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ORIGINAL ARTICLE

Managing malignant pleural mesothelioma: experience and perceptions of health care professionals caring for people with mesothelioma

Anne Warby[1,2] · Haryana M. Dhillon[1] · Steven Kao[2,3,4] · Janette L. Vardy[1,2,4,5]

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Abstract

Background Malignant pleural mesothelioma (MPM) has a poor prognosis and heavy symptom burden. Here, we investigate health professionals' attitudes to management and decision-making in people with MPM.

Methods Survey questions were based on previous interviews with health professionals, MPM patients, and caregivers. Surveys were sent to specialist doctors and nurses who treat MPM.

Results Surveys were completed by 107 doctors and 19 nurses from January–September 2014. Most doctors were respiratory physicians (50%) or medical oncologists (35%). Overall, 90% of doctors estimated ≥ 10% of eligible MPM patients did not receive chemotherapy; 43% estimated the rate was > 20%. Doctors believed clinical barriers to chemotherapy were clinician nihilism (70%); non-referral to medical oncology (49%); and lack of specialists in rural/regional areas (44%). Nurses perceived barriers as follows: delayed diagnosis (74%); non-referral to medical oncology (63%); lack of clinician knowledge (58%). Patient-related barriers were negative perception of chemotherapy (83%) and belief survival benefit not worthwhile (63%). Doctors' preference in decision-making was for the patient to make the decision while strongly considering the doctor's opinion (33%); equally with the doctor (29%); and using knowledge gained (23%). Nurses described their roles as providing patient support (100%); information (95%); intermediary (74%); and link to palliative care (74%). Overall, 95% believed they enabled better resource allocation and provided patients with holistic care (95%); clearer communication (89%); more time (89%); additional information (89%); timely referrals (89%).

Conclusions Caring for patients with MPM is challenging and complex. Health care professionals believe under-utilisation of chemotherapy is occurring, primarily due to clinician nihilism and lack of medical oncology referral.

Keywords Malignant pleural mesothelioma · Health care professionals · Chemotherapy · Decision-making

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✉ Janette L. Vardy
janette.vardy@sydney.edu.au

[1] Centre for Medical Psychology and Evidence-Based Decision-Making, The University of Sydney, Sydney, NSW 2006, Australia

[2] Asbestos Diseases Research Institute, Bernie Banton Centre, Gate 3, Hospital Rd., Concord, NSW 2139, Australia

[3] Chris O'Brien Lifehouse, 119-143 Missenden Rd., Camperdown, NSW 2050, Australia

[4] Sydney Medical School, The University of Sydney, Sydney, NSW 2006, Australia

[5] Concord Cancer Centre, Concord Repatriation General Hospital, Hospital Rd, Concord, NSW 2139, Australia

Introduction

Most patients diagnosed with malignant pleural mesothelioma (MPM) have unresectable disease at diagnosis and a median overall survival with treatment of 12 months [1]. In these people, cisplatin and pemetrexed chemotherapies is proven to prolong overall survival, providing a 3-month median survival benefit [1–3] and improvements in quality of life [4, 5].

Our previous research developed a model to estimate the optimal rate of chemotherapy utilisation in MPM, based on guideline recommendations and available clinical trial results. We found 65% of patients met indications for chemotherapy [6]. However, reported utilisation rates are variable, but increasing since the publication of the landmark Vogelzang study reporting benefit with pemetrexed [1], varying from 40% in the UK, with 59% of patients with good performance status [7], 60% in Belgium [8], 41% in the Netherlands [8],

54% in Australia [9], and 45% in the USA [10]. Given this variation in chemotherapy use in routine practice internationally, it is important to understand the reasons; whether it is due to patient or clinician preference, or other factors.

Our aim was to evaluate the perceptions of health professionals who treat MPM, regarding treatment decision-making, particularly in relation to chemotherapy, and to determine potential barriers and facilitators, and to explore the treatment experience of MPM patients, and their caregivers. Here, we report the health professionals' perceptions and how doctors make treatment decisions with people with MPM. The primary aim was to determine health care professionals' opinions regarding the proportion of eligible MPM patients not receiving chemotherapy and the main barriers to receiving treatment.

Methods

Development of survey

Qualitative interviews were used to identify concerns and perspective of MPM patients, caregivers, and health professionals (medical specialists and lung cancer nurses) who treat mesothelioma, about treatment for people with MPM (results reported elsewhere) [11]. Data were used to develop items for surveys of patients, caregivers, and health professionals to further investigate barriers and facilitators to treatment, and to review the diagnostic process, treatment, decision-making, and issues associated with MPM. Four separate but related surveys were developed by the authors, who include two medical oncologists with experience treating MPM, for each of the following groups: (1) specialist doctors who treat people with MPM; (2) specialist cancer nurses who care for people with MPM; (3) people diagnosed with MPM; and (4) caregivers of individuals diagnosed with MPM.

The health professionals' questions were reviewed by six doctors and nurses involved in treatment and care of MPM patients, two senior researchers and the Executive Officer from the Asbestos Diseases Research Institute (ADRI), two mesothelioma researchers from Southern Cross University, and a lawyer experienced in representing clients with MPM. Reviewers provided feedback on the survey instructions, questions, and response options, and whether any questions should be added. The final surveys (see Supplementary Appendix 1 for example) consisted of 43–44 items covering topics of diagnostic process; treatment decision-making; multi-disciplinary team meeting involvement; compensation; and chemotherapy utilisation.

Study data were collected and managed using REDCap electronic data capture tools hosted at The University of Sydney [12].

Participants

Health professionals (specialist doctors and nurses) were recruited through eight professional organisations and specialist colleges. Study information was circulated to members via five group e-mail and three electronic regular newsletters, with a link to the online questionnaire (Supplementary Table 1); reminders were sent according to the professional organisations' policy.

Snowballing techniques were also used, whereby those receiving the email were invited to forward it to colleagues who may have been suitable respondents.

Procedure

Surveys were completed anonymously, either online with a survey-specific hyperlink sent via e-mail or hard copy. The survey took ~20 min to complete, and submission of the survey was accepted as implied consent. The study was approved by the Concord Repatriation General Hospital Health Research Ethics Committee (HREC/12/CRGH/122).

Analysis

All respondents who submitted the questionnaire were included in the analysis. Descriptive statistics were used to report the data. The sample size was determined by accessibility of the population and responses. Due to health care professionals being members across multiple organisations and most organisations' members not treating MPM, it was not possible to determine the response rate for the survey. Postcode was used to determine work location, with the Accessibility Remoteness Index of Australia (ARIA) tool used to designate location into metropolitan, regional, and remote [13].

Results

In total, 126 health professionals (107 doctors, 19 specialist nurses) submitted the survey between January and September 2014 (Table 1). All but one were completed online. Missing data were minimal, ranging from 0 to 2% for individual questions (Supplementary Table 2). Unless indicated otherwise, the percentages reported were calculated using the following denominators: $N = 107$ for doctors and $N = 19$ for nurses.

Medical specialties included 53 (50%) respiratory physicians, 37 (35%) medical oncologists, 7 (7%) radiation oncologists, 3 (3%) palliative care physicians, 3 (3%) thoracic surgeons, and 4 (4%) doctors with dual accreditation. Median age was 43 years (range 31–75); 72% of doctors were male and all nurses were female. The majority worked in the public health system in metropolitan practices. Most nurses described their position as lung cancer care coordinators or clinical nurse consultants

Table 1 Participant demographic information

	Doctor $N = 107$	Nurse $N = 19$
Age (years)		
- Median	43	44
- (Range)	(31–75)	(29–68)
Sex		
- Male	77 (72%)	0 (0%)
- Female	27 (25%)	19 (100%)
- Missing	3 (3%)	0 (0%)
Median time since specialist qualifications: years (range)	12 (0–46)	6 (3–20)
Medical specialities		N/A
Respiratory physician	53 (50%)	
Medical oncologist	37 (35%)	
Radiation oncologist	7 (7%)	
Thoracic surgeon	3 (3%)	
Palliative care physician	3 (3%)	
Dual accreditation	4 (4%)	
Nursing specialties	N/A	
Lung cancer care co-ordinator		8 (42%)
Clinical nurse consultant (thoracic medicine/surgery or oncology)		7 (37%)
Clinical nurse specialist		3 (16%)
Other		1 (5%)
Location		
- NSW	33 (31%)	8 (42%)
- Queensland	15 (14%)	0 (0%)
- Victoria	28 (26%)	4 (21%)
- SA	7 (7%)	2 (11%)
- WA	10 (9%)	2 (11%)
- Tasmania	1 (1%)	1 (5%)
- ACT	1 (1%)	1 (5%)
- New Zealand	8 (7%)	0 (0%)
Unknown	4 (4%)	1 (5%)
Location type of practice		
- Metropolitan	84%	74%
- Regional	12%	21%
- Remote	0%	0%
- Unknown	4%	5%
Type of medical practice		
Public	50 (47%)	10 (53%)
Private	12 (11%)	4 (21%)
Mix of both	45 (42%)	5 (26%)

NSW, New South Wales; *SA*, South Australia; *WA*, Western Australia; *ACT*, Australian Capital Territory; *NT*, Northern Territory; *NA*, not applicable

(thoracic) and rated their position as most closely aligned with oncology (medical and/or radiation) (9/19, 47%) or combined thoracic surgery/respiratory medicine/oncology (7, 37%).

Doctors had been specialty qualified for a median of 12 years and nurses in a specialty position for 6 years. Doctors saw a median of five new MPM patients annually (range 0–50) and nurses 10 (range 1–40). Overall, 102 (95%) doctors were involved in the diagnosis of MPM patients. Only 47 (44%) reported their practice included a lung cancer nurse specialist, and 93% of these worked in metropolitan areas.

Nurses typically were first linked to MPM patients through inpatient ward (10, 53%); multi-disciplinary team meetings (MDTM) (10, 53%); medical specialist (10, 53%); or general practitioner referral (7, 37%). Nurses believed patients with MPM were not referred to them sometimes (42%) or frequently (16%).

Nurses described the main functions of their position as support for patients (19/19, 100%); information for patients (18, 95%); an intermediary between doctor and patient (14, 74%); interaction with palliative care (14, 74%); and interaction with allied health services (13, 68%). Only 4 (21%) nurses reported being always kept adequately informed of patient care, treatment, and changes by treating clinicians. Almost all nurses perceived involvement of a cancer nurse specialist benefited medical specialists providing care to MPM patients (18, 95%) by better resource management (18, 95%); viewing the patient holistically (18, 95%); clearer communication with patients (17, 89%); spending more time with patients/families (17, 89%); providing additional medical information to patients (17, 89%); undertaking timely referrals for patient services (17, 89%); better management of treatment (12, 63%); and timely referrals to other health professionals (15, 79%).

Barriers to treatment in MPM patients

Participants estimated the proportion of patients potentially eligible for chemotherapy not receiving it. Overall, 31% of doctors and 26% of nurses estimated 11–20% of eligible patients did not receive chemotherapy, and 43% and 26%, respectively, estimated it was greater than 20%.

The main clinical barriers to chemotherapy reported by doctors were clinician nihilism (75); non-referral of patients to a medical oncologist for an opinion (52); lack of services or access to cancer specialists in rural or regional areas (47). By contrast, nurses reported the main barriers as follows: delayed diagnosis (14); patients not being referred to medical oncology (12); and lack of clinician knowledge regarding treatment options (11) (Table 2).

Health professionals perceived the main patient-related barriers to chemotherapy to be as follows: negative perceptions of chemotherapy; patient perception of insufficient survival benefit from chemotherapy; and patient deferral of chemotherapy followed by rapid deterioration (Table 2).

Nurses perceived other interventions/treatments managed by nursing or allied health that may impact on feasibility or acceptability of chemotherapy for MPM to be education and breathlessness management, (both 18, 95%); general

Table 2 Perceived barriers to treatment in malignant pleural mesothelioma (MPM) patients

Question	Doctor $N = 107$	Nurse $N = 19$
Proportion of patients potentially eligible for chemotherapy who do not receive it		
0%	1 (1%)	1 (5%)
< 10%	10 (9%)	4 (21%)
10%	15 (14%)	4 (21%)
11–20%	33 (31%)	5 (26%)
> 20%	46 (43%)	5 (26%)
Missing	2 (2%)	0 (0%)
Clinical/clinician-related barriers to MPM patients receiving chemotherapy[a]		
I do not believe there are any clinical/clinician-related barriers to MPM patients receiving chemotherapy	16 (15%)	3 (16%)
Lack of clinician knowledge about treatment options	43 (40%)	11 (58%)
Lack of general cancer services or access to cancer specialists in rural or regional areas	47 (44%)	10 (53%)
MPM cases not being reviewed in a multi-disciplinary team meeting	44 (41%)	6 (32%)
Clinician nihilism regarding MPM	75 (70%)	7 (37%)
Delayed diagnosis of MPM	40 (37%)	14 (74%)
Non-referral of patients to a medical oncologist for an opinion on chemotherapy	52 (49%)	12 (63%)
Inadequate evaluation of a patient's performance status, reducing their suitability to be referred for chemotherapy	17 (16%)	3 (16%)
Lack of access to carboplatin through the PBS (i.e. carboplatin may be better tolerated than cisplatin but is not funded)	24 (22%)	3 (16%)
Medical professionals biasing patients against having chemotherapy	38 (36%)	6 (32%)
Lack of access to specialist MPM centres	22 (21%)	5 (26%)
Other	3 (3%)	0 (0%)
Missing	0 (0%)	0 (0%)
Patient-related barriers to MPM patients receiving chemotherapy[a]		
I do not believe there are any patient-related barriers to MPM patients receiving chemotherapy	11 (10%)	0 (0%)
Patient negative perception of chemotherapy regarding toxicity and impact on quality of life	87 (81%)	18 (95%)
Patient perception of insufficient survival benefit from chemotherapy	64 (60%)	15 (79%)
Logistical issues relating to chemotherapy treatment for patients in rural/regional areas	38 (36%)	8 (42%)
Patient nihilism regarding mesothelioma	31 (29%)	3 (16%)
Patient deferral of chemotherapy and then not being well enough to start due to rapid disease progression	50 (47%)	12 (63%)
Patients with symptoms not pursuing a diagnosis due to fear of mesothelioma	8 (7%)	5 (26%)
Other	0 (0%)	0 (0%)
Missing	0 (0%)	0 (0%)

[a] More than one response possible—so percentage may exceed 100

information for patients, pain management, and coordination of treatment (especially rural/regional patients), (all 16, 84%); and psychological support (15, 79%).

Treatment for MPM

Asked when it was appropriate for chemotherapy to be given to asymptomatic MPM patients with good performance status, most thought treat early following diagnosis (doctors 38, 36%; nurses 12, 63%); dependent on patient preference (doctors 37, 35%; nurses 3, 16%); or delay until patient becomes symptomatic (doctors 23, 21%; nurses 2, 11%).

The majority of medical oncologists ($N = 39$) reported usually giving 6 cycles of a platinum and pemetrexed for first-line chemotherapy (27; 69%). Overall, 23 (59%) medical oncologists would not recommend maintenance chemotherapy to

MPM patients who had a good response to chemotherapy with minimal side effects and good performance status. In total, 31 (79%) would recommend second-line chemotherapy on disease progression with reasonable performance status. Only medical oncologists were asked what was involved in the clinical decision to stop chemotherapy treatment. The most common reasons given to stop treatment were disease progression (36); toxicity (side effects versus benefits) (36); and patient preference (35).

Overall, 62% of doctors reported prophylactic radiotherapy to port sites was 'never' or 'rarely' used. In total, 24% of doctors stated referral for radical radiation therapy (with lung in situ), and 32% referral for extrapleural pneumonectomy would be considered at their institution. The main reason such referral was not considered was the perception of little or no evidence to support the efficacy of these treatment options for MPM patients. Some doctors noted neither treatment was available locally to their patients.

The allied health professionals who MPM patients were reportedly most likely referred to were social worker (doctors 45%, nurses 68%); dietitian (34%, 58%); and physiotherapist (25%, 42%) (Fig. 1).

Decision-making in MPM patients

Approximately 90% of doctors and 53% of nurses reported moderate-to-high level involvement in helping patients make decisions regarding treatment. The most common way doctors believed they assisted was engaging in discussions regarding treatment options (89/107). Nurses who assisted patients with treatment decisions (14/19) reported doing so by answering patient questions about treatment (14/14). Nurses reported MPM patients typically wanted 'a lot' or 'quite a bit' of input from cancer nurse specialists in the decision-making process (16, 84%).

Doctors reported a preference for patients to make treatment decisions, while strongly considering the doctor's opinion (33%). Overall, 47% of nurses perceived patients made the decision taking into account the doctors' recommendations. Table 3 presents full details.

Multi-disciplinary team meetings

The majority of doctors (85%) and nurses (74%) participated in MDTM, generally meeting weekly. For doctors, 62% attended a lung-specific MDTM. Doctors estimated 75% of their own MPM patients were presented and 49% of their colleagues' patients. Nurses perceived 29% of all MPM patients were reviewed. Participants indicated MPM patients should be presented at a MDTM: at diagnosis and when management changes (doctors 56%; nurses 50%); when the optimal treatment plan is unclear (doctors 18%; nurses 21%); or at diagnosis only (doctors 16%; nurses 14%). Full details in Table 4.

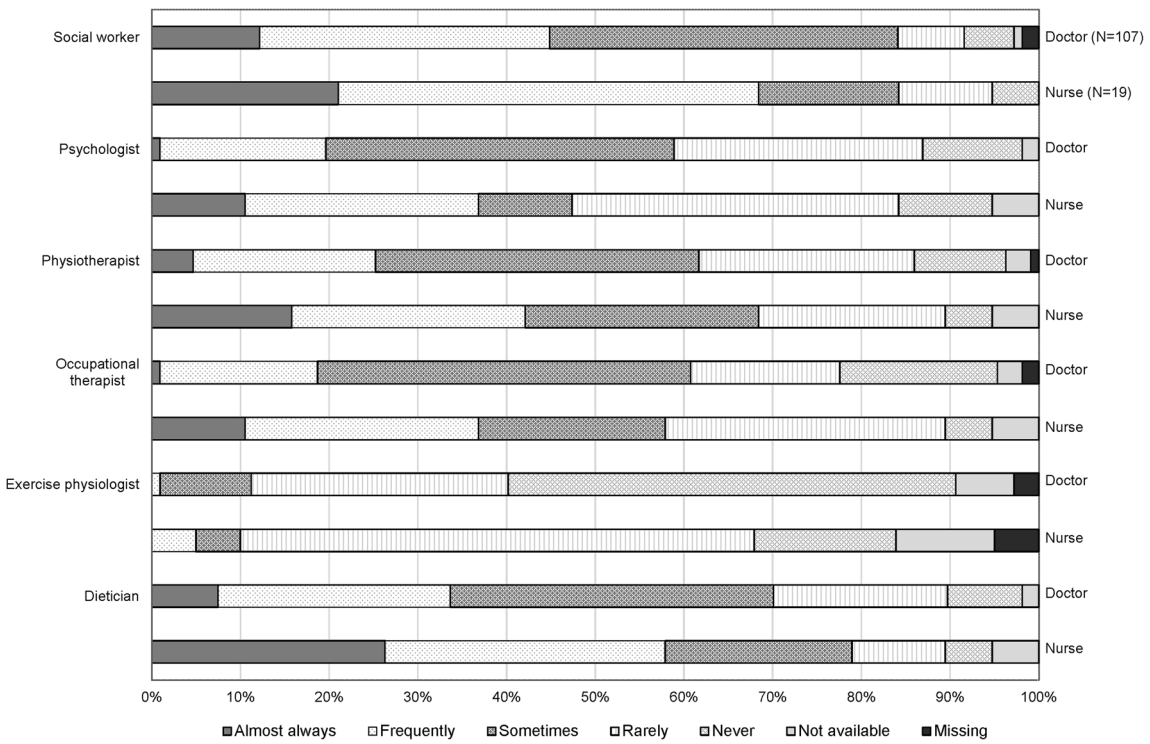

Fig. 1 Frequency of referral of patients with malignant pleural mesothelioma to allied health professionals

Table 3 Involvement in decision-making

Question	Doctor $N = 107$	Nurse $N = 19$
How involved are you in treatment decisions?	60 (56%)	5 (26%)
High level of involvement	37 (35%)	5 (26%)
Moderate level	9 (8%)	4 (21%)
Minimal involvement	1 (1%)	5 (26%)
No involvement		
How do you assist patients with decisions?[a]		
Doctor/nurse responses		
I am not involved in the decision-making process with patients	4 (4%)	5 (26%)
Detailed discussion(s) with patients about their treatment options	89 (83%)	10 (53%)
Providing patients with written information	46 (43%)	13 (68%)
Involvement of a specialist nurse when discussing treatment options with patients	22 (21%)	N/A
Making a decision over more than one consultation	61 (57%)	N/A
Providing general support for patients and their families in the decision-making process	70 (65%)	12 (63%)
Other	5 (5%)	1 (5%)
Nurse-specific responses		
Answering patient questions about treatment		14 (74%)
Participation in the consultation with the medical specialist and the patient		8 (42%)
Reviewing treatment options with patients following their consultation with the medical specialist		8 (42%)
Organise family consults with relevant clinical staff		10 (53%)
Doctors: What is your preference for patient involvement in decision-making?		
Nurses: Who in your opinion generally makes the decision about treatment?		
Patient makes the decision using all they know or have learned about the treatments	25 (23%)	1 (5%)
Patient makes the decision, but strongly considers the doctor's opinion	35 (33%)	9 (47%)
Patient makes the decision in conjunction with their family	8 (7%)	3 (16%)
Doctor and patient make the decision together on an equal basis	31 (29%)	3 (16%)
Doctor makes the decision but strongly considers the patient's opinion	7 (7%)	3 (16%)
Doctor makes the decision using all that is known about the treatments	0 (0%)	0 (0%)
Missing	1 (1%)	0 (0%)

NA, not applicable

[a] More than one response possible—so percentage may exceed 100

Other issues associated with MPM

Participants were asked about provision of information about compensation to MPM patients (Table 5). Overall, 95/126 (75%) stated they 'always' or 'almost always' recommend patients seek information about compensation. Of those who refer, they most commonly referred patients to government compensation bodies (66/123) and legal firms experienced in asbestos diseases compensation (50/123) or to obtain legal advice generally (47/123). Overall, 60% of participants reported being comfortable informing patients about compensation issues. Of the 15 participants who reported they were not comfortable, the main reason was lack of knowledge about compensation. In total, 26/107 (24%) doctors had been expert witnesses in compensation claims: 7/26 (27%) frequently, and 18/26 (69%) reported being comfortable with this role.

Although MPM is strongly associated with occupational asbestos exposure, respondents expressed concern regarding general practitioner awareness of patients' asbestos exposure. Main barriers to general practitioner's obtaining a detailed asbestos exposure history were perceived to be lack of time (92/126); complexity of information (71/126); lack of knowledge (64/126); and lack of awareness about MPM (51/126).

Australian 'Guidelines for the Diagnosis and Treatment of MPM' [14] were published the year prior to the survey being administered: 36/107 (34%) doctors reported having read these, and 12/19 (63%) nurses.

Table 4 Multi-disciplinary team meetings (MDTM) for patients with malignant pleural mesothelioma (MPM)

Question	Doctor $N = 107$	Nurse $N = 19$
Participation in lung/MPM MDT meeting (MDTM)		
Yes	91 (85%)	14 (74%)
No	16 (15%)	4 (22%)
Missing	0 (0%)	1 (5%)
If yes to participating in a MDTM:	$N = 91$	$N = 14$
- Which specialities are represented?[a]		
Lung cancer nurse specialist	48 (53%)	6 (43%)
Lung care co-ordinator	45 (49%)	5 (36%)
Medical oncology	90 (99%)	14 (100%)
Nuclear medicine	49 (54%)	10 (71%)
Palliative care	53 (58%)	3 (21%)
Pathology	79 (87%)	12 (86%)
Radiology	85 (93%)	13 (93%)
Radiation oncology	89 (98%)	13 (93%)
Respiratory medicine	89 (98%)	11 (79%)
Thoracic surgery	78 (86%)	13 (93%)
Allied health	25 (27%)	4 (29%)
Other	6 (7%)	5 (36%)
- Are all your MPM patients presented? (doctor question)		
Yes	68 (75%)	N/A
No	22 (24%)	N/A
Missing	1 (1%)	N/A
- Do you believe all MPM patients are presented to MDTM (nurse question)		
Yes	N/A	4 (29%)
No	N/A	6 (43%)
Unsure	N/A	4 (29%)
If not all patients presented, why not? [a]	$N = 22$	$N = 10$
Time constraints within MDT meeting	5 (23%)	1 (10%)
Consult with colleagues outside meeting	11 (50%)	5 (50%)
Decision already made on patient treatment	15 (68%)	4 (40%)
Other	1 (5%)	0 (0%)
- Do you believe your colleagues present all MPM patients to MDTM for review?	45 (49%)	
Yes	16 (18%)	N/A
No	28 (31%)	N/A
Unsure	2 (2%)	N/A
Missing	0 (0%)	
- When is MPM patient's case generally presented? [a]	$N = 91$	$N = 14$
During diagnosis pathway	42 (46%)	11 (79%)
Following confirmation of diagnosis (e.g. for initial treatment plan)	71 (78%)	12 (83%)
When decisions about treatment are needed	33 (36%)	10 (71%)
Other	0 (0%)	0 (0%)
- When should MPM patients be presented at MDTM?		
All patients at diagnosis only	15 (16%)	2 (14%)
All patients at diagnosis and when management changes	51 (56%)	7 (50%)
When optimal treatment plan is unclear	16 (18%)	3 (21%)
All should be presented, but is unfeasible	7 (8%)	2 (14%)
Most do not need to be presented as treatment plan is clear	1 (1%)	0 (0%)
Never, MDT meetings are poor use of time	0 (0%)	0 (0%)
Missing	1 (1%)	0 (0%)

NA, not applicable

[a] More than one response possible—so percentage may exceed 100

Discussion

Our survey sought opinions regarding treatment of people with MPM from health care professionals across Australia and New Zealand involved in treating this rare malignancy with a poor prognosis and high symptom burden.

Recently published American Society of Clinical Oncology Guidelines for MPM strongly recommend chemotherapy be offered to patients due to evidence of improved survival and quality of life [15]. They recommend considering close observation prior to commencing chemotherapy for asymptomatic patients with epithelial histology and minimal pleural disease

Table 5 Compensation issues for patients with malignant pleural mesothelioma (MPM)

	Doctor $N = 107$	Nurse $N = 19$
Do you recommend patients with MPM seek information about compensation?		
Never	2 (2%)	1 (5%)
Rarely	1 (1%)	0 (0%)
Sometimes	8 (7%)	3 (16%)
Frequently	16 (15%)	0 (0%)
Almost always	30 (28%)	1 (5%)
Always	50 (47%)	14 (74%)
Where do you usually refer patients for information about compensation?[a]		
State or Commonwealth compensation body	57 (53%)	9 (47%)
General legal advice	42 (39%)	5 (26%)
Legal firms who do compensation work for asbestos diseases	38 (36%)	12 (63%)
Tell them about one legal firm	8 (7%)	1 (5%)
Refer them to a specific solicitor	2 (2%)	2 (11%)
Tell them to contact a community-based asbestos diseases organisation	29 (27%)	7 (37%)
Refer them to a social worker	23 (21%)	6 (32%)
Other	9 (8%)	1 (5%)
Don't refer	2 (2%)	1 (5%)
Are you comfortable with your involvement in informing patients about compensation issues?		
Yes	64 (60%)	10 (53%)
Somewhat	29 (27%)	5 (26%)
No	12 (11%)	3 (16%)
Not applicable	0 (0%)	0 (0%)
Missing	2 (3%)	1 (5%)
If you are not comfortable, why not?[a]	$N = 12$	$N = 3$
Time-consuming process	1 (8%)	0 (0%)
Lack of knowledge about compensation	10 (83%)	3 (100%)
Not my role	3 (25%)	0 (0%)
Could be seen as a conflict of interest	3 (25%)	0 (0%)
Concerns patients do not understand my role/motivation	N/A	0 (0%)
Other	1 (8%)	0 (0%)

NA, not applicable

[a] More than one response possible—so percentage may exceed 100

who are not candidates for surgical resection. Our previous study estimated the optimal rate of chemotherapy utilisation to be 61% [6]. In this study, 88% of doctors estimated the proportion of potentially eligible patients who do not receive chemotherapy to be at least 10%, with 43% reporting it to be greater than 20%. In our companion study of MPM patients and caregivers, 72–77% reported receiving chemotherapy (unpublished data). Overall, 21% of doctors thought delaying chemotherapy for asymptomatic patients is appropriate; 36% preferred early treatment following diagnosis; and for another 35%, it was dependent on patient preference. Our survey preceded the guidelines and no information was provided regarding histology or amount of pleural disease, but our results highlight variable practices in the community and a need for active implementation of guidelines.

Our data show that health care professionals treating MPM believe a sizable proportion of MPM patients eligible for chemotherapy do not receive it. The main clinician barriers to patients receiving chemotherapy were believed to be clinician nihilism, non-referral to a medical oncologist, lack of service availability in rural or regional areas, delayed diagnosis, and lack of clinician knowledge about treatment options. This highlights a discrepancy with patients' and caregivers' preference, which was to consider and discuss all relevant treatment options. For this to occur, it is important patients are referred to medical oncologists to discuss the suitability of chemotherapy for each individual.

The main patient-related barriers to receiving chemotherapy were the same for doctors and nurses, reflecting broader community perceptions of chemotherapy as a toxic treatment with invariably negative consequences. We acknowledge perceived barriers to treatment may be different to actual barriers and further research is required to explore this. However, these data suggest a need to address community perceptions about chemotherapy and its capacity to reduce symptoms in many people with advanced cancer, in order to reduce patient barriers to accessing appropriate evidence-based care at the time of diagnosis.

Ultimately, it is the patient's choice to accept anti-cancer treatment or not; generally, based on weighing potential improved survival and reduced disease symptoms against treatment-related side effects. Reasons for declining cancer treatment are often multifactorial, but comorbidities, advanced age, uncertainty about benefits or concerns about treatment efficacy, fear of treatment side effects, poor doctor-patient communication, wishing to maintain control, and seeking a holistic approach or use of complementary and alternative medicine are most commonly cited, particularly in qualitative studies [16]. Kefflens and Leeuwen suggest that patients' decisions are often based on their values or experience, whereas physicians tend to be goal-orientated [17]. A systematic review evaluating lung cancer patients' preferences for chemotherapy reported > 50% believed moderate survival rates (rated as 6-month increased survival) made chemotherapy worthwhile, with smaller survival benefits accepted for metastatic cancer, but there was a wide individual variation in preferences. Younger patients, those with dependents, higher education, and poorer quality of life, were more likely to accept a smaller benefit [18]. However, much of this research predates improved treatments and supportive care therapies. Of note, community bias against chemotherapy seems based on earlier

treatment regimens and few supportive care therapies. For example, a small randomised pilot study comparing early versus delayed chemotherapy for people with MPM and stable symptoms reported no significant difference in time to symptomatic progression and no difference in quality of life [19]. However, since then, a new chemotherapy standard of care has demonstrated efficacy in this setting [1]. Research in the setting of incurable cancers such as MPM is lacking.

Almost all doctors reported a moderate-to-high involvement in helping patients make treatment decisions. Overall, their responses reflect a preference for shared decision-making approaches in which patients play an active role in decision-making. Only 7% preferred to make the decision themselves, suggesting a low preference for paternalistic care. In contrast, a larger proportion of nurses perceived the doctor made treatment decisions and this was similar to the proportion of patients reporting doctors made the decision. Taken together, these results suggest a reasonable level of shared decision-making occurring in practice, but perceptions about this vary between respondent groups. Additional training in shared decision-making communication strategies could assist all groups to achieve their preferred approach to decision-making.

Australian guidelines for MPM suggest patients should be treated in centres offering expert mesothelioma care [14]. Our data suggest doctors and nurses who treat MPM believe patients are more likely to receive appropriate care and have greater access to services if treated at specialist MPM centres. Overall, 21% of respondents indicated lack of access to specialist MPM centres as a barrier to MPM patients receiving chemotherapy, and 45% a lack of general cancer services or access to cancer specialists in rural or regional areas.

Recent MPM guidelines for ASCO, Europe, Britain, and Australia, recommend a multi-disciplinary model of care for people with MPM [14, 15, 20, 21], with the development of an individualised care plan [14]. The evidence for MDTM is not robust but there is a suggestion lung cancer MDTM increase chemotherapy utilisation [22] and may result in improved survival outcomes [23]. Due to the complexity of diagnosis and treatment of MPM, in the UK, specialist MPM MDTM have been recommended [24]. An evaluation of a specialist regional mesothelioma MDTM reported effectiveness in reaching a diagnosis and recommendations regarding further management [25]. Despite Australian recommendations all patients be presented at MDTM [26], 15% of surveyed doctors did not attend any MDTM meetings, and of those that did, some were not lung-specific but general MDTM. Interestingly, doctors estimated approximately three-quarters of their own MPM patients were presented at MDTM but believed only half of those their colleagues cared for were presented. In contrast, 81% of MPM cases were presented at British MDTM [7].

British guidelines recommend MDTM should include a MPM nurse specialist [21]. Our results suggest health care professionals who treat MPM believe specialist lung cancer nurses facilitate care of people with MPM and their families, yet many hospitals did not have access to one, and this was not restricted to smaller or rural centres. In 2014, there were reportedly < 20 lung cancer nurse roles in Australia (Lung Foundation Australia). Overall, 56% of doctors reported their practice did not include a lung cancer nurse specialist, and the majority (84%) were located in a metropolitan area. Even in hospitals where lung nurse specialists did exist, some MPM patients were not referred to them. Similarly, there was a lack of routine referral to allied health specialties including dietetics, social work, occupational therapy, psychology, and exercise physiology, even though > 90% of respondents indicated these specialties were available. This is despite people with MPM being recognised as having a poor prognosis and high symptom burden. Furthermore, the Australian mesothelioma guidelines recommend screening patients for psychological distress and unmet needs, and the inclusion of allied health professionals as members of the multi-disciplinary team [14]. Nurses reported slightly higher rates of referral to allied health professionals.

Australia has state and federal bodies to compensate MPM patients who develop MPM through occupational exposure, as well as the option of personal litigation, but many patients and families have little knowledge regarding how to access compensation. This is compounded by the overwhelming impact of a MPM diagnosis and prioritisation of medical care. Overall, 90% of doctors and 79% of nurses reported they generally recommend patients seek information about compensation, and most were comfortable in this role.

Our study has a number of limitations. We acknowledge the survey instrument was not fully validated. We are unable to calculate the response rate as survey links were distributed by a number of professional organisations with cross-membership, and snowballing techniques were used. Thus, we do not know how representative of the clinical population our sample is. The main medical specialties represented are respiratory physicians and medical oncologists, who are the main groups caring for these patients, but thoracic surgeons and radiation oncologists were under-represented. The number of nurses surveyed is small but likely reflects the true number of specialist lung cancer nurses in the country. In discussing additional services for MPM, there is likely over-representation of larger centres where more specialist staff, including allied health, are available. These facilities are likely to offer more specialised care for MPM patients than small centres, which may result in overestimation of MPM services available. Each of the factors identified above has the potential to lead to bias in our results. We have postcode rather than institution so cannot break down information by specific institutions. Finally, the data reflect the Australian health setting and may not be generalisable to other health services.

Strengths of our study include that we have obtained relatively comprehensive information about the issues faced by

126 health care professionals that treat people with a relatively rare tumour, and representing a wide geographical distribution across Australia and New Zealand.

Conclusions

Caring for patients with MPM and their families is challenging and complex. Health care professionals agree there is under-utilisation of chemotherapy in Australia with main reasons reported as clinician nihilism and lack of referral to a medical oncologist for an opinion about chemotherapy. Patient-related barriers were perceived to be negative beliefs about chemotherapy, toxicity, and lack of benefit. Lung cancer nurses are ideally placed to provide holistic, coordinated care for people with MPM and crucial support for patients and their families.

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Compliance with ethical standards

Conflict of interest Drs Vardy, Dhillon, and Kao report grants from icare Dust Diseases Care for the conduct of the study which is the basis of the submitted work. Dr. Kao reports personal fees to his institution from MSD, Roche, AstraZeneca, Pfizer, and BMS, outside the submitted work. Dr. Dhillon reports honoraria paid to her institution from MSD outside the submitted work. The authors have full control of all primary data and agree to allow the journal to review the data if requested.

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