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Research Article

Palliative care roles and responsibilities of mesothelioma clinical nurse specialists in the UK

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Mesothelioma is a rare incurable cancer caused by exposure to asbestos. Patients with mesothelioma have palliative care needs throughout the course of their illness, from diagnosis to the end of life. Mesothelioma clinical nurse specialists (CNSs) are central to providing care for patients with mesothelioma, but little is known about their role in providing palliative care. The aim of this study was to explore the views of mesothelioma patients and CNSs on the role of palliative care in mesothelioma, and explore which aspects of palliative care are provided by CNS's. The cross-sectional study included: (1) Secondary analysis of existing data from 510 mesothelioma patients who completed a 2019 survey of patient experiences and; (2) A survey of 23 Mesothelioma UK CNS's exploring their role in delivering palliative care. Data were analysed using descriptive statistics. Results indicated that 63% of mesothelioma patients did not feel that palliative care was needed at the time of survey completion. Data from the CNS survey showed that over 95% of CNS's felt they had a role in providing palliative care, and all CNSs had received some prior training or education in palliative care. Confidence in delivering palliative care was generally high with the mean score of 26.52 (SD = 2.68) out of a maximum of 30. CNS's are highly skilled at providing palliative care in mesothelioma, providing both specialist and generalist palliative care. However, work is required to encourage patients and their families to engage with palliative care earlier in the disease trajectory.

Keywords: Mesothelioma, Palliative care, Clinical nurse specialist, Nursing, End of life

Introduction

Mesothelioma is a rare, incurable cancer caused by exposure to asbestos. In the majority of cases mesothelioma will present in the pleura, but it can also occur in the peritoneum and in rare cases in the pericardium or tunica vaginalis testis[1,2]. Prognosis is poor with one and three-year survival rates 40% and 10%, respectively[3]. Few treatments are available; in the UK only around half of all patients will receive active anti-cancer treatment. Symptom burden is high and patients with mesothelioma have significant palliative care needs including fatigue, dyspnoea, pain, weight loss, anxiety, and low mood[4]. A 2020 literature review of palliative care needs in mesothelioma identified requirements for good palliative care including a coordinated team-based approach to palliative care, open and frank communication around the progression of the disease and the opportunity for patients and carers to discuss fears and anxieties around end of life issues[5]. In addition, mesothelioma is an industrial disease and as a consequence patients often face legal and compensation challenges unique to the condition.

Both specialist and generalist palliative care are acknowledged as important in the care of patients with mesothelioma, offering distinct but complementary approaches to care. Specialist palliative care (SPC) is care provided by those who have specialist training or expertise in palliative care, and generalist palliative care is defined as 'care provided by health or social care professionals other than those whose remit is SPC'[6]. In mesothelioma, clinical guidance recommends timely provision of palliative and supportive care[7,8] but the evidence base remains sparse and there is a lack of consensus about the most effective ways to provide palliative care[5,9]. Whilst there is evidence that early SPC improves quality of life among patients with a range of conditions,[10,11] the recent multicentre RESPECT trial found that early referral

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to SPC in pleural mesothelioma did not confer any additional benefits to quality of life, when compared with standard care[9]. It was hypothesized that current standards of palliative care management are already adequate to meet the palliative care needs of patients early in the disease trajectory, and therefore early SPC provides limited additional benefit. This theory has since been supported by qualitative research indicating mesothelioma clinical nurse specialists (CNSs) in the UK have an important role in providing both generalist and SPC and are involved in a patient care from early in the trajectory, often from diagnosis[12].

SPC services are facing growing pressures due to the aging population and increasing prevalence of long-term conditions. The COVID-19 pandemic has exacerbated capacity issues amid a significant increase in the demand for palliative and end of life care, particularly in the community[13]. CNSs across a variety of specialties play an important role in providing palliative care, and are particularly well-placed to provide the generalist palliative care required by most patients[12,14]. The CNS is in a unique position to provide palliative care due to their involvement across a range of settings including general practice, and the fact they are often in contact with patients, their families, other nurses and members of the multidisciplinary team[15]. A recent qualitative study of palliative care provision by mesothelioma CNSs in the UK found that these CNSs play a crucial role in providing palliative care. However, challenges with delivering good care were identified including inconsistent collaborative working alongside SPC services, perceived by CNSs as ‘vital but variable’. In addition, patient’s and family carer’s reluctance to engage with palliative care services was found to hamper timely initiation of palliative care[12]. Whilst this evidence reinforces the vital role that CNSs play in providing palliative care, little is known regarding patient’s views on palliative care in mesothelioma. Furthermore, there is sparse evidence on which aspects of palliative care are provided by CNS’s, what training they have received in palliative care, and their perceived confidence in delivering this care.

Methods

The aim of the study was to explore the views of mesothelioma patients and CNSs on the role of palliative care in mesothelioma, and explore which aspects of palliative care are provided by CNS’s.

Design: Cross -sectional study including: (1) Secondary analysis of existing data from 510 patients who completed the 2019 Mesothelioma Outcomes, Research and Experience (MORE) survey of patient experiences of mesothelioma and; (2) A survey of 23 Mesothelioma UK CNS’s exploring their role in delivering palliative care.

Data collection: The MORE survey was developed by the charity Mesothelioma UK and was piloted with volunteer patients. The survey comprised questions about: (i) patient experience of care and treatment; (ii) quality of life and; (iii) details of the individual clinical management of patients. The first two sections were completed by the patient, whilst the third section was completed by the patient and validated by a CNS.

Patients were recruited in May 2019 from across the UK and any patient ≥18 years with a diagnosis of mesothelioma was eligible to participate. Patients were recruited either directly by invitation from their CNS or via an open invitation posted on social media and in Mesothelioma UK newsletters. By these means, it is estimated that at least 70% of all UK patients with mesothelioma at that time were invited to participate. Participants were able to complete the survey in hard copy or via a weblink. The data were collected as part of a service evaluation and each mesothelioma CNS registered the survey with their NHS Trust Clinical Audit team. A subsequent data sharing agreement was set up between The University of Sheffield and Mesothelioma UK to facilitate the sharing of anonymized data.

The CNS survey was developed by the research team in collaboration with clinical experts, using the platform GoogleForms. It was piloted with two nurses and minor issues with wording and formatting were amended. The survey took approximately 15 min to complete and included five sections (i) respondent demographics; (ii) education and training in palliative care; (iii) role in providing palliative care; (iv) confidence in delivering palliative care assessed using the validated *Palliative Care Delivery Confidence Scale*[16]; and (v) difficulties in delivering palliative care to mesothelioma patients assessed using the validated *Difficulties in Palliative Care for Patients with MPM (DPCMPM) Scale*[17]. The Palliative Care Delivery Confidence scale generates responses from not confident at all to extremely confident across three domains (identifying when palliative care should begin, deciding when to refer to SPC, providing palliative care). Scores for the overall scale range from 3 to 30, with high scores indicating greater perceived confidence (Frey 2014). The DPCMPM scale assesses the perceived difficulty of delivering 15 different aspects of palliative care in mesothelioma. Each item is scored on a 5-point Likert scale from: 1 = not at all difficult, up to 5 = very difficult[17].

All mesothelioma CNSs in the UK ($n = 29$ at the time of study recruitment) were invited to participate in the online survey via an e-mail from the charity Mesothelioma UK (Mesothelioma UK funds all mesothelioma CNS's in the UK and provides operational support). The invitation e-mail included a link to an information sheet and the online survey. The survey was open for six weeks (21 October 2020–02 December 2020) and two reminder emails were sent during that time. Ethical approval was obtained from the School of Nursing and Midwifery research ethics committee at the University of Sheffield (reference: 036461).

Data analysis: All data were exported to SPSS v26 for analysis. Descriptive statistics (frequency, percentages, means, standard deviations) were calculated and qualitative data from the small number of free text questions was summarized and described narratively. Inferential analyses were not possible due to the small number of respondents.

Results

MORE survey

Completed surveys were received from 510 patients with mesothelioma, out of 662 patients invited (response rate 77%). The majority were male (n = 408, 80.1%) and over the age of 70 (n = 293, 57.5%). Most patients had been informed of the name of a CNS or other keyworker (n = 457, 90.9%). Almost 70% (n = 352) of patients were informed about a Mesothelioma UK-funded CNS, with 60% (n = 297) identifying that the Mesothelioma UK CNS nurse was their specialist nurse (Table 1).

When asked about palliative care provision 21% of patients (n = 104) said they had received support from a community palliative care nurse (Table 2). However the majority of respondents (n = 315, 63.3%) perceived that support from a palliative care nurse had 'not been needed'. Similarly, most respondents (n = 365, 73.4%) did not feel they required support in relation to end of life care planning, and a further 6.6% (n = 33) 'did not want to discuss it'. Only 8.7% (n = 45) patients had received support in relation to end of life planning.

Table 1 Access to and support provided by specialist nurses

Clinical nurse specialist input	n (valid %)
Informed of the name of specialist nurse	
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
Informed of a Mesothelioma UK funded nurse	
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

Patients 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 (n = 318, 63.7%), fatigue (n = 319, 63.9%) or pain (n = 308, 61.7%), with fewer experiencing a cough (n = 204, 41%) (see Table 3). Pain was the best controlled symptom with 48.5% of patients (n = 243) reporting that their pain was well controlled.

Clinical nurse specialist survey

A total of 23 mesothelioma CNSs responded to the survey (response rate 79.3%). The majority of CNS respondents were female (n = 22 95.7%) and aged between 45 and 54 years (n = 22, 95.7%). CNSs were predominantly based in a hospital setting (n = 21, 91.3%). Approximately half of the CNS's had previously worked in a SPC setting (n = 11, 47.8%). All CNS's had received some training or education in palliative care (n = 23, 100%), either through formal education such as an MSc or diploma (n = 12, 52.2%), or through training delivered in a SPC setting (11, 47.8%).

The survey asked about the different healthcare professionals involved in providing palliative care in mesothelioma (see Table 4). The majority of CNS's (n = 22, 95.7%) reported that it was their role to provide generalist palliative care, whereas SPC nurses were most commonly identified as being responsible for addressing a patient's SPC needs (n = 10, 43.5%). CNS's reported referring patients to a range of other services to meet their palliative care needs, most commonly community/hospital SPC teams (n = 23, 100%), and hospice (n = 22, 95.7%). Home nursing, breathlessness services, psycho-oncology, chaplaincy, community support, and out-of-hours services were also widely used.

Table 2 Palliative care provision for people with mesothelioma across the UK

Palliative care provision	n (valid %)
Was support received from a community palliative care nurse (e.g. Macmillan Nurse)?	
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
Was support received in relation to planning care towards the end of life?	
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

Table 3 Provision of symptom management for people with mesothelioma across the UK

Symptom management	*n* (valid %)
Did hospital doctors and nurses do everything they could to help control any breathlessness?	
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
Did hospital doctors and nurses do everything they could to help control any fatigue?	
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
Did hospital doctors and nurses do everything they could to help control any coughing?	
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
Did hospital doctors and nurses do everything they could to help control my pain?	
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

Table 4 Provision of palliative care for patients with mesothelioma and their families

Provision of palliative care for patients with mesothelioma	*n* (%)
Is it part of the Mesothelioma CNS role to provide generalist palliative care?	
Yes	22 (95.7)
No	1 (4.4)
Team member primarily responsible for addressing 'generalist' palliative care needs	
Mesothelioma CNS	12 (52.2)
Team effort	9 (39.1)
Lung cancer CNS	2 (8.7)
Team member primarily responsible for addressing 'specialist' palliative care needs	
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)
Services Mesothelioma CNSs usually refer mesothelioma patients to for palliative care	
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)

Table 5 Aspect of palliative care provided or advised upon by CNSs 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)
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)
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)
Information provision (mesothelioma and its effects, clinical trials, patient support groups)	23 (100)
Information provision (benefits and claiming compensation)	22 (95.7)
Information provision (managing emotions)	22 (95.7)

CNSs were asked which aspects of palliative care they provided for patients with mesothelioma (see Table 5). Respondents selected all applicable items. All CNSs provided symptom management, management of treatment side effects and support for family members and carers. Approximately two-thirds provided advance care planning ($n = 16$, 69.6%) with around half providing bereavement support ($n = 13$, 56.5%) and end of life care ($n = 11$, 47.8%). All CNSs ($n = 23$, 100%) reported they had an important role in information provision related to palliative care, mesothelioma, and its effects. Most also provided advice on benefits or compensation ($n = 22$, 95.7%) which are complex in mesothelioma due to the industrial nature of the disease.

Scores across all three domains of the Palliative Care Delivery Confidence scale were combined to provide an average, which derived the overall Confidence in Palliative Care Delivery score. Confidence was generally high with the mean score of 26.52 (SD = 2.68) out of a maximum of 30 (where higher scores indicate greater confidence). Scores from the Difficulties in Providing Palliative Care Scale (DPCMPM) indicate that 'working in a team with the same goal' was perceived to be the least difficult aspect of palliative care provision (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) (see Fig. 1). The aspects of palliative care perceived to be the most difficult to provide were: 'controlling pain and dyspnoea' (M = 3.39; SD = 1.03);

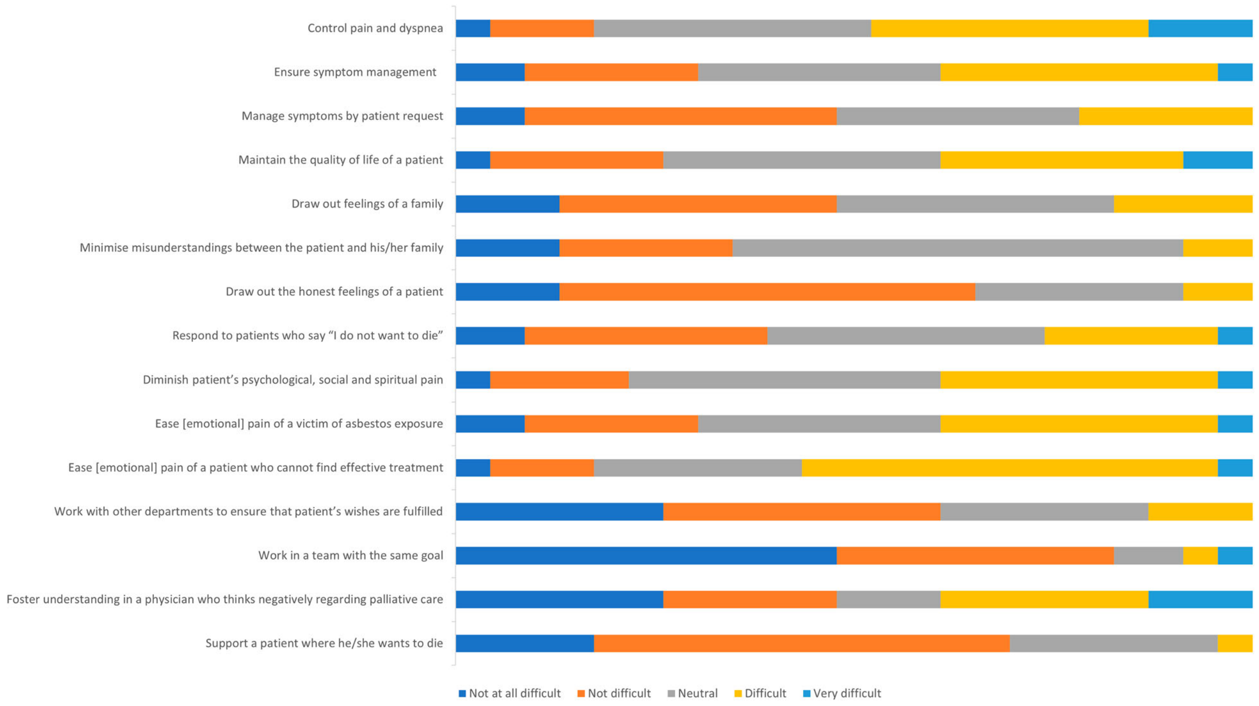

Figure 1 Perceived difficulty of providing different aspects of palliative care for patients with mesothelioma by Mesothlioma CNSs.

'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).

Discussion

This study, using data collected from patients with mesothelioma and the CNSs who care for them, highlights the significant role that mesothelioma CNS's play in providing palliative care. The vast majority of mesothelioma patients were aware of their CNS, and most patients felt the main physical symptoms of mesothelioma were well controlled by their care team. The high proportion of patients with a named CNS is encouraging from a palliative care perspective, as patients requiring palliative care can particularly value continuity of care and a single point of contact[5,18]. However, a high proportion of patients did not feel that palliative care and/or end of life care planning was needed at the time of survey completion. This is concerning given mounting evidence which indicates patients with mesothelioma have significant palliative care needs, often from diagnosis[4,5]. Whilst evidence on the value of a palliative approach is not disputed, public perceptions of palliative care remain synonymous with death, dying and hospice, leading many patients to feel reluctant to engage with palliative care[19,20]. Societal norms and taboos which discourage people from acknowledging or confronting death may also contribute to fear and misunderstandings around palliative and end of life care[19]. Reframing palliative care as a core component of the care package in mesothelioma may improve patient engagement, alongside emphasis on improving quality of life, benefits of early-stage engagement, and a clear message that it can be offered concurrently alongside anti-cancer treatments**.**

The survey of 23 mesothelioma CNSs found that the majority felt it was their role to provide palliative care, furthermore, all CNSs had received some prior training or education in palliative care. CNSs provided support or advice on many important aspects of both generalist and SPC. The level of palliative care skill and expertise amongst the mesothelioma CNS workforce is significant and perhaps surpasses what would be expected for a group who are not recognized as 'specialists' in palliative care. The recent RESPECT study reported early SPC did not improve overall outcomes for patients with mesothelioma in the UK and Australia[9]. One explanation for this finding was that existing service configurations already provided sufficient palliative care support for patients in the earlier stages of mesothelioma. The findings from our survey support this hypothesis and indicate that CNSs are central to supporting patients' palliative care needs, particularly earlier in the illness trajectory.

For patients with more complex support needs who require SPC, CNSs report referring to a range of other health care professionals, including SPC services. CNSs provide SPC themselves but work closely with other specialist teams with the aim of ensuring that seamless support is in place for the patient when symptoms become more complex. This finding supports existing evidence which suggests good partnership working between specialist and generalist palliative care providers is central to the provision of good palliative care[21,22]. 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 SPC services, and coordinated care[21]. These are areas for potential development in mesothelioma, to further support palliative care provision across the care continuum.

Confidence in the delivery of palliative care was reasonably high among CNSs, but some areas of palliative care were perceived to be more difficult to provide, including controlling pain and dyspnoea and maintaining quality of life. This indicates a need for ongoing education in palliative care, so CNSs can continue to gain confidence in the delivery of high quality care. There are growing calls for *all* nurses to receive education and training in generalist palliative care to meet increased demands, and palliative care education should be prioritized across the nursing workforce[13].

Limitations

Whilst the MORE survey captured experiences from a substantial sample of people with mesothelioma, patients who were at the end of life would presumably be less likely to participate, so views may not be fully representative. The CNS survey was based on a very small sample (due to the small number of mesothelioma CNS's across the UK). Therefore conclusions should be drawn with caution. All data were collected in the UK so international transferability cannot be guaranteed.

Conclusion

This study highlights the significant role that mesothelioma CNSs play in providing palliative care. Whilst CNSs support patients' palliative care needs and help manage a range of symptoms, many patients are reluctant to engage with palliative care, which remains a barrier to appropriate care for both patients and family. Strategies to address this should be prioritized including a reframing of the concept of palliative care to emphasize benefits of early-stage engagement for quality of life. Mesothelioma CNSs' have a high level of skill and expertise in palliative care and provide both specialist and generalist palliative care. The palliative care input provided by CNSs is likely to reduce the requirement for early referral to SPC. Whilst CNSs are confident in the delivery of palliative care, education and training should be prioritized to ensure they continue to provide a high level of care.

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Conflicts of interest None.

Ethics approval None.

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