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Clinical nurse specialist role in providing generalist and specialist palliative care: A qualitative study of mesothelioma clinical nurse specialists

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Abstract

Aim: To explore perspectives of Mesothelioma UK clinical nurse specialists (CNSs) on their role in providing palliative care for patients with mesothelioma and their families.

Design: A qualitative descriptive approach using focus group and interview methods.

Methods: Focus groups and semi-structured interviews were conducted with 16 Mesothelioma UK clinical nurse specialists using the online software Google Meet. Data collection was carried out in Jan-Feb 2021 and data were analysed using thematic analysis. The consolidated criteria for reporting qualitative research (COREQ) was used as the reporting guideline for this paper.

Results: Four main themes were identified from the data: Mesothelioma UK clinical nurse specialist 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.

Conclusion: This study provides valuable insights into palliative care needs in mesothelioma. Patients with mesothelioma and their families have significant palliative care needs throughout the course of their illness from diagnosis to the end of life. Mesothelioma UK CNS's play a crucial role in supporting patients' and families palliative care needs, and are highly skilled in providing this care.

Impact: By acknowledging the role of Mesothelioma UK CNS's in palliative care provision, and supporting collaborative working between specialist and generalist palliative care providers, there is the capacity to significantly improve palliative care in mesothelioma and improve outcomes for patients and their families.

KEYWORDS
clinical nurse specialist, end of life care, mesothelioma, nursing, palliative care

1 | BACKGROUND

Mesothelioma is a rare, incurable cancer with a high symptom burden (Moore et al., 2009). More than 90% of reported cases occur in the pleura, with 4–7% affecting the peritoneum, and fewer than 1% in the pericardium or tunica vaginalis testis (Musk & de Klerk, 2004). The UK has one of the highest incidence rates of mesothelioma internationally, with around 2700 new diagnoses each year (Cancer

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Research UK, 2021). Most cases of mesothelioma are caused by preventable asbestos exposure, which often occurs in occupational settings (Noonan, 2017). Despite some recent advances in treatment, mesothelioma typically progresses rapidly and the majority of people with the disease will die in a year of diagnosis (Cancer Research United Kingdom [CRUK], 2021).

Whilst the evidence base relating to palliative care in mesothelioma is very limited (Harrison et al., 2021), research has suggested that people with mesothelioma and their family carers have a wide range of palliative care needs throughout the trajectory of their illness, from diagnosis to the end of life (Tinkler et al., 2017). Palliative care needs in mesothelioma include a high physical and psychological symptom burden (commonly pain, dyspnea, fatigue, weight loss, anxiety and depression), communication and information needs, family carer burden and issues surrounding industrial disease compensation schemes (Harrison et al., 2021; Hoon et al., 2021). People with mesothelioma face challenges that are distinct from those seen in other cancers due to the complexity of the disease, rapidity of decline and the occupational causes (Kirkham et al., 2011). The importance of good palliative care in mesothelioma has been highlighted in the UK and internationally, and clinical guidance has been developed to support clinicians in providing palliative and supportive care (Scherpereel et al., 2010; Wiggins et al., 2007). Despite this, the evidence base is sparse and little is known about the most effective way to provide palliative care in mesothelioma (Harrison et al., 2021).

There is evidence from other conditions that early referral to specialist palliative care improves the quality of life of patients with palliative care needs, and also reduces health system costs and resource utilization (Smith et al., 2014; Temel et al., 2010). However, a recent multicentre randomized controlled trial in the UK and Australia (the RESPECT trial) found that early referral to specialist palliative care (SPC) in malignant pleural mesothelioma did not lead to any improvements in quality of life, when compared with standard care (Brims et al., 2019). The authors suggested that current standards of palliative care management in the UK and Australia are already adequate to meet the palliative care needs of patients early in the disease trajectory (Brims et al., 2019), and therefore early SPC did not confer any additional benefit. In the UK, palliative care management in mesothelioma is supported by a relatively recent innovation in patient care––the Mesothelioma UK Clinical Nurse Specialist (MCNS). MCNS's provide specialist support and care to people living with mesothelioma and their families, they have a wide remit supporting patients throughout the mesothelioma pathway including providing palliative and end of life care. MCNSs' are funded by the charity Mesothelioma UK who were established in 2004 and support a growing network of over 30 MCNS's, based in NHS hospitals around the UK.

In the UK, clinical nurse specialists (CNSs) working across a variety of fields play an increasingly important role in supporting patients with palliative care needs (Salamanca-Balen et al., 2018). Clinical Nurse Specialists have been found to demonstrate high levels of skill in managing complex conditions with palliative care needs. They bring specialized knowledge, skills and leadership into the clinical setting enhancing patient and family outcomes relating to palliative care (Seymour et al., 2002). For patients with mesothelioma, CNS's have been shown to play a crucial role in supporting patients and their families across the mesothelioma journey by facilitating communication and building relationships with patients and their families (Taylor et al., 2019). Whilst these skills are core components of a palliative care approach, there is little evidence on the specific role mesothelioma CNS's play in providing palliative care and supporting patients and families with palliative care needs. Nor is there evidence on the extent to which the MCNS role mitigates the need for early specialist palliative care. Therefore, the aim of this study was to explore perspectives of Mesothelioma UK Clinical Nurse Specialists (MCNS's) on their role in providing palliative care for patients with mesothelioma and their families.

2 | THE STUDY

2.1 | Aims

The aim of this study was to explore perspectives of Mesothelioma UK Clinical Nurse Specialists (MCNS's) on their role in providing palliative care for patients with mesothelioma and their families.

2.2 | Design

A qualitative descriptive approach (Doyle et al., 2020) was adopted using focus group and interview methods. A qualitative descriptive design was chosen as it recognizes the subjective nature of the problem, and the different experiences participants have, whilst presenting the findings in a way that directly reflects the initial research question.

2.3 | Participants

All MCNSs in the UK ($n = 30$) were invited to participate in a focus group or qualitative interview via an email from a member of the operational team at Mesothelioma UK. Those interested in participating contacted the research team directly and were invited to take part in a focus group ($n = 16$). Individual interviews were offered to those unable to attend a focus group, and to senior MCNSs whose participation might have influenced group discussion among more junior staff ($n = 3$). Information and consent sheets were shared with participants prior to participation and verbal consent was recorded at the beginning of each focus group or interview. Sample size was guided by pragmatism rather than theoretical influences such as saturation, and we attempted to recruit as many MCNS's as possible. However following data collection we were satisfied that no new themes were identified and saturation has been reached.

2.4 | Data collection

Focus groups were conducted via 'Google Meet' video conferencing software and interviews were conducted either using Google Meet or telephone. Focus groups and interviews were held in Jan-Feb 2021 and lasted between 30 and 60 min. A topic guide was developed based on previous literature (e.g., Harrison et al., 2021) and in collaboration with a patient and public involvement (PPI) representative (see Table 1). The topic guide explored 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. The focus group guide was not piloted, however, the research team reflected on the question guide after the first focus group and agreed no changes were required. Focus groups had two facilitators to enable one to lead the group, whilst the other navigated any technical difficulties and made field notes. Focus groups and interviews were digitally audio recorded and transcribed verbatim by a professional transcription service before being checked for accuracy by one of the facilitators.

2.5 | Ethical considerations

Ethics approval was obtained from a research ethics committee in a Health Sciences School at a UK University.

2.6 | Data analysis and rigour

Qualitative data were analysed with reference to Braun and Clarke's approach to reflexive thematic analysis to inductively explore and describe patterns across the data set (Braun & Clarke, 2021). To facilitate indexing and transparency, the data were 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. We used the consolidated criteria for reporting qualitative research (COREQ) as the reporting guideline for this paper.

TABLE 1 Topic guide questions

- 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 are 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?

3 | RESULTS

Sixteen MCNSs participated in three online focus groups and three individual interviews. At the time of recruitment, this represented more than half of the total number of MCNSs in the UK. Participant demographic information is shown in Table 2.

Four main themes were identified: MCNS role in relation to palliative care: 'being alongside' the person with mesothelioma and co-ordinating care, joint working with specialist palliative care, 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 underpinned by several subthemes, each of which is described in turn with key points illustrated by quotes. Table 3 provides a summary of the key themes and sub-themes.

3.1 | 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 emphasized the importance of 'being alongside' the patient and their family carer throughout their mesothelioma journey, and emphasized the need for palliative care from the point of diagnosis. Palliative care was perceived to be so integral to the MCNS role that participants struggled

TABLE 2 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%)

TABLE 3 Main themes and sub-themes arising from the analysis

Theme	Sub-themes
Mesothelioma UK CNS role in relation to palliative care: 'being alongside' the person with mesothelioma and co-ordinating care	• Palliative care is an integral part of the MCNS role • MCNS's provide a wide range of different aspects of palliative care • MCNS's have an important role in educating other health professionals about mesothelioma • Palliative care education and training for MCNS's is beneficial, but some gaps remain
Collaborative working with specialist palliative care services: vital but variable	• MCNS's work closely with specialist palliative care services to support patients with complex needs • Referrals to specialist palliative care can be complex and frustrating • MCNS's noted some characteristics of 'good' referrals to specialist palliative care
Patients and family carer's willingness to engage with palliative care services	• Patient and carers' negative perceptions of palliative care services are widely acknowledged and seen as a barrier to patients accepting palliative care. • MCNSs have developed strategies to facilitate engagement with palliative care services • Managing expectations and preparing patients and their carers requires a skilled approach
Impact of COVID-19 on palliative care provision for patients with mesothelioma and their family carers	• The COVID-19 pandemic, and in particular the move to remote consultations, has negatively impacted patient care • Increased numbers of patients presenting late in the course of the disease has been attributed to the COVID-19 pandemic. • The COVID-19 pandemic has led to greater difficulties accessing specialist palliative care • COVID-19 has also negatively impacted MCNS's training opportunities.

to single out the palliative components of their job, instead focusing on how palliative care was provided as part of individualized care throughout the patient journey.

> 'All the patients are palliative…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)

Aspects of palliative care routinely provided by MCNSs included managing symptom burden, psychological and emotional support, care co-ordination, 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.

> '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)

As well as providing patient care, MCNSs also play a vital role in educating other healthcare professionals about this rare disease and combating nihilistic attitudes.

> '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)

MCNSs described the benefits of the training they received, organized by the Mesothelioma UK charity. 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 on, thereby developing a collective knowledge that can be drawn on to enable the best support to be provided to patients with mesothelioma. However, participants also highlighted some training gaps in relation to palliative care.

> '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)

3.2 | Collaborative working with specialist palliative care services: Vital but variable

As described above, MCNSs are highly skilled in providing palliative care. However, all MCNS's acknowledged limitations to their own

knowledge, and described routinely referring to specialist palliative care to support patients with complex needs.

Barriers to referral were described. Several participants highlighted difficulties and delays when referrals to specialist palliative care had to go via district/community nursing services. This resulted in duplication of effort as multiple nurses (some without specialist mesothelioma or palliative care expertise) were assessing patients' need for palliative care. On occasion there were differences in opinion about whether patients required input from the specialist palliative care team.

> 'It is difficult because sometimes … 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 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. I always think with mesothelioma that sometimes like people kind of go along and then they just drop off the edge like, you know, 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)

> '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)

As mesothelioma is a rare cancer, those working in specialist palliative care may have limited or no knowledge of the condition; and additionally, may lack an appreciation of the specialist knowledge of MCNSs' in supporting mesothelioma palliative care needs. Participants felt this could present barriers to referrals, a solution to which was the sharing of knowledge and information about the specific challenges of mesothelioma that contribute to the unique palliative care needs. MCNSs used personalized approaches to enable referrals, for example telephoning specialist palliative care teams in addition to completing a referral form.

> '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 [other health care professionals] and educate them and explain to them, because sometimes they'll never have seen somebody with mesothelioma before'. (MCNS 16)

> 'I've started doing 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 … you're using the key words that trigger 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)

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 amenable to referral, (2) specialist palliative care input was provided in a timely and responsive manner (although individual MCNSs differed about the specific time), (3) referrals were enabled through collaborative relationships and open communication between MCNS and specialist palliative care teams and (4) SPC services were more integrated.

> '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…. [the] 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)

3.3 | Patients and family carer's willingness to engage with palliative care services

Issues around patient and carers' negative perceptions and misconceptions of palliative care services were widely acknowledged by MCNSs, and seen as a barrier to patients accepting palliative care. Fear, stigma and negative connotations associated with palliative care services 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 and the positive aspects of engaging with palliative care; using different terminology to avoid negative perceptions; and where appropriate referring patients to inpatient hospital services, as well as hospices.

> '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)

MCNSs recognized 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 and benefits 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 MCNSs to have difficult conversations, requiring a degree of 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)

3.4 | 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 recognized that this has negatively impacted on effective and compassionate communication with patients and their family carers, especially when having difficult conversations at 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 recognized the limitations of remote communication in terms of building rapport with the patient, and being able to judge when or if to share information or to broach issues without being guided by non-verbal cues.

> '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 (Do not Resuscitate) 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)

MCNSs attributed a recent increase in patients presenting late in the course of their disease to the COVID-19 pandemic. Due to the nature of mesothelioma this has devastating impacts. Delayed 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, have important conversations about palliative care, and an increased likelihood that the patient will be at a crisis point when they begin palliative care.

> '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)

Participants described differences in how specialist palliative care services responded to the pandemic. Some teams continued seeing patients, whereas others provided much of their support remotely. It was acknowledged that community palliative care services are under-resourced and this under-funding was more evident in 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)

The pandemic prevented some of the MCNSs from accessing training and also impacted their ability to educate other healthcare professionals about mesothelioma due to the cancellation of training sessions, study days and team meetings which had 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)

4 | DISCUSSION

Focus group and interview data from 16 Mesothelioma UK CNS's identified four key themes in relation to palliative care in mesothelioma. First, 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 individualized care. The majority of MCNS's in this study had previous experience of training in specialist palliative care, further emphasizing the skill and expertise of MCNS's in providing palliative care, and the centrality of palliative care to the MCNS role. Wider recognition of MCNS's high level of skill and expertise in palliative care will help ensure mesothelioma patients palliative care needs are met.

The 2019 RESPECT-meso trial found that early referral to specialist palliative care did not confer any additional benefits to quality of life over routine care, for patients with pleural mesothelioma (Brims et al., 2019). A more recent paper from this trial undertook a post hoc exploratory analysis of the symptom burden and unmet needs of trial participants. They reported a range of symptoms including fatigue, dyspnea, pain, weight loss, anxiety, low mood and anhedonia (Hoon et al., 2021). The role of MCNS's in meeting a range of palliative care needs, including those described by Hoon et al. (2021), suggest a key role for the MCNS in both meeting patients' palliative care needs, but also in mitigating the need for early specialist palliative care input. This theory is supported by evidence suggesting clinical nurse specialists in other (non-palliative care) disciplines can positively influence palliative care outcomes including involvement in treatment decisions, reduced hospitalisations, ED admissions and length of stay (Alessy et al., 2021; Salamanca-Balen et al., 2018). Whilst our qualitative data suggest MCNS's may contribute to a reduced need for early specialist palliative care, further research using quantitative methods is required to evaluate the extent to which MCNS input influences referrals to specialist palliative care, or influences patient outcomes relating to palliative care (e.g., pain, breathlessness and psychosocial symptoms).

Our data also suggest that joint working with specialist palliative care was perceived as vital, but was not always achieved. Partnership working between generalist and specialist palliative care services is known to support positive outcomes for patients with palliative care needs, for the health care system and for health professionals (Quill & Abernathy, 2013). However, our data clearly evidenced some challenges in relation to collaborative working with specialist palliative care, specifically in who takes responsibility for referrals and how those referrals are managed. Other mesothelioma research has found that when gaps exist in referral pathways, or continuity of care is disrupted, patients have reported feeling bewildered and abandoned (Clayson et al., 2005). Uncertainty and loss of control are compounded when a patient does not know who is co-ordinating their care, organized and co-ordinated services have been highlighted as a key requisite of palliative care in mesothelioma (Harrison et al., 2021).

Challenges in effective partnership working, and collaboration between specialist and generalist palliative care providers, have been identified in previous research (Gott et al., 2012). Evidence suggests that factors supporting good partnership working include appropriate and timely access to specialist palliative care and clear delineation of roles and responsibilities (Gardiner et al., 2012). Our evidence supports the importance of defining roles and of timely access, and priority should be given to addressing how these challenges can be overcome in clinical practice to facilitate improved collaborative working between specialists and generalists. Similarly, referral pathways from generalists to specialist palliative care teams can be variable and inconsistent and organizational change may be required to mitigate delays and improve efficiency. Such a focus on collaborative working is especially timely in light of recent health policy which places generalist healthcare staff, and in particular nurses, at the centre of palliative care provision (Ambitions for Palliative and End of Life Care, 2015).

MCNS's acknowledged the challenges of discussing palliative care with patients and their families. Misperceptions of the term 'palliative', alongside fear and stigma, contributed to a reluctance to engage with palliative care services, which could hinder the provision of effective support. 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. A recent study of patients with advanced cancer and their caregivers reported similar misperceptions of palliative care associating it with death, hopelessness, dependency and end of life comfort care for inpatients (Zimmermann et al., 2016). These perceptions

provoked fear and avoidance, and often originated from interactions with healthcare professionals. Participants emphasized the need for palliative care to be reframed and better explained by health care professionals (Zimmermann et al., 2016), similarly participants in our study spoke of their role in educating patients and their families with regards to palliative care. Rather than avoid using the term 'palliative care', which can exacerbate misunderstandings, evidence suggests a key aspect for promoting palliative care is use of the term itself alongside targeted educational strategies (McIlfatrick et al., 2014). Earlier conversations with patients and families about palliative care may help emphasize its important and positive role as part of the treatment journey and dispel myths (McIlfatrick et al., 2014). Perceptions of palliative care are influenced not only by interactions with health professionals, but also 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 (Hill 2021). To support this, the provision of accessible and dedicated information about palliative care in mesothelioma may be helpful for patients and families, for example, on websites or in paper form, to supplement improved communication from health professionals.

Finally, the COVID-19 pandemic has had a devastating and negative impact on people with mesothelioma, their family members, and on 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 et al., 2021). Recent evidence suggests the pandemic has led to increased late presentations of cancer (with a disproportionate impact on lung cancers) which brings about additional challenges for both the specialist palliative care and the MCNS workforce (UKCC 2020). Many of the changes made in response to COVID-19 are likely to remain, perhaps permanently (e.g. increased use of remote consultations). Whilst there may be positives such as increased flexibility and ease of access, the full impact and implications of these changes for patients and their families remain to be seen. Further research is needed to ensure the highest quality palliative care for patients with mesothelioma is maintained, whilst accommodating changes in service provision that persist as the legacy of COVID-19.

5 | LIMITATIONS

The study was conducted entirely in the UK and therefore applicability of findings to other countries may be limited. Whilst the original intention had been to conduct all data collection face to face, this was not possible due to COVID-19 restrictions. Detailed field notes were taken however, we acknowledge the limitations of online communications.

6 | CONCLUSION

This study provides valuable insights into palliative care needs in mesothelioma. Patients with mesothelioma and their families have significant palliative care needs throughout the course of their illness from diagnosis to the end of life. Mesothelioma UK CNSs' play a crucial role in supporting patients and families palliative care needs and are highly skilled in providing this care. Our findings have significant implications for palliative care provision in mesothelioma including the need to acknowledge the role of MCNS's in palliative care provision, the need to support collaborative working between specialist and generalist palliative care providers, and the need to improve both patient and public education and awareness around the role of palliative care.

AUTHOR CONTRIBUTIONS

CG had overall responsibility for the study and drafted the manuscript, MH collected and analysed data and contributed to drafts; BT analysed data and contributed to drafts, SH contributed to analysis and revised manuscript drafts.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the author(s).

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DATA AVAILABILITY STATEMENT

Data are available from the authors on request

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