themselves, more time with doctors and access to psychological support. In the studies that included bereaved relatives of people with mesothelioma, concerns were expressed about the lack of bereavement services; bereaved relatives felt they would have benefitted from grief counselling and/or a post-death consultation with a medical or palliative care specialist (Warby 2019, Lee 2009).

Table 2. Summarised results of the studies assessed in this systematic review.

First author, country and year	Study aim	Study design and methodology	Population, setting and sample size	Main findings
Arber et al, UK, 2013	To explore the patient's experience during the first 3 months following a diagnosis of malignant pleural mesothelioma (MPM)	Qualitative Grounded theory	MPM patients recruited from 2 hospitals N=10	The key concept was 'uncertainty and lack of control', which was underpinned by three themes: it's all bad news, good days and bad days and strategies of amelioration. Participants described worries about long-term outcome and speed of deterioration even in the early stage after diagnosis. One participant described seeking referral to palliative care. Palliative care referral was a positive experience/ turning point. Patients' lack of control was added to by not understanding who was in charge of their care.
Ball et al, UK, 2016	To establish whether the psychological needs of patients with pleural mesothelioma are the same as patients with advanced lung cancer	Review Meta ethnography	17 articles, including 5 with MPM patients only and 9 with advanced lung cancer only and 3 mixed MPM and lung cancer N=unknown	Common themes across the studies were grouped into ten 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. Lack of referral to specialist palliative care and supportive care provision was noted as a particular issue for those with MPM. Those with MPM expressed concern about death and the process of dying. As well as the need to ensure their affairs were in order to reduce the burden on family.
Bibby et al, UK, 2017	To describe the characteristics of patients who chose active symptom control over chemotherapy and explore their reasons for doing so	Quantitative Prospective observational study	MPM patients recruited from 1 hospital N=139	Active symptom control was chosen by 33% of participants. Participants choosing active symptom control were older, had poorer performance status and were more often female. Reasons for choosing active symptom control included: benefits of

				chemotherapy did not justify the risk of side effects (5/15), a desire to prioritise quality of life in the context of no current symptoms (4/15), needle/hospital phobia (3/15), prior negative experiences of chemotherapy (2/15), pursuit of experimental treatment in another country (1/15). Reasons were only documented for one third of participants who chose active symptom control.
Brims et al, Australia and UK, 2019	To examine the effect of regular early specialist palliative care on HRQoL in patients with MPM and their carers compared with standard care alone	Quantitative Randomised controlled trial	MPM patients and their carers recruited from 19 UK hospitals and 1 large Australian site N=174 patients N=145 carers	Routine early referral to specialist palliative care did not result in a statistically significant difference in quality of life or mood at 12 and 24 weeks post-randomisation for patients with a good performance status when compared to standard care alone. Carer satisfaction with end-of life care was measured using the FAMCARE-2 questionnaire. Scores were significantly higher in the intervention arm at 12 and 24 weeks indicating that routine early referral to specialist palliative care was helping to meet the needs of carers compared with standard care.
Clayson et al, UK, 2005	To describe the experience of mesothelioma and its meaning for patients	Qualitative Grounded theory	MPM patients recruited from 3 hospitals N=15	The findings were described across 4 themes: coping with symptoms, the burden of medical interventions, finding out about mesothelioma, and psychosocial issues. The offer of palliative care from a Macmillan nurse at the time of diagnosis was distressing and provoked fear. Symptom burden provided a constant reminder of disease progression. Some patients demonstrated acceptance of the terminal nature of the diagnosis, others made plans to deal with their death and possessions. The benefit and compensation process aggravated the situation and persists for relatives after the patients die.

Dooley et al, Australia, 2010	To investigate the specific psychological consequences of mesothelioma	Quantitative Retrospective observational study	Mesothelioma patients recruited via a lawsuit filed against their employer N=49	People with mesothelioma reported higher levels of depression and anxiety and significantly more traumatic stress symptoms than the normative group for the Trauma Symptom Inventory. The symptom cluster related to the re-experiencing domain suggests that the physical manifestation of the illness served as a constant reminder of health status. Clinical interviews highlighted the financial pressure that their illness had placed on their family.
Hughes et al, UK, 2008	To explore patients' lived experience of mesothelioma	Qualitative Phenomenological approach	MPM patients recruited from local palliative nursing service (Macmillan) referrals N=5	Six themes were identified: physical effects, loss of intimacy, isolation, pursuing compensation, sharing experiences and supportive care. The majority of supportive care was sought out by patients from GPs, specialist palliative care or psychological services. Participants wanted the right support at the right time and suggested that they could not take in information about supportive/palliative care in the early stages due to the overwhelming amount of information provided. Pursuing compensation dictates how limited time together is spent and requires a joint effort between the patient and carer. Carer's need the opportunity to speak with healthcare professionals in confidence, alone.
Kao et al, Australia, 2013	To determine the proportion of MPM patients who received active anticancer treatments in the last month of life and identify potential factors associated with chemotherapy use	Quantitative Retrospective observational study	MPM patients recruited from compensation scheme (Dust Diseases Board of New South Wales) N=147	Patients who received two or more lines of chemotherapy were more likely to be receiving chemotherapy in their last month of life. Patients who received chemotherapy at the end of life had shorter survival compared to those who did not receive chemotherapy at the end of life. Authors suggest careful consideration of when to cease chemotherapy is required, including timely and frank discussion with the patient and their family. There was a trend for

				lack of palliative care involvement to be associated with use of chemotherapy in the last month of life.
Lee et al, Australia, 2009	To describe the needs and experiences of people with mesothelioma and asbestos-related lung cancer, their carers, and service providers in the Latrobe Valley community	Qualitative Descriptive case study	Patients with mesothelioma and asbestos related lung cancer, carers and healthcare/ legal professionals recruited from advertisements Mesothelioma patients N=2 Carers N=6 Professionals N=5	Three main themes: illness experience, carer and family roles, and services and service gaps. Referral to palliative care occurred late in the illness due to discomfort associated with acknowledgement of dying, which resulted in poor symptom control and a lack of support for carers. A lack of holistic and co-ordinated care was described, as well as difficulty accessing reliable and accurate information. The effort and time required to seek compensation was particularly burdensome given the declining health of the patients. Carers expressed concerns about the lack of bereavement services. One carer described palliative care nurses as “the angels of death”.
Mercadante et al, Italy, 2006	To examine the epidemiological characteristics and symptom burden of mesothelioma patients when admitted to home palliative care	Quantitative Retrospective observational study	Mesothelioma patients recruited from a home palliative care service N=56	Patients had a consistently high physical and psychological symptom burden (depression and anxiety). Three quarters of patients had pain (18 moderate, 2 severe) despite receiving high doses of opioids. The principal pain site was the chest. Pain was significantly associated with the amount of oral morphine delivered and dyspnea. The average duration of home palliative care admission was 54.8 days (which corresponded with death for all except two participants). Authors thought pain management could have been improved if patients were referred to palliative care earlier.
Nagamatsu et al, Japan, 2014	To evaluate the effect of both the Educational Program on Palliative Care for Patients with MPM and the Palliative	Quantitative Prospective pre-test post-test	Nursing staff recruited nationwide from hospitals, home visiting nurse stations and health care centres	The educational program on palliative care for MPM for nurses was effective in reducing perceived difficulties experienced by nurses caring for patients with MPM. Post-test difficulty scores were lower than the pre-test scores. Participants positively evaluated

	Care for MPM Handbook for Nurses in Japan		N=27	the educational program for validity, clarity, clinical usefulness and the facilitators. Quotes from the evaluation provided information about the educational needs of staff to enable them to meet the palliative care needs of mesothelioma patients: physicians lack of knowledge about what medicines to prescribe; the lack of information/handbooks on the topic; the desire to learn more about communication with a dying patient; concern about 'failure' to control symptoms.
Nagamatsu et al, Japan, 2019	To determine the needs of patients within the health service by quantifying the requests to their physicians and qualitatively analysing their responses	Quantitative Retrospective survey	MPM patients recruited nationwide from cancer hospitals and support groups N=73	Patients with MPM had a variety of unmet needs from their physicians. Patients wanted clear and understandable explanations about MPM, particularly in relation to the curability and prognosis of the disease. Participants wanted their physician to deliver treatment based on the patient's perspective by accepting and empathizing with their anxiety and pain. Physicians conveying information about the benefits of palliative care and advising the patient to introduce it at an early stage was perceived to be helpful as it gave the patient time to prepare. Patients who did not receive palliative care made more physician requests than those who received palliative care.
Walker et al, United States, 2019	To explore the lived experience of MPM in the United States and identify unmet patient needs	Qualitative Phenomenological approach	MPM patients recruited from University medical centre N=7	Three major themes: uncertainty/worry about the future, value in relationships and adapting to a new norm. Uncertainty/worry about the future stemmed from a lack of clarity about when the MPM would progress and how or when death would occur. Awareness of the incurable nature of the condition was referred to as a 'death sentence', and the most common coping strategy was 'taking life one day at a time'. Some employed practical strategies by making

				<p>advanced preparations. Patients expressed concern about symptom management at the end of life, particularly in relation to pain and breathlessness. MPM patients preferred a personalised, coordinated, team based approach with open and honest communication. Worries about loss of control at the end of life were expressed. Spiritual or religious rituals and support helped participants to maintain a sense of control.</p>
<p>Warby et al, Australia, 201</p>	<p>To document the experience of MPM patients and their caregivers</p>	<p>Quantitative Retrospective survey</p>	<p>MPM patients and their informal carers recruited from support groups nationwide, a regional compensation scheme, and advertisements in 2 hospitals Patients N=78 Carers N=106</p>	<p>A palliative care referral had been received by 31% of patients, compared to 85% of caregivers (many were bereaved). Of the patients who had not received palliative care, none felt it could have helped them, but 13% of carers whose patients did not receive palliative care felt it could have helped them. The majority of participants received 'sufficient' support (71%). 35% of patients would have liked more information about what to expect with their disease. Almost all patients sought compensation for their MPM (97%). Caregivers would have liked to talk to someone by themselves (41%), more time with doctors (30%), access to psychological support (29%), and clearer information (31%). Bereaved caregivers requested grief counselling (39%) and a post-death consultation with a medical (25%) or palliative care specialist (23%).</p>

Discussion

This systematic integrative review presents an overview of the palliative care needs of people with mesothelioma and their families. This review demonstrates that people with mesothelioma and their carers have a wide range of palliative care needs. The needs of patients and carers were underpinned by a cross-cutting theme of uncertainty and categorised into five areas of need/themes: (1) organisation and co-ordination of services, (2) communication and information needs, (3) management of care needs and high symptom burden, (4) consideration of the impact of seeking compensation, and (5) family carer needs.

The review revealed the need for a co-ordinated and team-based approach to palliative care, to ensure patients receive seamless care. Open and frank communication around the curability, prognosis and progression of the disease is crucial, but information should be individualised to each patient's needs. Patients and carers should be given the opportunity to explore their fears and anxieties and prepare themselves for the end of life both emotionally and practically. In addition, the process of seeking compensation compounds an already difficult situation by dictating how the limited time the patient and carer have left together is spent. Studies detailing the needs of family carers found they would like the opportunity to speak with a healthcare professional alone and bereaved relatives felt they would have benefitted from grief counselling or a post-death consultation with a doctor.

The conflicting findings around the importance of early referral to specialist palliative care warrants further investigation into partnership working and the role thoracic, oncology and mesothelioma teams play in providing generalist palliative care.

Chapter 2: Secondary analysis of the MORE survey data relevant to palliative care

Introduction

Chapter one summarised and described the palliative care needs of patients with mesothelioma and their families. However, the ways in which MCNS's support patients with palliative care needs remains unknown. Previous evidence suggests that CNSs in the UK can improve the experience of care among patients with mesothelioma (Warnock et al., 2018), help with anticipating communication needs (Taylor 2019), and improve the experience of diagnosis (Taylor 2019). Internationally, evidence suggests CNSs have an important role in palliative care provision, supporting patients with a wide range of conditions. CNS interventions have been found to be effective in reducing health care resource use such as hospital admissions, re-hospitalization, length of stay and health care costs (Salamanca-Balen 2018). CNSs may have the potential to enhance quality at neutral or lower costs to health care systems while enhancing or delivering similar clinical or patient-reported outcomes.

In spite of this body of international evidence, patients with mesothelioma in the UK have previously had variable access to CNS support (either from an MCNS or a lung CNS). For example, the National Mesothelioma Audit report in 2018 (for the audit period 2014-16 in England and Wales) showed that in England, only 54% of patients were recorded as being assessed by a CNS, with significant variation by region. The Royal College of Physicians has described the role of the CNS as 'pivotal' in the care of patients (Royal College of Physicians, 2018a). For patients with mesothelioma, they recommend a target of 90% receiving an assessment by a CNS and, and 80% receiving CNS support at the time of diagnosis (Royal College of Physicians, 2018b).

The Mesothelioma Outcomes, Research and Experience (MORE) survey was conducted by Mesothelioma UK in 2019 (Mesothelioma UK, 2020). MORE was a UK based observational prospective cross-sectional survey to collect data on patient experience in mesothelioma and support received from an MCNS. Data was collected from patients about their experiences of mesothelioma, their health-related quality of life and current clinical management. This chapter begins by describing how the data was collected and analysed. Following an overview of participant demographic information, insights gained from the quantitative data analysis relevant to palliative care are presented across three themes; MCNS input, palliative care provision and symptom management.

Methods

Data collection

The cross-sectional MORE survey was completed by people with mesothelioma across the United Kingdom (UK). People with mesothelioma were invited to complete the survey whilst attending hospital appointments or support groups either using the MCNS's digital tablet, requesting a weblink via email or using a paper version available from Mesothelioma UK and MCNSs.

The questionnaire for the MORE survey was developed by Mesothelioma UK, before being piloted with volunteer patients and amended based on their feedback. The survey comprised questions about: 1) patient experience of care and treatment, 2) quality of life, and 3) details of the individual

clinical management of mesothelioma patients. The first two sections were completed by the patient, whilst the third section was completed by the patient and validated by an MCNS.

The data was collected as part of a service evaluation and each MCNS registered the survey with their NHS Trust Clinical Audit team.

Analysis

Descriptive statistics (frequency and percentages) were calculated in SPSS v26 for questions from section 1 relevant to the patient's relationship with an MCNS, the provision of palliative care and symptom management. Some preliminary analyses were undertaken to explore if any relationships existed between the different variables but due to a large proportion (>50%) of respondents selecting the options stating that they did not need palliative care support at home or that end of life planning was not applicable these analyses were not included.

Results

Response rate and missing data

Of the 662 questionnaires distributed, 510 were returned resulting in a response rate of 77%. 505 responses were validated by an MCNS and two respondents were not included due to missing data.

Demographic information

The majority of responders were over the age of 70 (57.5%), and only a very small number were under the age of 50 (3.8%). Of the responders who specified their gender, the majority were male (80.1%). Responders came from England (90.4%), Scotland (6.4%) and Wales (3.2%).

Clinical nurse specialist input

Awareness of MCNSs was high amongst patients and they were perceived to be accessible and communicate clearly (see table 3). The majority of respondents had been informed of the name of a MCNS (70%) or other specialist nurse (19.3%) or key worker (1.6%). Almost 70% of respondents were informed about a Mesothelioma UK funded CNS, with 60% identifying that the MCNS nurse was their specialist nurse. Other respondents were not informed (21.8%) or did not know/remember (8.3%). Most respondents (90.4%) perceived that it was easy to contact their nurse specialist and felt that when they spoke to their nurse specialist they were able to answer questions in an understandable way (94.9%).

Table 3. Access to and support provided by specialist nurses

Clinical nurse specialist input	n (valid %)
<i>Informed of the name of specialist nurse</i>	
Yes, Mesothelioma UK Nurse	352 (70)
Yes, other Nurse Specialist	97 (19.3)
Yes, other keyworker	8 (1.6)
No	26 (5.2)
Don't know / I can't remember	9 (1.8)
No response	11
<i>Informed of a Mesothelioma UK funded nurse</i>	

Yes, my nurse specialist is a Mesothelioma UK Nurse	297 (60)
Yes, I was informed by my nurse specialist or other keyworker	49 (9.9)
No, I was not informed	108 (21.8)
Don't know / I can't remember	41 (8.3)
No response	8
<i>How easy was it to contact your nurse specialist?</i>	
Very easy	324 (66)
Fairly easy	120 (24.4)
Not very easy	20 (4.1)
Very difficult	5 (1)
Don't know/ I can't remember	22 (4.5)
No response	12
<i>Does your nurse specialist answer important questions in an understandable way?</i>	
Yes, completely	420 (84.8)
Yes, to some extent	50 (10.1)
No	11 (2.2)
Don't know/ I can't remember	14 (2.8)
No response	8

Palliative care provision

The majority of respondents (63.3%) perceived that support from a community palliative care nurse had not been needed (see table 4). Of those who felt community palliative care had been needed (n=183), 56.8% patients had received support, 16.4% had received support to some extent and 26.8% had not received input. Most respondents (73.4%) did not feel they required support in relation to end of life care planning, at the time of survey completion. Of those who perceived it was applicable (n=132), 37.9 % of respondents had not received support in relation to planning care for the end of life, 32.6% had received support, 25% did not want to discuss it and 4.5% could not remember.

Due to mesothelioma being an industrial disease, all patient deaths are referred to the coroner. The majority of respondents or their family members (66.2%) were not informed about the role of the coroner or procurator fiscal (in Scotland).

Table 4. Palliative care provision for people with mesothelioma across the UK

Palliative care provision	n (valid %)
<i>Was support received from a community palliative care nurse (e.g. Macmillan Nurse)?</i>	
Yes	104 (20.9)
Yes, to some extent	30 (6)
No	49 (9.8)
No, support at home has not been needed	315 (63.3)
No response	5
<i>Was support received in relation to planning care towards the end of life?</i>	

Yes	43 (8.7)
No	50 (10.1)
Did not want to discuss it	33 (6.6)
Don't know/ I can't remember	6 (1.2)
Not applicable at present	365 (73.4)
No response	6
<i>Were you or a family member informed about the role of the coroner / procurator fiscal?</i>	
Yes	136 (27.4)
No	329 (66.2)
Don't know/ I can't remember	32 (6.4)
No response	6

Symptom management

Participants were asked whether hospital doctors and nurses did everything they could to control four of the main symptoms of mesothelioma: breathlessness, fatigue, cough and pain. More than half of participants had experienced breathlessness (63.7%), fatigue (63.9%) or pain (61.7%), with fewer experiencing a cough (41%) (see table 5). Coughing was the least well controlled symptom with 20.6% of respondents reporting that hospital doctors and nurses did not do everything they could to control their coughing, followed by fatigue (16%), breathlessness (7.2%) and pain (1.3%).

Table 5. Provision of symptom management for people with mesothelioma across the UK

Symptom management	n (valid %)
<i>Did hospital doctors and nurses do everything they could to help control any breathlessness?</i>	
Yes, they did	216 (43.3)
Yes, to some extent	79 (15.8)
No, they didn't	23 (4.6)
I haven't had this symptom	181 (36.3)
No response	4
<i>Did hospital doctors and nurses do everything they could to help control any fatigue?</i>	
Yes, they did	169 (33.9)
Yes, to some extent	99 (19.8)
No, they didn't	51 (10.2)
I haven't had this symptom	180 (36.1)
No response	4
<i>Did hospital doctors and nurses do everything they could to help control any coughing?</i>	
Yes, they did	107 (21.5)
Yes, to some extent	55 (11.1)
No, they didn't	42 (8.5)
I haven't had this symptom	293 (59)
No response	6
<i>Did hospital doctors and nurses do everything they could to help control my pain?</i>	

Yes, they did	241 (48.5)
Yes, to some extent	63 (12.7)
No, they didn't	4 (0.8)
I haven't had this symptom	191 (38.4)
No response	4

Discussion

This analysis of the 2019 MORE survey indicates that the vast majority of mesothelioma patients were aware of their MCNS, and satisfaction with the MCNS role was generally high. It should be acknowledged that the recruitment strategy for the MORE survey may have biased responses as many participants were recruited via an MCNS, and therefore patients who did not have an MCNS were less likely to participate. Nonetheless, these findings provide some preliminary evidence that support from an MCNS is valuable to patients and their families, a finding supported by evidence from CNS's in other conditions (Salamanca-Balen 2018). A recent integrative review firmly established the CNS as a valuable member of the multidisciplinary team in enhancing cancer care services, contributing to improving patient outcomes with regards psychological support, information provision, symptom management, service coordination and patient satisfaction (Kerr 2021). Our findings broadly align with the findings from this review.

The high proportion of patients with a named MCNS is encouraging from a palliative care perspective, as patients requiring palliative care can particularly value continuity of care and a single point of contact (Harrison 2021, Nazareth 2008). However, a high proportion of respondents did not feel that that palliative care and/or end of life planning was needed at the time of survey completion. This may reflect the fact that some respondents were at an early stage in their disease trajectory and receiving anti-cancer treatment or were enrolled in clinical trials. Alternatively, it may reflect a reluctance to engage with palliative care due to connotations with death and dying, and public perceptions of palliative care as synonymous with death (Gill 2021). Societal taboos which dissuade many from discussing or acknowledging death undoubtedly contribute to this reluctance to engage with palliative care.

In terms of symptom management, pain was the symptom perceived to be best controlled by hospital doctors and nurses, with other key symptoms generally well controlled in the majority of patients. Again, this may be reflective of participants who responded to the survey, who may have represented the 'most well' mesothelioma patients. An alternative explanation suggests effective collaborative and multi-disciplinary working between the various clinical providers involved in caring for patients with mesothelioma. MCNS's are central to supporting patients and managing symptoms, and are key providers of generalist palliative care. However, their central involvement with a patient also means they are well positioned to co-ordinate a patient's care, referring on to specialist teams to help effectively manage symptoms as they become more complex. This indicates a possible duality in the role of MCNS; providing palliative care themselves but also acting as a central co-ordinator for other services.

Chapter 3: Survey of palliative care provision delivered by mesothelioma clinical nurse specialists

Introduction

The MORE survey data presented in chapter two indicates that MCNSs are central to supporting patients and their families, are key providers of generalist palliative care and have important roles in relation to symptom management and coordination of care. These insights were gained from quantitative data collected from mesothelioma patients. The next stage of the study therefore sought the perspectives and experiences of MCNSs themselves regarding the palliative care they provide to mesothelioma patients and their families. While evidence consistently supports the role of CNS in palliative care provision, the role is not clearly articulated and the palliative care expertise of CNS's is not always acknowledged (Salamanca-Balen 2018). Moreover, evidence specific to mesothelioma CNS's is limited. In recent studies MCNS's have been reported as contributing to communication needs (Warnock 2018), care co-ordination, symptom management, treatment options and supporting quality of life (Tod 2014, Taylor 2019). Whilst these are all areas of care that fall within the remit of palliative care, the explicit role that MCNS's play in providing palliative care, and the range of palliative care interventions they employ, have not been explored until now.

This chapter describes the collection and analysis of survey data from MCNSs about their role in palliative care provision.

Method

Study design

A descriptive cross-sectional design was selected to survey MCNSs across the United Kingdom (UK). The purpose of the online survey was to describe: 1) the demographics of the MCNS workforce; 2) education and training in palliative care; 3) provision of palliative care; 4) confidence in delivering palliative care; and 5) difficulties in delivering palliative care to mesothelioma patients. Ethical approval was obtained from the School of Nursing and Midwifery research ethics committee at the University of Sheffield (reference: 036461).

Sample and recruitment

All MCNSs were invited by email to participate in the online survey. MCNSs are a relatively recent innovation, their role includes providing holistic support from diagnosis to the end of life through symptom control and the provision of information and support. The email was sent by a member of the operational team at Mesothelioma UK. The invitation email included a link to the information sheet and online survey. The survey was open for six weeks (21 October 2020 - 02 December 2020) and two reminder emails were sent to all MCNSs during that time.

Data collection instrument

The online survey was developed using Google Forms. It included a number of questions designed by the study team to collect demographic information, details of education and training, aspects of palliative care provided by MCNSs and details of the other professionals they work with to deliver palliative care. Additionally, two existing scales were included in the survey: 1) Palliative Care

Delivery Confidence (Frey 2014) and 2) Difficulties in Palliative Care for Patients with MPM (DPCMPM) Scale (Nagamatsu 2014).

The Palliative Care Delivery Confidence scale, which has been demonstrated to have good reliability and validity, includes three items: identifying when a palliative approach should begin; deciding when a referral to specialist palliative care services should be made; and providing palliative care. Responses are provided through numerical rating scales with responses ranging from not confident at all (1) to extremely confident (10). Scores for the overall scale range from three to thirty, with high scores indicating greater perceived confidence (Frey 2014).

The DPCMPM scale measured the difficulty of delivering different aspects of palliative care and was developed by a team of healthcare professionals with experience of caring for people with mesothelioma, thus conferring some content validity (Nagamatsu 2014). The 15-item self-report inventory includes questions about the difficulties of symptom management and maintenance of quality of life, spiritual care, care of family and care coordination of medical services for patients with Malignant Pleural Mesothelioma. We broadened the use and asked more generally about patients with all types of mesothelioma. The purpose of including the inventory was to determine whether there were any aspects of palliative care provision for people with mesothelioma that were perceived to be particularly difficult. Each item was scored on a 5-point Likert scale (very difficult=5; difficult=4; neutral=3; not difficult=2; not at all difficult=1).

The survey was developed in collaboration with Mesothelioma UK to ensure the relevance of the clinical content. The survey was also piloted with two members of the research team to resolve any issues with the wording and formatting. The survey took approximately 15 minutes to complete and responses were recorded automatically using Google Forms.

Data analysis

The survey data collected via Google Forms was exported into Excel and anonymised before being imported into SPSS v26 for analysis. Descriptive statistics (frequencies, percentage tables, mean, standard deviation [SD]) were employed. The qualitative data from the small number of open-ended questions was summarised and described narratively.

Results

Survey response rate and data completeness

A total of 29 MCNSs were eligible for inclusion in the survey. Of the eligible population, 23 (79.3%) MCNSs completed the survey. There were originally 24 responses, but we identified one duplicate response (identical email address provided), which was removed prior to analysis. No missing data were identified.

Demographic information

The majority of MCNS respondents were female and aged between 45 and 54 (see table 6). Most of the participants were employed at band 7 on the NHS agenda for change pay structure, which is indicative of the seniority of role (nursing roles start at a band 5). The vast majority of MCNSs were based in a hospital setting. Approximately half of the respondents had previously worked in specialist palliative care. The MCNS respondents had been working with patients with mesothelioma for a mean of 16.6 years (SD=7.2), but had only been in their role as an MCNS for a mean of 3.9 years (SD=4.3), which is reflective of the role having only been established by Mesothelioma UK in recent years.

Table 6. Demographic profile of Mesothelioma UK CNS survey respondents

Demographic characteristics	n (%)
<i>Age group</i>	
35 - 44	4 (17.4)
45 - 54	12 (52.2)
55 - 64	7 (30.4)
<i>Gender</i>	
Male	1 (4.4)
Female	22 (95.7)
<i>Agenda for Change pay band</i>	
Band 6	1 (4.4)
Band 7	15 (65.2)
Band 8	7 (30.4)
<i>Setting</i>	
Hospital	21 (91.3)
Hospital and community	2 (8.7)
Community	0 (0)
<i>Previously worked in specialist palliative care</i>	
Yes	11 (47.8)
No	12 (52.2)

Education and training

All 23 (100%) MCNS respondents had received some training or education in palliative care. The type of training received is documented in table 7. Of the 65% who had attended palliative care training or a course, most MCNSs (n=8) described study days which were primarily offered in-house, with topics including: end of life care, symptom management/control and communication/difficult conversations (including do-not-resuscitate order conversations). Other training included: masters level modules (n=3), specific palliative care qualifications (n=2), conference attendance (n=1).

Table 7. Type of training or education in palliative care received by Mesothelioma UK CNSs

Training or education in palliative care	n (%)
Attended palliative care training or course	15 (65.2)
MSc	7 (30.4)
Worked in a hospice	7 (30.4)
Worked in other specialist palliative care setting (not hospice)	7 (30.4)
Diploma in Palliative Care	5 (21.7)
Shadowing	4 (17.4)
Placement	3 (13.0)
PhD	0 (0)

All but one respondent (n=22; 95.7%) would take up training in palliative care if it were offered. The respondent who would decline the offer of palliative care training felt that the course they had attended was sufficient for their role, but they would attend an update. Of the 22 respondents who would take up palliative care training the preferred format was an online course (n=19; 82.6%),

followed by a face-to-face course (n=16; 69.6%), then experience working within a specialist palliative care setting (n=8; 34.8%). Participants were allowed to select more than one format. Two participants specified other formats, including updating current knowledge and being provided with the opportunity to participate in reflective practice.

Provision of palliative and end of life care for patients with mesothelioma and their families

In order to provide a more detailed description of the palliative care provided to mesothelioma patients we asked the MCNSs about which healthcare professionals provide palliative care and who MCNSs refer to when palliative care input is required (see table 8). All MCNS respondents (100%) felt that it was their role to advise on the generalist palliative care needs of patients with mesothelioma and their families, and the vast majority of MCNS respondents (95.7%) felt that it was their role within the clinical team to provide generalist palliative care. It was perceived that the team member primarily responsible for addressing generalist palliative care need was the MCNS (52.2%), whereas specialist palliative care nurses were most commonly identified as being responsible for addressing the patient’s specialist palliative care needs (43.5%). The most common teams to refer to for palliative care of mesothelioma patients were the community specialist palliative care team, local hospital specialist palliative care team and local hospice palliative care team.

Patients with mesothelioma are commonly entitled to compensation and benefits due to the industrial nature of the disease. The organisations MCNSs most frequently work with/refer to when providing information about compensation and benefits were asbestos support groups and Mesothelioma UK welfare and benefits advisors. Other organisations that MCNSs refer patients to for advice around compensation and benefits identified in the free-text comments included: Veterans UK and Macmillan information and support service/benefit advice.

MCNSs rated the quality of the palliative care provided to mesothelioma patients. On a scale of 1-10 (10=excellent), MCNSs rated the quality of specialist palliative care slightly higher (M=8.09, SD=1.38) than the quality of generalist palliative care (M=7.39; SD 1.64). The range of responses for quality of specialist palliative care is shown in figure 1 and generalist palliative care in figure 2.

Table 8. Provision of palliative care for patients with mesothelioma and their families

Provision of palliative care for patients with mesothelioma	n (%)
<i>MCNS role to ‘provide’ generalist palliative care</i>	
Yes	22 (95.7)
No	1 (4.4)
<i>MCNS role to ‘advise’ on generalist palliative care</i>	
Yes	23 (100)
No	0 (0)
<i>Team member primarily responsible for addressing ‘generalist’ palliative care needs</i>	
Mesothelioma CNS	12 (52.2)
Team effort	9 (39.1)
Lung cancer CNS	2 (8.7)
<i>Team member primarily responsible for addressing ‘specialist’ palliative care needs</i>	

Specialist palliative care nurse (e.g. Macmillan)	10 (43.5)
Team effort	6 (26.09)
Mesothelioma CNS	5 (21.7)
Palliative care physician	1 (4.4)
It varies too much to say	1 (4.4)
<i>Services MCNSs usually refer mesothelioma patients to for palliative care</i>	
Community Specialist Palliative Care team	23 (100)
Local hospital specialist palliative care team	23 (100)
Local hospice specialist palliative care team	22 (95.7)
Intensive home nursing service / hospice at home	11 (47.8)
Breathlessness service	11(47.8)
Psycho oncology team	11 (47.8)
Community support workers / social prescribing / voluntary sector	10 (43.5)
Chaplaincy	10 (43.5)
24/7 palliative care hub or other 24/7 helpline	9 (39.1)
<i>Organisations MCNSs work with/refer to when providing information about compensation and benefits</i>	
Asbestos support groups	22 (95.6)
Mesothelioma UK welfare & benefits advisors	18 (78.3)
Specialist lawyers	12 (52.2)
Citizens Advice	4 (17.4)

Figure 1. Mesothelioma UK CNS perceptions of the quality of generalist palliative care provided to patients with mesothelioma

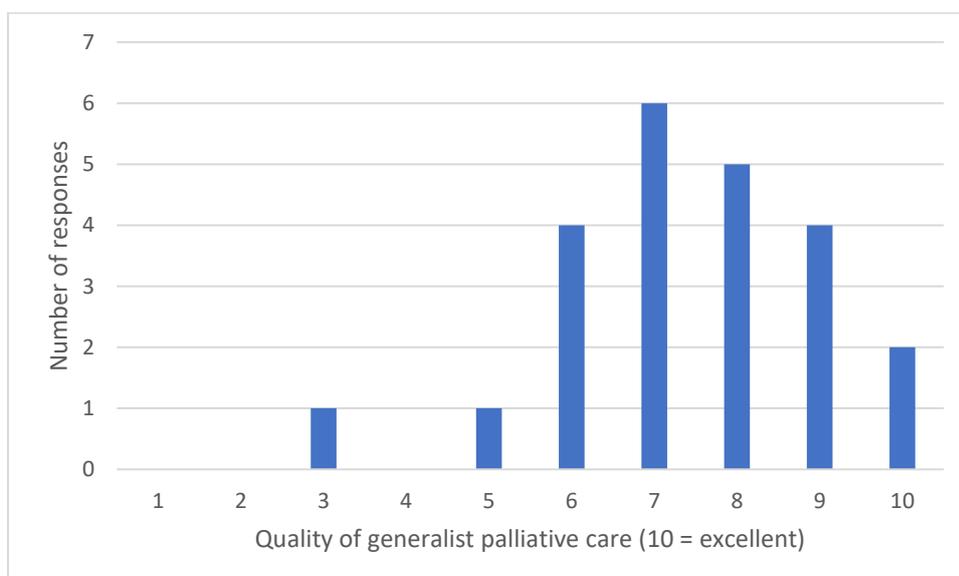
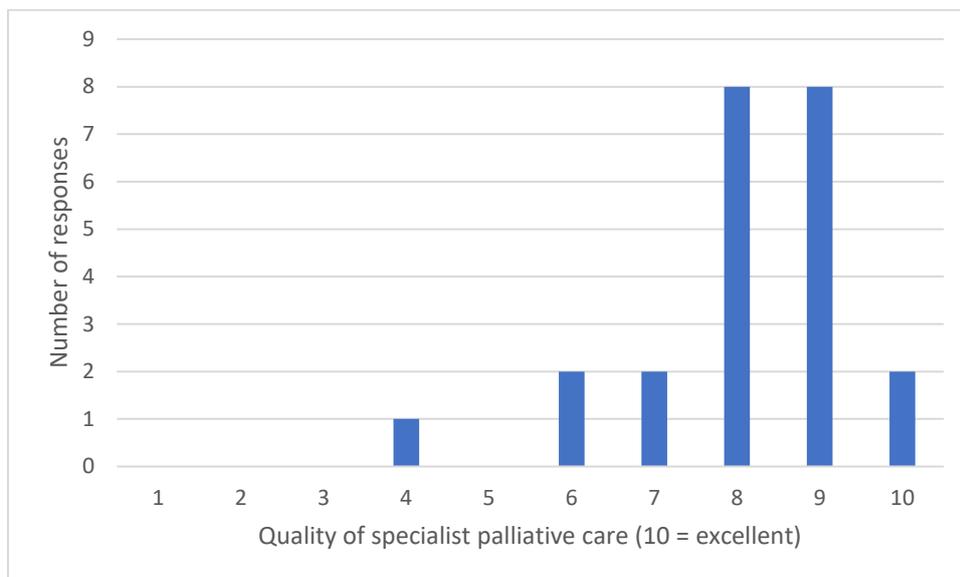


Figure 2. Mesothelioma UK CNS perceptions of the quality of specialist palliative care provided to patients with mesothelioma



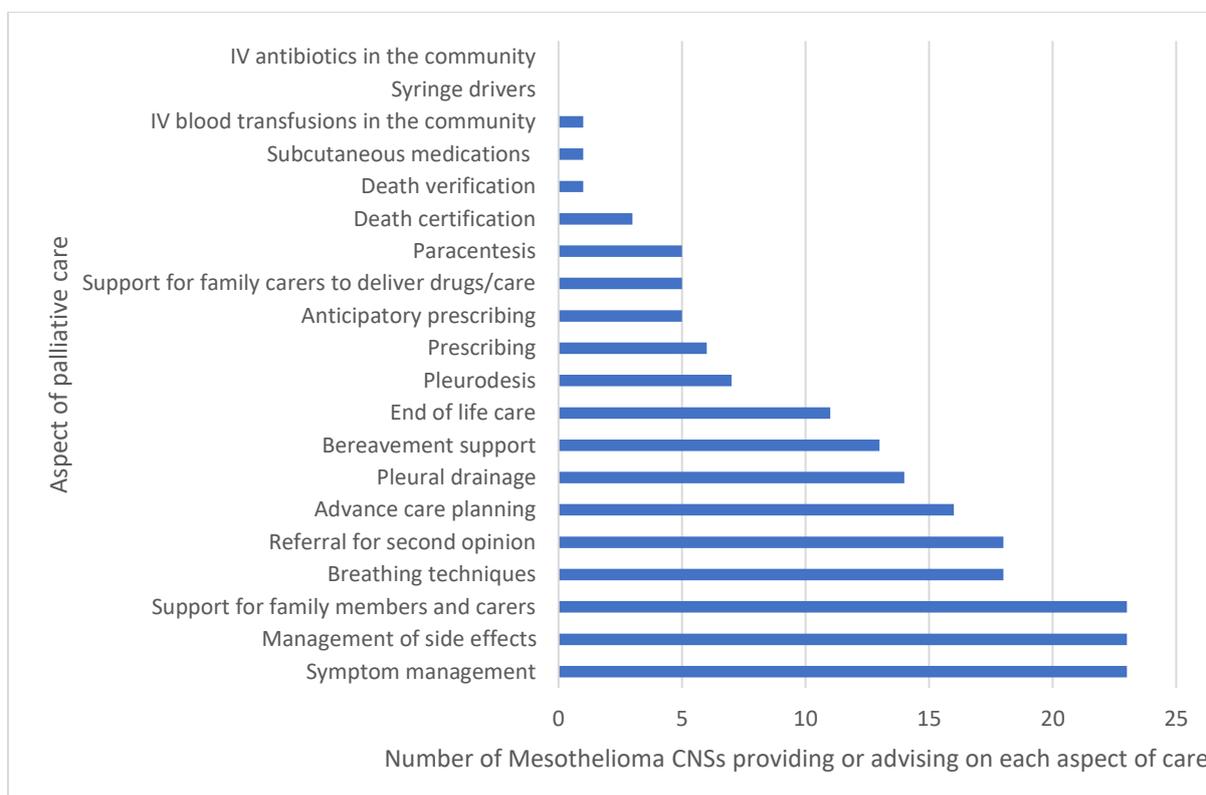
MCNS respondents selected whether or not they provided or advised upon certain aspects of palliative care for patients with mesothelioma (see table 9). Respondents selected all applicable items. All MCNSs provided symptom management, management of treatment side effects and support for family members and carers. Advance care planning was provided or advised upon by 69.6% of respondents, bereavement support by 56.5% and end of life care by 47.8%.

Table 9. Aspect of palliative care provided or advised upon by MCNSs for patients with mesothelioma

Aspect of care provided	N (%)
Symptom management	23 (100)
Management of side effects	23 (100)
Support for family members and carers	23 (100)
Breathing techniques	18 (78.3)
Referral for second opinion	18 (78.3)
Advance care planning	16 (69.6)
Pleural drainage	14 (60.9)
Bereavement support	13 (56.5)
End of life care	11 (47.8)
Pleurodesis	7 (30.4)
Prescribing	6 (26.1)
Anticipatory prescribing	5 (21.7)
Support for family carers to deliver drugs/care	5 (21.7)
Paracentesis	5 (21.7)
Death certification	3 (13.0)
Death verification	1 (4.4)
Subcutaneous medications (including specialist medications)	1 (4.4)
IV blood transfusions in the community	1 (4.4)

Syringe drivers	0 (0)
IV antibiotics in the community	0 (0)

Figure 3. Aspect of palliative care provided or advised upon by MCNSs for patients with mesothelioma



MCNSs selected the topics they usually provide information about for patients with mesothelioma (see table 10). Respondents were able to select more than one option. The three topics that patients were least likely to provide information about were referral to the coroner, improving performance status and spiritual well-being. Other topics of information provided to patients with mesothelioma identified in the free-text comments included: prognosis, planning for future care/advanced care planning and signposting to supportive services available in the community (such as day therapy at local hospice or Maggie’s centres).

Table 10. Topics of information provision for patients with mesothelioma

Topic for information provision	n (%)
Mesothelioma and its effects	23 (100)
Accessing clinical trials	23 (100)
Patient support groups	23 (100)
Diet, nutrition and exercise	22 (95.7)
Managing emotions	22 (95.7)
Benefits	22 (95.7)
Claiming compensation	22 (95.7)

Referral to the coroner	20 (87.0)
Improving performance status	19 (82.6)
Spiritual well being	17 (73.9)

Respondents were given the opportunity to provide additional free-text comments about providing palliative care for people with mesothelioma and their families. Qualitative comments highlighted a lack of community palliative care, disparity in access across different geographical areas and a lack of appreciation of the palliative care needs of the people with this progressive but rare disease. The provision of palliative care was perceived to be fundamental to the role of an MCNS and was described as a rewarding part of the role that needs to be part of an “*on-going organic process*”. Others described the importance of collaborating and communicating within and across teams to ensure patients’ palliative care needs are met. One respondent felt there was a lack of access to opportunities for meaningful reflective practice, which was required due to the emotional drain experienced by those delivering palliative care. One participant described an example of good practice, which was ceased due to staffing changes:

“In my hospital I found a Palliative Care Consultant with a special interest in Mesothelioma and we developed together a clinic which sat alongside the Lung Cancer Oncology clinic offering symptom support. It worked very well as patients who came to clinic who had symptoms such as pain the Consultant could see that day so that they did not have to come back for another appointment. Sadly, when the Consultant left no one was willing to continue the clinic.”

Confidence in palliative care

Confidence in palliative care delivery was assessed by combining scores from three questions with responses ranging from 1 (not confident) to 10 (extremely confident). Scores were combined to provide an average, which was the overall Confidence in Palliative Care Delivery. The mean scale score was 26.52 (SD=2.68) out of a maximum of 30. When exploring each of the three question individually MCNSs rated themselves as slightly more confident in identifying when palliative care should begin (mean=9.09, SD=0.996) and deciding when a referral to specialist palliative care should be made (mean=9.09, SD=0.9), compared to providing palliative care (mean=8.35, SD=1.23).

Difficulties in providing palliative care

The responses to the question on areas of perceived difficulty of providing different aspects of palliative care for patients with mesothelioma are shown in figure 4. The DPCMPM was scored on a 5 point Likert scale ranging from not difficult at all (1) to very difficult (5). Working in a team with the same goal was perceived to be the least difficult aspect (M=1.83; SD=1.07), along with supporting a patient where he/she wants to die (M=2.17; SD=0.78) and working with other departments to ensure that patient’s wishes are fulfilled (M=2.26; SD=1.01); all of which are more process-based, generic aspects of palliative care. In contrast, the aspects of care perceived to be the most difficult to provide were more specific to mesothelioma: controlling pain and dyspnea (M=3.39; SD=1.03); easing the pain of a patient who cannot find effective treatment (M=3.39; SD=0.94); maintaining the patient’s QoL (M=3.17; SD=1.03); and diminishing the patient’s psychological, social and spiritual pain (M=3.17; SD=0.94).

Figure 4. Perceived difficulty of providing different aspects of palliative care for patients with mesothelioma by MCNSs

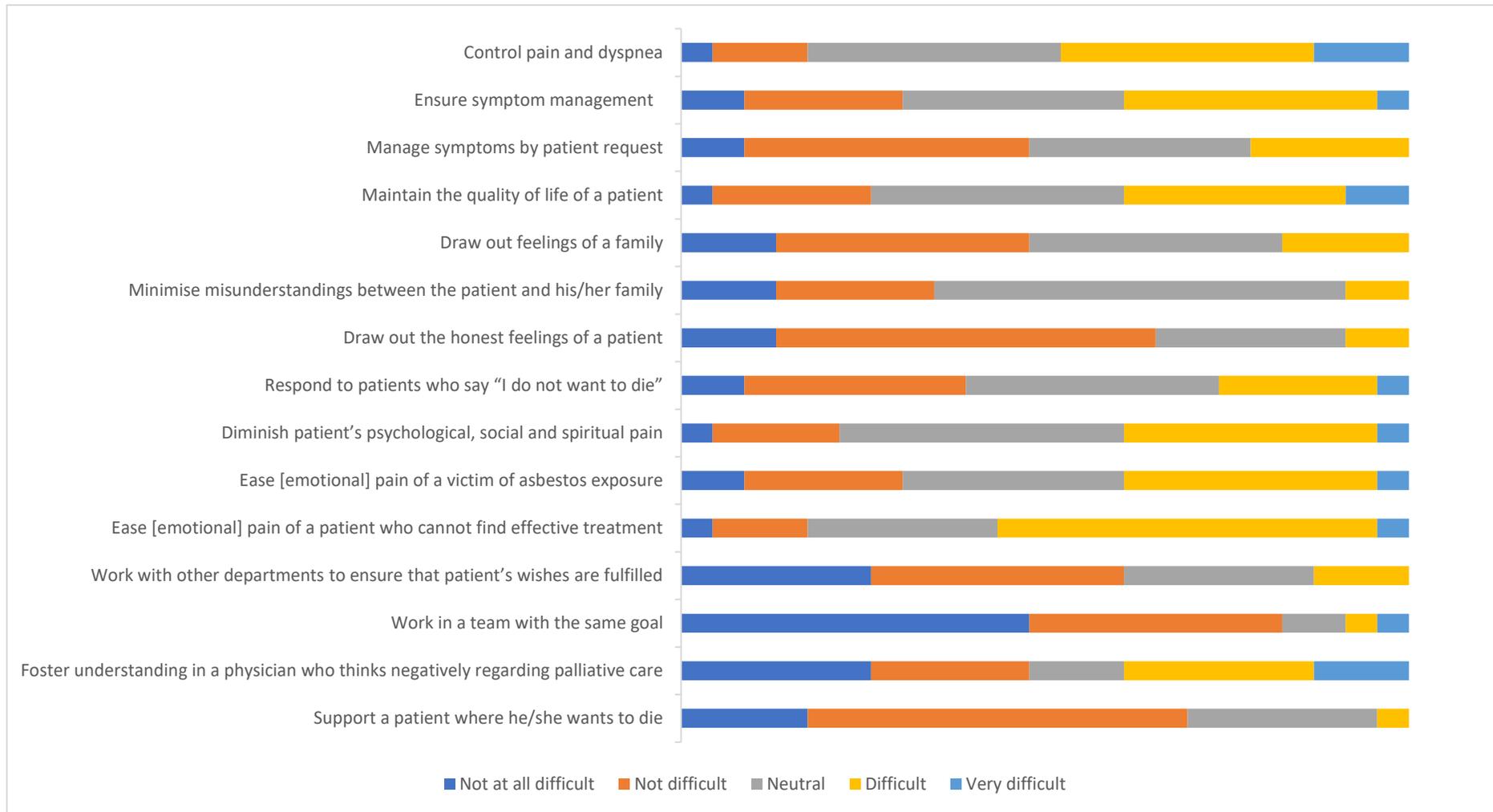


Table 11. Means and standard deviations for each item on the DCPMPM

Subscales	Item	M	SD
Symptom management and maintenance of quality of life	Control pain and dyspnea	3.39	1.03
	Ensure symptom management	3.04	1.07
	Manage symptoms by patient request	2.65	.94
	Maintain the quality of life of a patient	3.17	1.03
Care of family	Draw out feelings of a family	2.57	.95
	Minimise misunderstandings between the patient and his/her family	2.61	.84
Spiritual care	Draw out the honest feelings of a patient	2.30	.82
	Respond to patients who say "I do not want to die"	2.83	1.03
	Diminish patient's psychological, social and spiritual pain	3.17	.94
	Ease [emotional] pain of a victim of asbestos exposure	3.04	1.07
	Ease [emotional] pain of a patient who cannot find effective treatment	3.39	.94
Care co-ordination of medical services	Work with other departments to ensure that patient's wishes are fulfilled	2.26	1.01
	Work in a team with the same goal	1.83	1.07
	Foster understanding in a physician who thinks negatively regarding palliative care	2.78	1.45
	Support a patient where he/she wants to die	2.17	.78

The 13 items on the DPCMPM scale can be grouped into four subscales. The subscales include different numbers of items (see table 11). In order to compare scores on the four subscales we calculated standardised means by dividing the subscale scores by the number of items included in each subscale (see table 12). The domain of palliative care perceived to be most difficult to provide for mesothelioma patients was symptom management and maintenance of quality of life (standardised M=3.07; standardised SD=0.89), in contrast the domain perceived to be the least difficult to manage was the care co-ordination of medical services (standardised M=2.26; standardised SD=0.72).

Table 12. DPCMPM subscale scores raw and standardised

	M	SD	Standardised M	Standardised SD
Symptom management & maintenance of QoL	12.26	3.54	3.07	0.89
Care of family	5.17	1.70	2.59	0.85
Spiritual care	14.74	4.05	2.95	0.81
Care co-ordination of medical services	9.04	2.90	2.26	0.72

Discussion

This survey of 23 Mesothelioma UK CNS's found that nearly all MCNS's felt it was their role to provide or advise upon palliative care, and nearly all MCNS's had received prior training or education in palliative care. MCNS's provided support or advice on a number of aspects of palliative care. The level of palliative care skill and expertise amongst the MCNS workforce surpasses what would be expected for a group who are not recognised as 'specialists' in palliative care. The recent RESPECT study reported early specialist palliative care did not improve overall outcomes for patients with mesothelioma (Brims 2019). One suggested explanation for this finding was that existing service configurations already provide sufficient palliative care support for patients in the earlier stages of mesothelioma. The findings from our survey support this explanation and indicate that MCNS's are central to supporting patients' generalist palliative care needs, particularly earlier in the illness trajectory.

For patients with more complex symptoms who require specialist palliative care, MCNS's report referring to and working with a range of other health care professionals, including those in specialist palliative care services. MCNS's provide specialist palliative care themselves but work closely with other specialist teams to ensure seamless support is in place for the patient when symptoms become more complex. This finding supports existing evidence which suggests that good partnership working between specialist and generalist palliative care providers is central to the provision of good palliative care (Gardiner 2012, Gott 2012). Factors supporting good partnership working have been found to include good communication between providers, clear definition of roles and responsibilities, opportunities for shared learning and education, appropriate and timely access to specialist palliative care services, and coordinated care (Gardiner 2012). These are areas for potential development in mesothelioma, to further support palliative care provision.

Confidence in the delivery of palliative care was reasonably high among MCNS's, however the majority of respondents also reported they would be interested in more training around palliative care. Inclusion of palliative and end of life care education within the strategic agendas of healthcare organisations may assist towards the delivery of sustainable changes in clinical nursing practice (Stacey *et al.*, 2017). When asked about difficulties in providing palliative care, the factors that were perceived by respondents to be less difficult were those that might not necessarily be impacted upon by the mesothelioma diagnosis (e.g. working in a team with shared goals, collaborating with others and supporting a patient to die in a place of their choosing). In contrast, the factors that were

perceived to be more difficult to palliate, such as controlling pain and dyspnea and maintaining quality of life, are factors associated with the course of the disease; supporting the suggestion that mesothelioma is a difficult disease to palliate (Cordes 2003). A recent study on symptom burden in pleural mesothelioma found that unmet needs are common, but mainly centred around information provision and communication. They reported 25.9% of patients wanted more information about their condition, 24.7% about their care and 21.2% about their treatment. In addition, 79.1% were concerned about the effect of their illness on family (Hoon 2021). This reinforces the important role of information provision and communication in palliative care in mesothelioma, support that is often an integral component of the MCNS role.

In summary, MCNS's are highly skilled in providing palliative care, and play a central role in the provision of this care. Both generalist and specialist palliative care are important in supporting patients with mesothelioma and a range of health professionals are involved in providing this care.

Chapter 4: Focus groups and interview exploring the role of Mesothelioma UK clinical nurse specialists in meeting the palliative care needs of patients and families

Introduction

Secondary data analysis of the MORE survey responses (chapter 2) collected from patients indicate that MCNSs are central to supporting patients and their families, are key providers of generalist palliative care and have important roles in relation to symptom management and coordination of care. The survey of MCNSs (chapter 3) provided information about the demographic, education and training of this workforce, as well as insights regarding their perceptions of and experiences of providing palliative care to mesothelioma patients and their families. While the survey data presented across these earlier chapters certainly enhance understanding of mesothelioma palliative care needs and the role of MCNSs, qualitative data was sought to complement and embellish these insights, particularly around barriers and facilitators to receiving high quality palliative care. There are very few qualitative studies that focus on experiences of patients with mesothelioma, either from the perspective of the patient (Arber 2013; Clayson 2005), or from the perspective of the health professional (Taylor 2019). Lung cancer CNSs have been reported by patients to help manage communication across the diagnostic pathway and between the multi-disciplinary team members. Lung CNSs' have also been reported as having a multi-dimensional impact on symptom management leading to improvements in quality of life (Tod 2014). Despite this, there is a lack of qualitative data from MCNSs specifically regarding their role in palliative care provision. This chapter describes the collection and analysis of qualitative data, generated from a series of focus groups and interviews with MCNSs. Key findings from this stage of the study are presented.

Method

Study design

A qualitative descriptive approach (Braun and Clarke 2006) was adopted using focus group and interview methods to explore the palliative and end of life care provided to people with mesothelioma and their families from the perspective of MCNSs. MCNSs are uniquely placed to understand the palliative care journey due to the close relationships they build with mesothelioma patients and their families. Aspects of care explored in the focus groups and interviews included the role of MCNSs, the palliative care needs of patients with mesothelioma and their carers and the barriers and facilitators to receiving high quality palliative care. Ethical approval was obtained from the School of Nursing and Midwifery research ethics committee at the University of Sheffield (reference: 036461).

Sample and recruitment

All MCNSs in the UK were invited to participate in a focus group or qualitative interview via email from a member of the operational team at Mesothelioma UK. Those interested in participating were invited to contact the research team directly. Interviews were offered to any senior members of the team whose participation might have influenced group discussion, and to those unable to attend the

focus group sessions. Information and consent sheets were shared with participants prior to participation and the consent sheet was read aloud by the facilitator at the start of each interview or focus group to enable verbal consent to be recorded.

Data collection

The focus groups were conducted via ‘Google Meet’ video conferencing software. Participants taking part in interviews had the option of using video conferencing software or the telephone. Focus groups and interviews followed the same topic guide (see table 13). Focus groups had two facilitators to enable one to lead the group, whilst the other navigated any technical difficulties participants were having and made fieldnotes from the discussion. Both focus groups and interviews were digitally audio recorded and transcribed verbatim before being checked for accuracy by one of the facilitators.

Table 13. Topic guide questions

Main questions from the topic guide
<ul style="list-style-type: none"> • Please could you tell me a little bit about the wider role you play as Mesothelioma UK clinical nurse specialists in supporting patients with mesothelioma and their families? • What do you perceive to be the main palliative care needs of patients with mesothelioma and their families? • Please could you each tell me a little bit about how you’re involved in providing palliative care to patients with mesothelioma and their families? • Who else do you work with to provide this care? • What skills or attributes do you draw upon when delivering palliative care to mesothelioma patients and their families? • When mesothelioma patients receive high quality palliative care, what does it look like? How is that achieved? • What are the barriers to patients with mesothelioma and their families receiving high quality palliative care? • What could help to improve the palliative care services currently provided to patients with mesothelioma and their families? • What support or training might help you to improve the palliative care you provide to patients with mesothelioma and their families?

Data analysis

Qualitative data were analysed with reference to Braun and Clarke’s (2006) approach to thematic analysis to inductively explore and describe patterns across the data set. To facilitate indexing and transparency, the data was coded using NVivo (Version 1.4, QSR International). All transcripts were coded by one researcher (MH) with a second researcher (CG) independently coding a third of the data to prevent lone researcher bias. The coding frameworks developed independently by both researchers were largely similar, minor discrepancies were discussed and resolved through consensus. The involvement of two researchers in the interpretation of the data and theme development and naming strengthens the credibility of the research.

Results

Sixteen MCNSs participated in three online focus groups, two one-to-one online interviews and one one-to-one telephone interview. At the time of recruitment, this represented more than half of the total number of MCNSs. Participant demographic information are show in table 14.

Table 14. Participant demographic information

Mesothelioma clinical nurse specialists (n=16)	
Gender	
Female	15 (93.8%)
Male	1 (6.3%)
Previous experience of working in palliative care	
Yes	6 (37.5%)
No	10 (62.5%)
Years of work in mesothelioma clinical nurse specialist role	
< 2 years	4 (25%)
2-5 years	5 (31.3%)
6-10 years	6 (37.5%)
>10 years	1 (6.3%)

Four main themes were identified: MCNS role in relation to palliative care, joint working with specialist palliative care and community services, patients and family carer’s willingness to engage with palliative care services, and the impact of COVID-19 on palliative care for mesothelioma patients. Each theme is described in turn with key points illustrated by quotes.

Mesothelioma UK CNS role in relation to palliative care: “being alongside” the person with mesothelioma and co-ordinating care

When describing their role as an MCNS, participants emphasised the importance of “being alongside” the patients and their family carer throughout their mesothelioma journey. The provision of palliative care was perceived to be so integral to the MCNS role, given the terminal nature of the disease, that participants struggled to single out the palliative components of their role, instead focusing on the importance of providing individualised care. Patients’ needs were perceived to vary significantly depending on symptom burden and disease progression.

“I think erm it’s- it’s been- err cause all the patients are palliative when- from when we first meet them, so it’s the degree of palliation that they need, and it’s being able to assess what support they, each patient and their family needs along the way.” (MCNS 2)

“So I do think erm a lot of it is very, very individualised. It’s very, very much erm about giving as much hope as we can, for the best quality of life, for as long as possible for that person in their own particular situation, and [...] being there. We’re there, and that’s, that’s what they really, I think, appreciate, is they keep coming back to us to- to check things out, or to query things that they can’t say to other people. So erm, yeah, I think the individuality of it and listening and hearing and being there for that person. Being alongside really.” (MCNS 6)

The majority of MCNSs provide care not only to mesothelioma patients at the hospital in which they are based, but also provide advice and support to people with mesothelioma in the wider region. When the patient and MCNS were based at the same hospital, they typically met at the point of diagnosis. If diagnosis occurred at a relatively early stage of the disease, MCNSs provided support through treatment and/or trials. Other aspects of care routinely provided by MCNSs included managing symptom burden, psychological and emotional support, signposting for benefits and compensation advice, running support groups, identifying when specialist palliative care input is required and providing support for family carers both prior to and post-bereavement. The aspects of care provided by MCNSs are illustrated by quotes in table 15. As well as providing patient care,

MCNSs also play a vital role in educating other healthcare professions about this rare disease and combating nihilistic attitudes. Participants spoke about providing training, awareness days and informal training through one-to-one discussions with health care professionals who had not heard about mesothelioma previously.

“There needs to be far more awareness with GP surgeries and community nurses. Erm, you know, a lot of GPs I’ve spoken to recently have never even heard of mesothelioma, let alone know what it is. Er so when we ring them to say look you need to flag up to make sure- they need you know- they’re imminently going to die so therefore they need to be referred to the coroner and things like that, the GP surgeries don’t know, you know, so they haven’t got the education.” (MCNS 10)

Table 15. Quotes to illustrate the difference aspects of care provided by MCNSs to people with mesothelioma and their families

Aspect of care	Quote
Diagnosis, treatments and trials	My meso UK role requires me to erm, er do face-to-face contact when able with patients, erm offering them support and guidance at diagnosis and going through different treatment options with them. Erm exploring their thoughts and feelings about that. (MCNS 14)
Managing symptom burden	They often have quite a large symptom burden at the point of diagnosis, so I will help the doctors look at their analgesia, look at their breathlessness and make referrals to other members of the AHP team that would help improve those symptoms. (MCNS 4)
Psychological and emotional support	The erm psychological support is inherent in everything that we do and, and obviously if people express a need for- or if we identified a need to erm deal with an active depression or issues with severe anxiety or perhaps identifying that they’re just not coping we may need to refer on to other services. But a lot of the work that we do whether it’s face-to-face or by telephone is the emotional, psychological support. That really is our bread and butter. (MCNS 14)
Signposting for benefits and compensation advice	probably the sort of key erm elements of the role erm are the signposting for benefits and legal advice at an early stage, and getting that put to one side, cause that’s something that’s really, really important and often isn’t picked up erm by other members of the team. It’s often left to us to coordinate that. (MCNS 5)
Support groups	I facilitate a patient-carer information and support group every erm- we meet every two weeks throughout lockdown virtually, erm used to be err once a month face to face erm prior to March. (MCNS 5)

Identifying when specialist palliative care is needed	I mean the way that we tend to work is that we obviously see palliative care as being for complex symptom management, erm and I don't think there's a- a dividing line is there really, when you- when you're doing that. I think it's just when it feels that- that you've tried everything that you can, as- and need that expert advice. So it's probably a bit woolly, but I think we- we tend to do the- the basic symptom control, the pain control, that side of things. Erm breathlessness management, up to a certain point, but then when people obviously- when people need a bit more intensive support. (MCNS 12)
Supporting family carer	We do at least one call post-bereavement, we try and do maybe two and it does depend on the, on the situation but it almost feel good for us as well as the professional, that we're not just finishing with that death. That we are actually there, you know, even if it's just saying, you know, to the wife "you did such a good job, you really, you know, looked after him or her very well, you did everything you could". (MCNS 7)

Another key feature of the role highlighted by the MCNSs was care co-ordination. Typically, multiple healthcare professionals are involved in providing care and treatment for those with mesothelioma, which can be confusing for the patient. MCNSs described drawing upon their professional networks to ensure patients received appropriate and timely referrals and acting as a "sounding board" for patients who have received different information from different professionals. Co-ordinating patient care was perceived to be more difficult when the patient was based in a different local area, as participants were less familiar with the services and did not necessarily have existing professional relationships and networks to draw upon.

"I think fundamentally about- probably- a massive part of my role is just making sure that people are able to erm, feel that they're heard and have that contact number. Erm sometimes they identify us as being the sort of jam in the sandwich erm, the guys that keep erm everything flowing, stuck together and they know where to go to get the signposting to other services." (MCNS 14)

The key skills and attributes required for the MCNS role were perceived to include: communication skills, expertise in mesothelioma, experience, courage, tenacity, empathy, patience and advocacy skills. In terms of communication, participants emphasised the importance of "really listening" to the patient, as well as assessment and counselling skills. Drawing upon prior knowledge and experience built up over a period of many years was seen to be vital, particularly as the majority of participants had previously worked in relevant areas such as lung cancer or specialist palliative care. The importance of courage was discussed in relation to having difficult conversations about palliative care, the involvement of the coroner and potential need for a post-mortem, and championing mesothelioma patients' needs with other healthcare professionals.

"You need to be able to erm appropriately utilise your knowledge and education skills in- in a way that's individual for each patient, and it's like a jigsaw, you're putting together this physical skill with this psychological impact it's having. You often have to be reframing the way people are looking at things, and really analysing what has been told to them. So it's a

lot of erm, sort of erm- like, yeah, listening, jigsaw- jigsaw process of- of fitting everything together, and using all that- that catalogue of skills and experiences that you have, whether it be of drugs, whether it be of- of physical anatomy, whether it be of- of psychological erm difficulties, coping strategies, and so on.” (MCNS 6)

“And to have the courage to speak to people about post-mortems erm when they’ve just been given a diagnosis, to have the courage to say that we’ll be alongside you, we’ll help you. You know, if we can- if you keep in touch with us, we’ll try and help you as much as possible. Erm, the courage to speak to other professionals that might be shutting the door on people, err courage to say well this person does actually need a home visit from your palliative care team if at all possible.” (MCNS 3)

MCNSs described the benefits of the training they received due to being part of the Mesothelioma UK charity and felt privileged to be provided with regular updates in their field. Another benefit of being part of the Mesothelioma UK team included the information exchanged through the network of MCNSs, primarily via a WhatsApp group, which enabled experiences to be shared and reflected upon, thereby developing a collective knowledge that can be drawn upon to enable the best support to be provided to patients with mesothelioma. Participants also highlighted training gaps in relation to palliative care (see box 1).

“I think that’d be fabulous if they were allocated erm, some secured time to go and sit with our colleagues in the, the palliative care clinics or maybe out in the community just to see, you know, what’s available and what they have access to, cos a lot of the time they do come up with the, the newest things that we haven’t heard of. So, I think some sort of education refreshers, the way we do over-, we have our clinical trials updates, the same type of thing I think would be very beneficial.” (MCNS 9)

Training gaps

- Opportunities to network and reflect on palliative care provision
- Communication skills training updates (particularly given the increased use of remote technologies for difficult conversations due to the pandemic)
- Educational updates around palliative and end of life care to ensure current best practice is followed (particularly around the medications available for symptom control)
- Opportunities to shadow or work alongside specialist palliative care colleagues
- Opportunities to interact with patients in the community when staff are primarily hospital-based in order to understand the issues facing patients and staff.

Box 1. Training gaps highlighted by participants

Joint working with specialist palliative care and community services: vital but variable

As described above, MCNSs are highly skilled in providing palliative care and perceived that palliative care was weaved into the care they provided to patients with mesothelioma from the point of diagnosis. Whilst some participants described routinely attempting to make an early referral to the specialist palliative care team, the majority of MCNSs described a more individualised approach. This

approach involved managing the patients' palliative care needs until they felt they could no longer manage their physical symptoms adequately, or the patient needed palliative care in the community, at which point an onward referral would be discussed. MCNSs described providing much needed psychological and emotional support using their expert communication skills as part of the palliative care provided to patients.

"Cause all the patients are palliative when- from when we first meet them, so it's the degree of palliation that they need, and it's being able to assess what support they,- each patient and their family needs along the way." (MCNS 2)

"When I do my initial assessment, regardless of where the patient has come from, I, my preference will be to engage in the palliative care services there and then. Even if it's just a one-off assessment to get to know you visit and a contact telephone number etc. just to engage them and link them in." (MCNS 9)

"Erm, and there were some things that I feel comfortable with, you know, erm, you know, our bread and butter, you know, you get to a certain point with pain and then you think this is really complex and I'm not winning here and I really need to refer on now. [...] So, it's always, you know, it's very individualised and personalised and it's different from patient to patient." (MCNS 8)

The difference in referral practices appeared to reflect MCNSs palliative care experience and regional variation in specialist palliative care, either because of limited resources affecting availability or variability in the referral pathway. Several participants highlighted difficulties and delays when referrals to specialist palliative care had to go via district/community nursing services. Such referrals resulted in duplication of effort as multiple nurses were assessing patients need for palliative care. Furthermore, as the district nurses have less knowledge and experience of mesothelioma, MCNSs sometimes disagreed with the district nurse about whether the patient required input from the specialist palliative care team, which was a source of frustration for the MCNSs. It was recognised that those working in specialist palliative care can, similarly to district nurses, have limited or no knowledge of mesothelioma. Participants felt this could present challenges to referrals and felt that it was important to share knowledge and information about the combination of specific features of mesothelioma that contribute to the unique palliative care needs in this condition. These include the fact that the disease is incurable and essentially palliative from diagnosis, an industrial disease with complex and often difficult to control symptoms, and a disease in which patients often experience a very rapid decline towards the end of life. MCNSs described using their intuition to navigate the different referral pathways and establish the best way to get their referrals accepted. This was commonly achieved by making phone contact with other teams, rather than just completing a referral form, in order to build relationships, acknowledge colleague's expertise, or demonstrate their own expertise.

"They all have different referral routes in, for example, some of them we have to refer to the district nurses before we can get the palliative care. So, the district nurses will do an assessment, despite the fact that me as a specialist mesothelioma nurses has done that assessment." (MCNS 9)

"It is difficult because sometimes those teams it doesn't matter what we say, it's only when the district nurse team say that the patient needs something and, you know, you can ring somebody upon up and be on the phone and think oh they sound awful but the district nurse has been out and said "no, no I think they're ok" and it's the district nurses they're going on

and, I mean I always think with mesothelioma that sometimes like people kind of go along and then they just drop off the edge like, you know, it's really and it can be quite quick and, and it's difficult. I suppose we need to try and work with the district nurses and educate them and explain to them, because sometimes they'll never have seen somebody with mesothelioma before." (MCNS 16)

"I've started doing is a quick telephone call before I do the referral and just explaining and almost saying "I wonder could you help me out with your expertise" it's, it's really, you know, again, like [0:33:02.7 MCNS8] said you're using the key words that trigger they're, that they're the specialist team and, you know, and I'm contacting you as, as the specialists in mesothelioma they've been referred to us and we've reached our limits." (MCNS 9)

In response to the regional variation in specialist palliative care provision participants also described providing more input and bridging gaps in areas with less specialist palliative care resource, to ensure patients palliative needs are supported to some extent, wherever they might live.

"Where we foresee that there is gonna be an issue we, we can try and keep involved there. And we also have that contact with their consultants here as well, so they know that if they come through us then usually we can speak to their consultant and, you know, get a plan for them so I think that, you know, that's a, a good thing for them. I think the fact that there's more Meso nurses throughout the country is really good and I think that that will help, help people you know when we can bridge a gap where there is gaps in community services and hospital services." (MCNS 16)

Participants also described substantial variation in GPs knowledge of mesothelioma and engagement in palliative and end of life care provision for this patient group. The engagement of GPs facilitated high quality palliative care through advance care planning and timely provision of interventions, including pain relief. Where GPs did not engage with the Gold Standard Framework² or the provision of palliative care more generally, this created additional workload for the MCNSs who described spending time educating GPs or stepping in to provide additional support and care co-ordination to fill the gaps, where possible. The push to keep patients in their own home at the end of life during the COVID-19 pandemic, has further emphasised the variation in palliative care provided by GPs.

"You've got some really good GPs, but we've also got some appalling GPs, and I think COVID has polarised them, so we've got some really fantastic GP practices that are happy to sort out district nurses, happy to go and do home visits, then feedback to you about what's going on, and- and working with you to try and make sure those people stay at home, and others that will not do anything, and it makes life a little bit more difficult, and you have to have those conversations because as I say, trying to prevent these people from coming into hospital unless it's the absolute last resort at the minute, which is- yeah, is not what we're used to." (MCNS10)

When asked about the characteristics of a good referral to specialist palliative care, MCNSs described scenarios in which 1) the topic of palliative care had been broached early in the patients' journey so the patients were well prepared and agreeable to referral, 2) specialist palliative care input was provided in a timely and flexible manner (although individual MCNSs differed regarding

² <https://www.goldstandardsframework.org.uk/>

the specific time), 3) collaborative relationships and open communication between MCNS and those working in specialist palliative care and 4) SPC services that are more integrated (see box 2).

“A good referral to specialist palliative care I think is when the family and the patient are, erm, fully informed and, er, agreeable to that referral. When they, erm understand that palliative care is a, specialist palliative care team is a crucial part of the team. Erm, and it’s also that it’s timely. So, you know, patients can develop symptoms rapidly and their, their, their final weeks and months of life can be upon you very quickly and you haven’t got time to wait and so they need that support. If you need that specialist support for your patients, erm, you need it promptly. Erm, and so I think that, you know, so I, I think timely, er, smooth referral and keeping that good communication going, because patients, you know, drift in and out of specialist palliative care along their journey and, er we need to make sure that, erm, that flow back and forth, is timely and that the door’s always open.” (MCNS15)

Characteristics of a good referral to specialist palliative care

- 1) Palliative care discussed early in the patients’ journey to ensure they are well prepared and agreeable to referral.
- 2) Specialist palliative care input provided in a timely and flexible manner.
- 3) Collaborative relationships and open communication between mesothelioma CNS and those working in specialist palliative care.
- 4) Integration of SPC into the mesothelioma pathway.

Box 2. Characteristics of a good referral to specialist palliative care

Patients and family carer’s willingness to engage with palliative care services

Issues around patient and carers understanding of palliative care services and the negative connotations associated with palliative and hospice care were widely acknowledged by MCNSs, and seen as a barrier to patients accessing palliative care services. Participants described how the introduction of terminology, such as hospice, invoked fear and forced patients to confront their own mortality. Fear and the perceived stigma associated with services such as Macmillan was thought to result in delayed access to vital services for some patients.

“Erm and often people are very scared at the word palliative, they think that means that they’re automatically dying, and it’s about erm sort of demystifying death for all patients, so that we can talk about it in a very good way, erm not scare people, do lots of advanced care planning, so that before they even get to the point where they become less well, they are prepared, and that often makes people less scared and anxious.” (MCNS 4)

Strategies used by MCNSs to facilitate engagement with palliative care services included building a strong therapeutic relationship with the patient to engender trust, educating patients about what the different services can provide, using different terminology to avoid stigma, and referring patients to inpatient hospital services, rather than hospices, that were able to provide the same services.

“I think the, the first step would be wider acknowledgement and more open discussions about what palliative care offers and, I tend to not to really use the word palliative care now. I used to, I used to use the word palliative care instead of hospice services and Macmillan and now I’ve gone from palliative care to specialist symptom team, that’s what I, that’s how I address them as now and that seems to be the way in. So, maybe it’s more education around what, what the different teams do.” (MCNS 9)

Willingness to engage with palliative care was discussed in the wider context of the need for greater public awareness and understanding of palliative care more generally. One issue specific to mesothelioma relates to the disease being terminal from the point of diagnosis, which means there is a “very short window of opportunity” for people with mesothelioma to adjust and be willing to accept input from palliative care services. MCNSs recognised that one of their roles was to help patients to have realistic expectations and part of that role required them to convince patients of the importance of accepting symptom management from those best equipped to provide it. Managing expectations and preparing patients and their carers for what is to come required MCNS to have difficult conversations, which was perceived to require the MCNSs to have courage and excellent communication skills.

“I think when patients erm, patients want to survive first and foremost. They want more time with their family and erm, I think it’s, you know, a significant part of my role is to help patients to have realistic expectations and realistic hopes. Erm and try to get them and their loved ones and us as a, as care team all on the same page, so they’re all working to the same agenda because, erm, you know that, that’s where you get the best out of that therapeutic kind of relationship.” (MCNS 15)

A discrepancy between the willingness of mesothelioma patients and their carers to engage with palliative care services was also reported. Family carers were often described as bringing the palliative care needs of the patient to the attention of the MCNS, rather than the patient themselves. In some instances, despite carers descriptions of the patients being in crisis, patients continued to deny that they required any additional input, putting the MCNS in a difficult position. Carers contacting the MCNS typically focused on the patient’s physical symptoms.

“I think there can be a real discrepancy between patient wishes and relatives wishes sometimes, and you’ll get relatives ringing you up going they really need some help, and then you talk to the patient going oh I’m fine thank you very much.” (MCNS 12)

Impact of COVID-19 on palliative care provision for patients with mesothelioma and their family carers

Much of the palliative care provided by MCNSs has been delivered remotely during the COVID-19 pandemic. Participants widely recognised that this has negatively impacted on their ability to communicate with patients and their family carers, especially when having difficult conversations around the time of diagnosis and when patients were moving toward the end of life. The absence of visual cues and touch were reflected on by several participants. Participants also recognised the limitations of remote communication in terms of building rapport with the patient, which in turn impacted on the confidence and trust the patient was willing to place in them.

“It’s more difficult on a Zoom call or on the phone erm because normally when you see the patient and you see them regularly in clinic, you build up that rapport with them as well, so then you can pick up those cues, and you can judge how much information they’re happy to have, and when to pick up information and whether to talk about DNR as we’ve mentioned and things like that. So the non-verbal communication is just- I think is key, and I think that’s what we’re lacking at the minute, because you can’t pick up those non-verbals on the phone or on Zoom calls, which is- is- makes it a little bit more difficult to have those conversations.” (MCNS 10)

“Erm, the coroners issue is an awkward one and we used to always do that at the first consultation. But some of the first consultations have gone to the telephone with the consultant. If it’s a video consultation, we’re often include it in that. So, now it’s a little bit more awkward trying to find out if that conversation has taken place.” (MCNS 7)

Remote consultations were acknowledged to have made it more difficult to communicate with family carers. Family carers were perceived to have been “pushed out” of the patients care experience as they are not able to attend clinic or treatment appointments with the patient. MCNSs recognised that carers can have different information needs, which can be harder to address when all conversations occur remotely with the patient able to hear. To overcome these difficulties MCNSs described providing opportunities for family carers to contact them individually at another time or even going out to the car park to talk to the carer.

“So, relatives are left in the car park and I have been up in the car park with umbrella stood outside cars talking to the relatives erm, be it for talking about what changes we’ve made to the medication or it’s maybe the scan results things like that.” (MCNS 7)

The COVID-19 pandemic was perceived to have increased patients’ anxiety, which has resulted in MCNSs spending a greater proportion of their time providing psychological support.

“There’s lots of anxiety at the moment and erm fear around what’s happening and err accessing treatment safely, so I’m spending a lot of time doing psychological support as well in my role.” (MCNS 4)

Support groups facilitated by MCNSs were initially cancelled at the start of the pandemic, and have subsequently moved online. However, the limitations of online support groups were widely acknowledged, including the lack of visual cues, the inability to take someone to one side and talk one-to-one, or to use touch to express sympathy and compassion amongst members. Furthermore, several groups that were in the process of being established have been put on hold during the pandemic.

“So providing those palliative care needs where you would’ve taken the patient aside in a support group, then having that as a Zoom conversation with many other people who are at a different part of the trajectory, that is really difficult, and that’s where your communication skills again really come in.” (MCNS 13)

MCNSs attributed a recent increase in patients presenting late in the course of their disease to the COVID-19 pandemic. Late presentation can result in patients missing the opportunity for treatment, which in some areas can mean they do not encounter the MCNS. For those who are still able to

access the support of an MCNS, there is less opportunity to build rapport and for the patient to reach a stage of being willing to accept palliative care input before they reach a crisis point.

“Erm very much erm over the last year I would say, our palliative care input into our lung cancer patients and mesothelioma patients due to late diagnosis has gone through the roof, and we’re doing far more support and palliative care for our patients than we ever were.” (MCNS 4)

Community specialist palliative care services response to the pandemic was described as varied. Some continued seeing patients, whereas others were providing much of their support remotely. It was acknowledged that community palliative care services are under-resourced and that this was made even more apparent by the pandemic. Several participants advocated for resources to be diverted from hospital palliative care into community palliative care services. In one area, staff shortages due to the pandemic led to a waiting list for palliative care.

“COVID has made an enormous impact on community palliative care. I mean we deal with quite a varied erm- cause we’re quite a big area, there’s quite a few community palliative care pods, and they’re all struggling, and they’re doing a lot of their support on the phone, and erm patients don’t like that. They’re finding that they don’t feel like they’re getting the adequate support from some of the community palliative care teams.” (MCNS 2)

MCNSs also described the increased importance of persuading patients to engage with palliative care services at a time when relative’s visits to hospital were limited even for those at the end of life.

“Sometimes you have to almost force that conversation in order to try and prevent them from coming into hospital, erm because that’s the last place you’d want them to be.” (MCNS 10)

The pandemic has prevented some of the MCNSs from accessing training and has also impacted their ability to educate other healthcare professionals about mesothelioma due to the cancellation of training sessions, study days and team meetings which have previously provided a forum for MCNSs to share information.

“So not this September obviously cos of Covid, but the September before [name of colleague] had organised, erm, a mesothelioma study day where it was available to all kind of health practitioners from in the hospital and, you know she sent out invites to people in hospices and people in the community and I think that, you know, we were driving to do something like that again, but it’s as the situation is allowed and we’re allowed more than three people in a room together.” (MCNS 16)

Discussion

Focus group and interview data from 16 Mesothelioma UK CNS’s identified four key themes in relation to palliative care in mesothelioma. Firstly, the MCNS contribution to palliative care was described as so integral to the MCNS role, that participants struggled to single out the palliative components of their job, instead focusing on the importance of providing individualised care. This finding resonates with the other phases of this study which have emphasised the skill and expertise of MCNS’s in providing palliative care, and the centrality of palliative care to the MCNS role.

Secondly, joint working with specialist palliative care was seen as vital but variable. However MCNS's were able to identify some characteristics of a 'good' referral, including discussions of palliative care early in the disease trajectory; timely input from specialist palliative care; collaborative working between MCNS and specialist palliative care and; earlier and more seamless integration of specialist palliative care into the mesothelioma pathway. This finding resonates with other mesothelioma research which has found that when gaps exist in referral pathways, or continuity of care is disrupted, patients have reported feeling bewildered and abandoned (Clayson 2005). Uncertainty and loss of control are compounded when a patient does not know who is co-ordinating their care (Lee 2009) and organised and co-ordinated services have been highlighted as a key component of palliative care in mesothelioma (Harrison 2021).

Thirdly, MCNS's acknowledged the difficulties of discussing palliative care with patients and their families. Misunderstandings of the term 'palliative', alongside fear and stigma, contributed to a reluctance to engage with palliative care services, which could then hamper efforts to support these patients. Public perceptions of palliative care, and long held societal taboos around discussions of death and dying have undoubtedly contributed to this reluctance to engage with palliative care (Hill 2021). Perceptions of palliative care are influenced by a triad of culture, socioeconomic position, and health literacy. To improve integration of palliative care services and improve access to palliative care, evidence suggests increasing exposure to, and education in, palliative care from earlier in the disease trajectory (Hill 2021).

Finally, the COVID-19 pandemic has had a hugely negative impact on people with mesothelioma, their family members, and the MCNS workforce. COVID-19 has made communication and consultations more challenging, has impacted on treatments and care, and has increased the support needs of mesothelioma patients and carers (Taylor 2021). Recent evidence suggests the pandemic has led to increases in late presentations of cancer, and in particular lung cancers, which brings about additional challenges for both palliative care and the MCNS workforce (UKCC 2020). Many of the changes made in response to COVID-19 (such as increased use of remote consultations) are likely to remain, perhaps permanently. However, the impact of these changes on patients and their families remains to be seen.

Recommendations

The final phase of this study was an online workshop held with nine key stakeholders, to develop recommendations from the study findings. Stakeholders were identified via existing networks and comprised individuals with expertise or personal experience in mesothelioma and/or palliative care. This included clinicians in palliative care (n = 1) and mesothelioma (n = 2), academics (n = 4), patients and bereaved caregivers (n = 2). Stakeholders were invited via e-mail and asked to attend an online meeting using the platform GoogleMeet. During the workshop, stakeholders were presented with a short PowerPoint which summarised the study findings from chapters 1-4 of this report and findings from additional data from bereaved caregivers, collected for a previous project (Harrison, under review). Stakeholders were then asked to consider and discuss some of the key challenges highlighted by the results, with a view to developing potential recommendations for research, policy and clinical practice. A facilitated round table discussion format was used to brainstorm ideas, which were refined into recommendations and potential solutions. The workshop lasted 90 minutes and was recorded, detailed notes were also taken. Notes from the online workshop were written up and draft recommendations were circulated to the group within two weeks for comment and feedback. Final recommendations were generated and agreed for clinical practice, for further research and for policy and funders (box 3).

Recommendations for clinical practice

Valuing the Mesothelioma UK Clinical Nurse Specialist role in palliative care is central to supporting patients:

- Increasing the profile and visibility of Mesothelioma UK CNS's nationally and regionally will help ensure all health care professionals working with mesothelioma patients are aware of the MCNS workforce and are able to contact their local MCNS if required.
- Wider recognition of Mesothelioma UK CNS's high level of skill and expertise in palliative care may help facilitate partnership working with specialist palliative care and other health professionals providing generalist palliative care.
- Supporting enhanced collaborative working between Mesothelioma UK CNSs, other generalist palliative care providers, and the specialist palliative care workforce will improve outcomes for patients and families.
- Referral pathways from MCNS to specialist palliative care are variable and can be inconsistent, organisational change may be required to mitigate delays and improve efficiency.

Disjointed and un-coordinated care remains one of the most challenging issues for patients:

- Greater transparency and honesty between health professionals and patients about the challenges of achieving co-ordinated care may help to manage patients' expectations.
- Patients/families can play a role in co-ordinating their own care and encouraging this can empower patients and their families. However, this may be more difficult for disadvantaged groups, and the mechanisms for how patients/families co-ordinate their care require further research (see below).
- Establishing what constitutes a 'gold standard' care pathway incorporating palliative care, may be useful as a benchmark to aim towards.

Negative perceptions of the term 'palliative care' persist and can discourage patients and their families from accepting this care:

- It is important **not** to avoid using the term 'palliative care', rather to ensure that it is explained correctly and introduced as early as is appropriate into patient and carer conversations.
- Earlier conversations with patients and families about palliative care should be encouraged, emphasising its important role as part of the treatment journey and dispelling myths.
- The provision of accessible and dedicated information about palliative care in mesothelioma may be helpful for patients and families, for example on the Mesothelioma UK website.

Support for family caregivers is crucial and could be improved:

- Family carers can be signposted to support that is specifically targeted at them, for example Mesothelioma UK support groups.
- Practical information for carers on providing support at the end of life, and what to do after a person dies, could be helpful. Consider the potential for developing such resources for the Mesothelioma UK website.
- Family carers often value the opportunity to speak alone with health professionals, guidance for remote/virtual communications should include ways to encourage this.

Recommendations for further research

- There is a lack of research evidence that includes patient and family perspectives on palliative and end of life care. Future research should seek to capture these views, in particular views on the term 'palliative care' and how best to introduce this.
- Future research developing/evaluating palliative care interventions in mesothelioma needs to acknowledge the central role that Mesothelioma UK CNS's play in delivering palliative care. Future research designs need to appropriately account for and value this influence.
- Further research is needed to explore if and how patients and their families can play a role in co-ordinating their own treatment and care pathways, to improve continuity of care.

Policy and funder recommendations

- The study findings provide ample evidence that Mesothelioma UK CNSs make a significant and highly skilled contribution to palliative care and are likely to reduce the need for early specialist palliative care. Further expansion of the Mesothelioma UK CNS workforce is warranted to ensure mesothelioma patients from anywhere in the UK can access support from an MCNS.
- On-going palliative care education/training opportunities may be valuable for Mesothelioma UK CNSs to consolidate existing expertise.
- Accessible and dedicated information about palliative care in mesothelioma may be helpful for patients and carers and could be incorporated into the Mesothelioma UK website, complementing existing information about end of life care.
- Inequalities persist and continue to influence the availability of care and treatment in mesothelioma, including palliative care. Greater policy commitment to reducing health inequalities is needed at national level.

Box 3: Recommendations for improving palliative care in mesothelioma and supporting the MCNS role in providing palliative care

Conclusion

This mixed methods study exploring palliative care needs in mesothelioma and the role of the Mesothelioma UK CNS in meeting palliative care needs has generated a substantial body of novel and original evidence. Findings from the study indicate that patients with mesothelioma have significant palliative care needs throughout the course of their illness, and families and carers also have palliative care needs which are distinct from the needs of the patient. Mesothelioma UK CNSs have a central role in supporting patients and families palliative care needs and are highly skilled in providing this care. MCNS's also play an important role in co-ordinating care and achieving continuity of care for patients. There is an important distinction between specialist and generalist palliative care in mesothelioma, with each playing a crucial role. Good partnership working between MCNSs, other generalist palliative care providers and specialist palliative care is crucial to ensure patients receive co-ordinated and seamless care. Challenges to good palliative care in mesothelioma include misunderstandings of the term 'palliative care' and reluctance amongst patients and families to engage with this care, in addition to the huge disruptions and challenges brought about by the COVID-19 pandemic. A series of recommendations have been developed from this work which are aimed at providing direction for changes to clinical practice, opportunities for further research, and recommendations for policy and funders.

Amendments to protocol

Two amendments were made to the original study protocol:

1. We originally planned to undertake a secondary analysis of qualitative data gathered as part of completed and ongoing research projects at The University Sheffield, namely the MARS 2 qualitative assessment study; the 'RADIO Meso' study on communicating a mesothelioma diagnosis, and the 'MiMES' study (Military Mesothelioma Experience Study). Preliminary analysis of data from these studies identified very little material relevant to the current study, with little reference made to either palliative care or the role of the Mesothelioma UK CNS in providing palliative care. Therefore we did not undertake this analysis as planned. As an alternative, we included an analysis of data from nine interviews with bereaved caregivers of people with mesothelioma, undertaken as part of a Masters dissertation by Liz Darlison. The data from these interviews was written up and has been submitted as a journal article (Harrison, under review), and also contributed to the overall recommendations from this study.
2. We had intended collecting qualitative interview and focus group data face to face, however this was not possible due to COVID-19 restrictions. As an alternative we collected data virtually and over the telephone, in line with guidance from The University of Sheffield.

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