Final Report

Exploring variability in patient pathways and experiences of care in peritoneal mesothelioma in the United Kingdom

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Executive Summary

Mesothelioma is a rare cancer that affects the mesothelial membranes, the only known cause is asbestos exposure. Peritoneal mesothelioma is the second most common presentation of mesothelioma, and accounts for 7-30% of all cases. Patients with peritoneal mesothelioma (PM) have different symptoms, treatments, care & support needs to patients with pleural mesothelioma, yet the evidence base on peritoneal mesothelioma is sparse. As a consequence, there is considerable variability in the care received by PM patients across the UK. In order to explore the extent of this variability, the aim of this study was to understand how people living with PM experience care and treatment, and explore variability in access to care and treatments across the UK. This knowledge will help healthcare professionals understand what patients consider important to their pathway and ensure a focus on these areas in practice.

The study used a mixed-methods design to explore variability in the care pathway of people with PM, and to explore the patient experience of the care pathway. The two phases of the study were:

1. A cross-sectional survey of 47 PM patients and family members exploring patient characteristics, pathway to diagnosis and treatment, experiences of treatment and care.
2. Seven individual case studies of PM patients, their family carers and key professionals (health professionals, lawyers, asbestos support workers etc) involving qualitative interviews and review of patients medical and nursing case notes. Seven patients were recruited, each patient nominated one family carer and six patients nominated a key professional (one patient did not nominate a professional). Patients took part in serial qualitative interviews (up to three) over the course of 12 months. Carers and professionals were interviewed once each. Medical and case note data were extracted and recorded on a standardised proforma.

Findings revealed poor experiences of diagnosis and significant delays due to non-specific symptoms and challenges with differential diagnoses. There was significant variability in the pathway to diagnosis, with many different oncology specialties involved in the diagnostic process. Results also suggested considerable variability in ongoing management and treatment options, with PM patients managed under a variety of oncology specialists. Treatment options were not uniform across the UK and patients were not always provided with sufficient information with which to make an informed decision about treatment. Patients who were referred to the National Multidisciplinary Team (NMDT) for PM benefitted from the specialist advice and support that was available, but there was an assumption that referral to the NMDT was only an option for surgical patients. Support from a clinical nurse specialist (CNS), and particularly a mesothelioma CNS, was associated with improved experiences for PM patients and their families.

The study highlights the need for improved timely diagnosis, enhanced communication between healthcare providers and patients, and referral to specialist mesothelioma multidisciplinary teams.

Recommendations for practice were co-produced by a stakeholder group including health care professionals, researchers, patients and advocacy workers. The recommendations are intended to enhance the experience of the PM pathway, reduce variability in care and treatment, and provide equity of care for PM patients across the UK.

Recommendations for clinical practice:

- **Improve compassionate and timely delivery of diagnosis**
  - ✓ Consider asbestos exposure outside of the ‘typical’ industries; higher index of suspicion for those who may have had secondary exposure
  - ✓ Forward planning before delivering a PM diagnosis to ensure diagnosis is given sensitively
  - ✓ Give accurate disease-specific information, at the right time
  - ✓ Take care around prognosis and differentiate between pleural and PM prognoses
  - ✓ Signpost to support services including Mesothelioma UK and asbestos support groups

- **Reduce variability in treatment and management pathways**
  - ✓ Provide good partnership working and communication between different health professionals across disciplines
  - ✓ Refer all patients diagnosed with PM to a mesothelioma clinical nurse specialist
  - ✓ Support patients and carers to look after their mental health and well-being
- **Refer all PM patients to specialist MDT’s**
  - ✓ All PM patients should be referred for discussion at a mesothelioma MDT and should be considered for referral to the NMDT
  - ✓ Referral to the NMDT can be considered for non-surgical patients, particularly to address complex needs.
  - ✓ Engage patients in decision making throughout the treatment pathway, not just regarding surgery
- **Share accurate information about the pros and cons of seeking compensation**
  - Signpost to asbestos support services, for support, benefit and compensation advice, seeking compensation
- **Support**
  - Ensure patient has a local Clinical Nurse Specialist, and Mesothelioma UK CNS if available
  - Support for patients and carers to look after their mental health and wellbeing

Background

Mesothelioma is a rare cancer that affects the mesothelial membranes, the only known cause is asbestos exposure. Mesothelioma is most commonly encountered in the pleural membranes. The second most common location is the peritoneum, which accounts for 7-30% of all cases (Moolgavkar et al., 2009). Between 2016-2018, 260 cases of peritoneal mesothelioma (PM) were diagnosed in England and Northern Ireland (Royal College of Physicians, 2020). The mean age at diagnosis was 68, with 64% of cases occurring in men and 36% in women. Compared with those living with pleural mesothelioma, the population of people living with PM are younger and there are more women.

Despite a limited evidence base, there is an increasing awareness that those living with PM have different experiences to those living with pleural mesothelioma. Evidence suggests that it takes longer for patients with PM to be diagnosed (Senek et al., 2021), and patients with PM often report that their diagnosing doctor lacked sufficient knowledge (Ejegi-Memeh et al., 2020). Evidence also suggests variability in access to, and experiences of, care in patients living with PM in the UK (Senek 2021).

The National Mesothelioma Audit 2019 recommended that all patients diagnosed with PM should be referred for discussion at a mesothelioma multidisciplinary team (MDT), should be signposted to Mesothelioma UK resources and, for patients with good performance scores, should be considered for referral to the national peritoneal mesothelioma MDT based in Basingstoke (Royal College of Physicians, 2020). Whilst referral rates to the national MDT have improved (Royal College of Physicians, 2018, 2020) it is unclear whether a standard pathway to referral is being followed nationally, and whether access is uniform across the UK.

In order to explore the extent of this variability, the aim of this study was to understand how people living with PM experience care and treatment and explore variability in access to care and treatments across the UK. This knowledge will help healthcare professionals understand what patients consider important to their pathway, and ensure a focus on these areas in practice.

Aim

To explore variability in care pathway of people with peritoneal mesothelioma, and to explore the patient experience of the care pathway.

Objectives

1) To explore the variability and experience of care in the PM pathway
2) To explore the patient and family members experience of the PM pathway from diagnosis to referral, treatment and care
3) To develop recommendations to improve care for people living with PM

Design

The study used a mixed-methods design to explore variability in the care pathway of people with PM, and to explore the patient experience of the care pathway.

The two phases of the study were:

1) A cross-sectional survey of PM patients and family carers exploring patient characteristics, pathway to diagnosis and treatment, experiences of treatment and care.
2) Individual case studies of PM patients, their family carers and key professionals, involving serial qualitative interviews and review of medical and nursing case notes.

This research was approved by the NHS research ethics committee (REC reference 21/PR/1486, IRAS ID 300947). Informed consent to participate was received from all participants.

Methods

Participants

Participants were eligible for inclusion if they met the following criteria: a confirmed diagnosis of PM, aged over 18 years, living in the United Kingdom, able to read/write English and were able to provide informed consent. Participants for the cross-sectional survey in phase one were recruited using a multi-pronged sampling strategy incorporating convenience and snowball sampling. Information about the questionnaire was shared via The Peritoneal Malignancy Institute Basingstoke (PMI), HASAG (a national asbestos support group charity), mesothelioma support groups, Mesothelioma UK, and the Mesothelioma UK Research Centre (MURC). The study was also widely shared via social media to gain wider participation. We aimed to recruit a diverse sample of at least 50 patients for the survey.

Participants for the case studies in phase two were recruited using convenience sampling methods. Patients who completed the survey in phase one were asked to provide contact details if they were interested in participating in the case study phase. Each patient was then asked to identify one family carer and up to three professionals who were involved in their care. Family carers were defined as anyone providing unpaid help and support to the patient, and were not necessarily blood relatives. Professionals were defined as anyone in a professional role who supported the patient, including health care professionals, lawyers and asbestos support group staff.

We aimed to recruit up to seven case studies. Purposive sampling was used to select a range of participant demographics and variation in experience such as age, gender and time since diagnosis.

Phase 1: Cross-sectional survey

Survey content was informed by previous evidence (e.g. Taylor 2023, Senek 2021) and collected data on demographic characteristics; pathway of treatment and care (including details of diagnosis, referrals, number of specialties seen by, time to diagnosis, onward referral (or not) to NMDT, CNS involvement and treatments offered and received and experiences of care. Surveys were completed on-line via GoogleForms and the survey was open between February and December 2022. Data were analysed using descriptive statistics and exploration of the relationship between patient variability of treatment and care using bivariate correlations, when appropriate. SPSS version 28 was used for the analysis.

Phase 2: Case study series

Patients were asked to take part in serial qualitative interviews (up to three) over the course of 12 months. Carers and professionals were interviewed once each. Each interview took place online or over the phone, depending on patient preference, and lasted up to one hour. All interviews were undertaken between February and December 2022.

Interview topic guides were developed on the basis of existing literature and previous studies conducted by the research team (Ejegi-Memeh et al., 2021) semi-structured interview schedule focused on patients/carers experiences of living with peritoneal mesothelioma (from before diagnosis to current), experiences of the care pathway, diagnosis, referral, treatment; barriers and facilitators to a consistent care pathway; satisfaction with care. The interview schedule for professionals asked about perceived variability in the PM patient pathway, and any implications of this. Interviews were recorded, transcribed verbatim and imported into Quirkos© software for analysis.

Four steps in data analysis were followed: (1) The patient and carer transcripts were re-read through for accuracy and any patterns were noted; (2) A descriptive framework based on key experiences in the peritoneal pathway was developed. These were developed separately and then coded , revisions to the coding framework were made following team discussions. The framework was further revised and applied to transcripts to be tested and verified; (3) data for all patients, carers and professionals was coded and (4) then populated the framework with data from patients, carers, and professionals. Developed codes were then organised into potential themes which were arranged in tables and revised following team discussions. To ensure that the themes were grounded in the data, they were supplemented by direct quotes from the participants. All participant names are pseudonyms.

For the case note review, data was collected from hospital medical records, using a standard proforma which collected information on date first presented to a HCP, presenting symptoms, any alternative diagnoses documented, hospital specialist/s referred to, date diagnosis received, who gave diagnosis, number of hospital admissions, treating specialty oncologist, named CNS. The data obtained were entered onto a pseudonymised case report form and given a unique study number.

Patient and Public Involvement

Participant and public involvement (PPI) was embedded throughout the current study from the initial idea to the design stage. A patient expert sat on the steering committee and was involved throughout, providing feedback on all study documents. In addition, members of the Mesothelioma UK Research Centre PPI panel have reviewed all participant resources, e.g. interview schedules, questionnaires, consent forms.

Results

A total of 47 patients (30 women and 17 men) responded to the survey between February 2022 and December 2022 (Table 1). Overall, most patients had epithelioid mesothelioma (47%), 2% biphasic, 4% well differentiated papillary mesothelial tumour, 19% had multiple sites of mesothelioma, and a quarter did not know which type of mesothelioma they had (25.5%). Half (51%) of the respondents had a spouse as a carer and 25% of the respondents had a higher level of education (postgraduate). Seven patient case studies were recruited, each case study included the patient, a nominated carer/family member and a nominated support person (one patient did not nominate a support person). Case study characteristics are noted in Table 1: Study Demographics.

Table 1: Study Demographics

Survey: Patient participants		
		Number (%)
Gender	Female Male	30 (63.8%) 17 (36.2%)
Ethnicity	White British White Other Other/didn't say	41 (87.2%) 4 (8.5%) 2 (4.2%)
Age (years)	<30 30-39 40-49 50-59 60-69 70+	2 5 3 10 11 16
Highest level of education completed	Secondary school Further Education (A levels etc) Higher education (degree) Postgraduate Other/didn't say	12 (25.5%) 7 (14.9%) 15 (31.9%) 12 (25.5%) 1 (2.1%)
Case study: Patient participants		
Gender	Female Male	5 2
Mean Age		64 years
Case study: Carer participants		
Gender	Female Male	3 4
Mean Age		72 years
Case study: Professional participants		
Gender	Female Male	4 2
Role	Mesothelioma CNS Consultant oncologist Asbestos support charity worker	2 2 2

Years professional experience in mesothelioma	5 -10 years	2
	10-15 years	1
	20-25 years	3

Pathway to Diagnosis

The survey and interview data revealed considerable variation in the symptoms that patients experienced prior to receiving their diagnosis. The most reported presenting symptoms were abdominal pain, tiredness, change of bowel habit, shortness of breath, sweating and weight loss. Interviews with patients reported the nature of the symptoms of PM had led to some delaying going to their GP as they had not recognised its seriousness or as something they should attend to urgently.

"He [doctor] was quite puzzled by the whole thing, but I said that it was so much like the feeling I'd had when I had had gall bladder trouble that I wondered if there was something going on in that area, maybe crystals forming or something not draining away". Case Study (CS) 1 patient

Whilst patients experienced a range of symptoms there was less variation in their initial contact with HCP's (Table 2: Survey Results). Interviewed professionals noted at this point there could be further delays with onward referral to the hospital partly due to non-specific presenting symptoms. It was suggested by the professional that patients who presented with symptoms that were more closely associated with cancer, referred to as 'red flag' cancer symptoms, were more likely to be referred relatively quickly to the hospital. Patient and carer interviews described some staff appeared uncertain about the meaning of test results or expressed surprise when the results identified mesothelioma. Others recalled the GP and medical team they were referred to had not considered the potential of PM and this had extended the time taken to reach a diagnosis.

"And so, I had my first face-to-face appointment with this consultant at [private] hospital in [city]. He seemed puzzled and he asked me if I had a rash. And I thought no, I haven't, but it's a slightly odd question. But he examined me physically, he felt my abdomen and he said, we'd better get a CT scan organised." CS1 patient

"Patient clearly has had a long and frustrating route to diagnosis as often occurs in patients with rare tumours." CS2 professional

Table 2 summaries survey data relating to diagnosis and highlights that whilst most patients initially presented to their GP, a wide range of health professionals were involved in the diagnosis. Many patients experienced a lengthy wait before a diagnosis was confirmed, with a median delay of 321 days before receiving a final diagnosis. Almost half of surveyed patients (45%) perceived avoidable delays in their diagnosis.

Table 2: Survey results

Survey results	Number of patients

Initial contact with HCP	GP – 35 Nurse at GP surgery – 2 Emergency department - 3
Number of days from presenting symptoms to a HCP to receiving a PM diagnosis	14 – 2557 days (median 183 days)
Informed of an alternative diagnosis	18
Oncology management team	Lung oncologist – 25 Gynaecologist – 5 colorectal oncologist – 3 Cancer of unknown primary – 3
Referral to NMDT	16
Patient request for second opinion	4
Treatments offered	Chemotherapy - 30 Immunotherapy – 9 Clinical trial - 4
Received CRS and HIPEC	16
Patient experience of investigation and diagnosis process	Satisfied - 64% Not satisfied – 36%

Survey results and case note review data indicated extended diagnostic pathways were partly explained by the broad range and multiple specialities patients were referred to (Table 3) and shows multiple alternative diagnoses were given (Table 4). Eighteen surveyed patients and four case note patients were informed of an alternative diagnosis before PM diagnosis (Table 2 and 3); ovarian cancer (n=5), endometriosis (n=3), cancer of unknown primary (n=3), pseudomyxoma Peritonei (n=3), no cancer found (n=2), irritable bowel syndrome, appendicitis, sarcoma, paraganglioma, peritonitis, mullerian tumour, pancreatic cancer (n=1). Whilst 70% of patients said the diagnosis was understandable, 19% said the diagnosis was not understandable and 38% said the diagnosis was not given in a sensitive way.

Table 3: Hospital specialist first referred to with mesothelioma symptoms

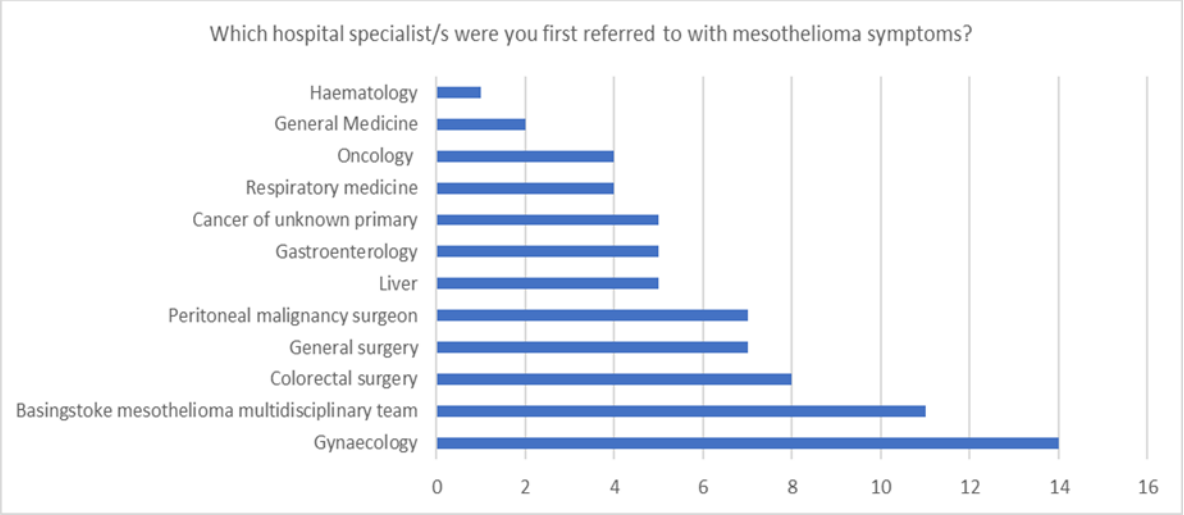

Table 4: Case note review data

Patient Case	Time to diagnosis	Specialist giving diagnosis	No. of differential diagnoses	No. of specialists referred to	Oncology team treated under	Referral to NMDT?	First treatment
C1 (F)	210	Sarcoma consultant	3	5	Lung	✓	Chemotherapy
C2 (F)	30	Gynaecologist	0	1	Lung	✓	CRS & HIPEC
C3 (M)	180	Lung Oncologist	1	3	Lung	x	Diagnostic Surgery at local hospital resulted as treatment
C4 (M)	90	Respiratory Medicine	3	3	Lung	x	Chemotherapy
C5 (F)	-	Gynaecologist	0	2	Lung	✓	Immunotherapy
C6 (F)	120	Lung Oncologist	0	0	Lung	✓	Chemotherapy
C7 (M)	30	Cancer of Unknown	1	2	Lung	✓	Chemotherapy

		Primary Team					

Management

Survey results demonstrate variation in oncology speciality for ongoing management and treatment for PM patients (Table 2). Sixteen patients were referred to the NMDT and/or a peritoneal malignancy surgeon. Six patients sought a second opinion from the NMDT for diagnosis confirmation and surgical opinion for CRS & HIPEC. Two patients had a second opinion with a mesothelioma oncology expert and two patients sought a second opinion overseas. Case note data showed one patient asked their GP to refer them to another oncologist to explore the option of an immunotherapy clinical trial. Professionals interviewed demonstrated a recognition that much of their experience came from pleural mesothelioma as this formed the largest part of their clinical caseload, which could have implications for ongoing management. Patients were often overwhelmed by the various treatment options, and navigating this complex treatment landscape could be challenging.

“No, there’s always challenges because it’s an unusual, it’s a rare diagnosis and that’s always challenging for patients isn’t it and it potentially comes via a team that are not used to looking at the patterns of mesothelioma”. CS7, professional

“We’re all talking about this miracle drug that’s going about, and I’m not going to pronounce it ‘cause I can’t. So there’s that support as well. And I think, when I get to the point where my results are showing a decline, I will then get in contact with the private oncologist, if the NHS are still saying that there’s no treatment, but if you’ve had treatment and then, with the NHS, if you’ve had treatment, and then there’s a span of nine months to 12 months, if it re-occurs they will provide further treatment, but I don’t know. My oncologist is saying nothing at the moment.” CS5 patient

Access to the NMDT could bring benefits and in Scotland referral to the NMDT was described as routine practice. However, there was evidence that this may not be consistent practice across England as some oncologists may not be aware of the NMDT, others were more likely to refer only if surgery was felt to be a treatment option. Factors influencing referral to the NMDT were awareness of the NMDT, the local MDT decision to refer, for example, deciding not to refer due to the delays in waiting for NMDT meeting outcomes (NDMT being monthly), and individual perspectives of the local team on benefits of surgery verses SACT in PM. Referral (or not) to the NMDT could be a source of considerable stress and anxiety for patients.

“It was a bit unfortunate to begin with because in [city] they were going to do that operation on me, which they can do on peritoneal mesothelioma, which means stripping out, well basically cutting right back and a big margin around about where the tumour is. That was all going to take place, and I understood that I might be sent to [national MDT centre] for this or it might take place in [city], but there was ongoing discussion about this. And then all of a sudden, the [city] team said we’re not going to do the operation.” CS1 patient

"For peritoneal cancers in general we often involve the (national) peritoneal cancer unit. But that's certainly in my mind not about primary management of the disease, but we consult them for the specific aspects of surgical intervention if us as a mesothelioma MDT and them as the peritoneal cancer MDT think that surgery may have something to offer." CS3 - professional

Treatment

Of the surveyed patients, 87% were satisfied with their treatment. There was no relationship between type of mesothelioma and treatments offered or treatment satisfaction. Seeing a gynaecological oncologist was associated with being less satisfied with treatment (Pearson statistic -.395, p<=0.01 n=47), though these numbers are small. No other specialist had a significant link to satisfaction with treatment. Patients were asked if they were offered various treatments, such as chemotherapy, immunotherapy, and clinical trials (table 2). No patients received radiotherapy. Most patients referred to the NMDT were recommended SACT. Sixteen patients received CRS & HIPEC at the PMI surgical centre. Review of case note data revealed one patient and their family enquired with the oncology clinic registrar about CRS & HIPEC offered at the NMDT. The professional explained there was significant peritoneal involvement and therefore first line treatment would be chemotherapy. The case notes continued with the doctor explaining that if there was a suitable response to chemotherapy, referral to the NMDT would be appropriate.

"And then my current oncologist who is at [town] Hospital we'd asked her about this operation, so we were very focused on would I or not get sufficient shrinkage through my chemotherapy to be allowed to be sent to [national MDT centre] to have that surgery. But they decided they would not do the surgery because of the proliferation factor." CS1 patient

Whilst patients were generally often only referred to the NMDT for consideration of surgery, the mentality around this was changing and many health professionals recognised the value of the NMDT outside of surgery.

"Well, I think the national peritoneal MDT has made a big difference.[…] if they get as far as being discussed at our [city] regional one, then hopefully we get them pointed in the right direction. And I'm there generally just to say, refer them, refer them to [national MDT centre], jumping up and down usually." CS2 professional

Survey data showed vast variability of the PM pathway. However, there was no significant correlation between satisfaction (in investigation or treatment) and time to referral or time to diagnosis (Table 5). There was no significant correlation between avoidable delays and satisfaction with investigation and diagnosis or delays and satisfaction with treatment. There were no relationships between presenting symptoms and the first specialist the patient was referred to (Table 6). There was no significant correlation between avoidable delays and patients perception of how delays affected their quality of life (pearson .269, p=0.11, n=47). Lack of correlations are likely due to small sample size or that indeed the peritoneal mesothelioma pathway is hugely varied between patients.

Table 5: Relationship between satisfaction and time delays

	Time to first referral	**Time to diagnosis**
Satisfaction with investigation	Pearson -.030 p value .868 n = 33	Person .049 p value .788 n = 32
Satisfaction with treatment	Person .104 p value .565 n = 33	Person -.111 p value .544 n = 32

Table 6: Relationship between presenting symptoms and first referral

	First specialist seen		
	n	Person correlational statistic	P value
Abdominal symptoms	47	.123	.411
Appetite/ nausea	47	.283	.054
Back pain	47	.213	.150
Sweating	47	-.219	.139
Shortness of breath	47	-.259	.079
Accidental discovery	47	.026	.861
Other	47	.132	.375

Support

Strengths of multi-professional working emerged in the patient, carer and professional's interviews where doctors, CNSs, asbestos support groups, legal professionals and community health staff were all described as contributing different areas of expertise. Surveyed patients were asked to rank professionals that had the most positive impact on their care. Hospital doctors and nurses were ranked as having the most positive impact, second to asbestos support groups. All patients had been involved with asbestos support groups which played a valuable role in peer support, guidance in navigating and applying for benefits and advising on potential legal claims. They were proactive about contacting and visiting the patients and had an important role in making the patient feel "not forgotten". CNSs were described as providing information and support throughout the patient pathway, acting as a vital point of contact for patients and enabling access to other services, such as asbestos support groups and national charities such as Mesothelioma UK. However, it was noted that CNSs from different disease sites may have little experience in mesothelioma, particularly those from colorectal or gynaecology oncology services. Concerns were raised about the lack of specialist knowledge the CNSs might have about the range of support services available for PM patients, leading to possible delays in accessing these services.

Interviewer: "You also said that people don't always know who to refer to in your area."
Participant: "No they don't. Because they don't come under, like, the lung cancer nurses who know the meso pathway; they come under colorectal nurses who really may not see many patients. I mean, they might only see one. That might be the only person they see." CS4 - Professional

Survey results showed 35 patients reported having a Clinical Nurse Specialist (CNS). Of these, the majority (n=31) were lung cancer and/or mesothelioma nurse specialists. Fourteen survey patients did not have a CNS. In the interviews, those patients who had experience of the NMDT reported how highly they valued the involvement of the PM nurse specialist.

"Mesothelioma UK or it might have been [NMDT centre] got in touch with her and gave much more of an idea of what it was that was going on." CS2 – family carer

Patients' experience of having a rare cancer within a rare cancer led the cohort to feeling ostracised, isolated and forgotten. Disease specific support groups, online support and patient information days were mentioned as being important in the interviews as well as peer support being highlighted by carers. These activities were seen as positive experiences due to the sharing of information, meeting others with the same illness and providing emotional support. Interview data also suggested support groups were a good way for patients to find out about treatment and clinical trial options. This form of support was helpful for many, but due to personal preference was not for everyone.

"They do feel very ostracised, even within the mesothelioma community, because there's not as many people to share those experiences and to get that information from, and create a positivity, that I think we are starting to do with pleural." CS1 - Professional

"The camaraderie….we understand how we all feel." CS2 - patient

"There's so much going on which gives you hope." CS5 - patient

The legal process of engaging in a compensation claim was described as lengthy and stressful at times. However, the access to additional private care and treatment that was enabled by a successful claim was considered very positive. Some participants questioned the common phrasing of the occupational exposure question *"Have you been exposed to asbestos?"* which may not be effective in picking up non-traditional causes of asbestos exposure. HCPs need to be aware that jobs in a variety of settings (e.g. schools and hospitals) can involve exposure to asbestos, as can non-occupational causes.

Palliative and End of Life Care experiences

As patients faced with the prospect of an incurable cancer, participants unsurprisingly had many concerns for the future, including the process of death, dying and bereavement. Some patients described a lack of compassionate and empathetic care amongst some health professionals, borne out of a nihilistic attitude to mesothelioma.

"He did say that as it is at the moment, there's more than a 50% chance that it will return, and if it does, and these were his words, basically, I would probably die a slow and painful death over the space of about 18 months should it return." CS3 - patient

Other patients spoke about the importance of honest, open and compassionate palliative and end of life care, and the value of being prepared for 'what lies ahead'. Patients did not single out a particular health professional who they felt should introduce 'difficult conversations', rather it was perceived to be integral to all aspects of care provision.

"I'm no stranger to death. I know what it's all about and, and I'd rather know because, as I say, whether I know or not it's there, it's a fact. So, I'd rather know than if it happened and then go, well, no one told me that". CS3 - patient

Nurses were perceived as particularly important in supporting patients palliative care needs, particularly around the end of life but also preparing family and carers for a post mortem (if required) and a coroners inquiry.

"I mean, that kind of tells me not what's happening now, but what is going to happen in the future? And it could be sooner rather than later, where I'm not going to be able to breathe well, to be able to get to a shop or a doctors or… So there was a lot, at that time, when you are being confronted with your near future, you know? The nurse talked about what was happening now, what was going to happen mid-term and what was going to happen six months before I was going to die". CS7 - patient

Overall experience of the diagnostic and treatment pathway

A total of 64% of surveyed patients were satisfied with their experience of the investigation and diagnosis process. Thirty-six percent responded as not satisfied (Table 2). Surveyed patients were asked what could have improved their experience of the diagnostic and treatment pathway. Responses included a quicker diagnostic phase, improving diagnostic communication and giving specific information about PM. Patients reported what worked well in their pathway, which included a timely, thorough, well-coordinated and compassionate delivery of diagnosis, and receiving information regarding treatment plans including surgery and future options.

"It was very useful that [CNS] at [city] knew straight away to direct me to [national MDT centre], I think that was really helpful. So, I don't know if in other hospitals they'd be quite so, that link would be quite so strong, so that was really good." CS2 - patient

"But I mean, it was the way she delivered it, with holding my hand and looking me straight in the eye, and being very, very compassionate." CS7- patient

The lack of connectivity between local cancer centres and specialist centres was a concern for some patients. Some patients identified a gap in communication and uncertainty about who was responsible for their care at particular points in the pathway.

"Being passed around and having to be on top of your own care - at one point I thought, am I dealing with [local hospital], or am I dealing with [NMDT centre]." CS7 - patient

Discussion

This study provides valuable insight into the patient experience of the diagnosis and treatment pathway for peritoneal mesothelioma. It provides evidence that PM is difficult to diagnose, and patients present with non-specific symptoms that are often concluded to be more common illnesses.

These non-specific symptoms often cause a long-drawn-out diagnostic phase before a final diagnosis is reached, in our study the average time between first symptoms and diagnosis was around 183 days. Ideally, PM should be included in the differential diagnosis of patients with a peritoneal neoplasm, however this is understandably challenging given its rarity. When teams communicate well and specialist MDTs are utilised, patients are likely to have an enhanced experience of the care pathway. Our findings highlight the value of the NMDT in centralising treatment recommendations for this rare cancer with the aim of providing equity in care, although it appeared not to be routine practice across the UK. Review at the NMDT also demonstrated positive patient satisfaction levels along with identifying patients suitable or not suitable for surgery e.g. CRS & HIPEC.

Communicating a diagnosis

Patients commented on the need for better communication and discussion around diagnostic tests, communication of diagnosis, and treatment options including CRS & HIPEC. When communicating a PM diagnosis, HCPs are faced with balancing the provision of accurate information whilst maintaining hope (Lelorain 2018). Taylor et al (2019) studied the challenges associated with communicating a mesothelioma diagnosis which included lack of time allocated to patients and carers at diagnosis, lack of access to ongoing training for HCP's delivering diagnoses and lack of suitable clinical environments in which to deliver information. Furthermore, Wittmann et al (2011) study of esophagogastric cancer found some patients wanted a great deal of information regarding their illness compared to the HCP's perception. It is important that the patient understands their rare cancer and for some patients there will be high information needs, specifically about the stage of disease, treatments available and if it can be cured. By identifying how much information a patient wishes to receive and the best way to deliver this information, patient experience can be positively impacted.

PM management and multidisciplinary team working

While our findings show that referral to the NMDT for peritoneal mesothelioma patients does not appear to be routine practice in England, the wider literature shows that there may be benefits to MDT referral for mesothelioma patients. MDTs have been integrated in routine cancer care in the UK since 2000. Specifically, the NHS Cancer Plan recommends that all cancer patients should be discussed in cancer-specific MDT meetings (Dept of Health 2000). To facilitate this, the UK Department of Health Mesothelioma Service Framework (Dept of Health 2007) recommends mesothelioma cases be discussed at a specialist mesothelioma MDT meeting to provide opportunity for discussion among experts. The benefits of a specialist mesothelioma MDT are enhanced patient satisfaction, staging, diagnostic accuracy, classification of subtype, treatment, and increased recruitment in clinical trials (Bibby 2017, Harden 2020). Brandl et al (2020) suggests centralising expert surgical opinion is effective at selecting patients appropriate for CRS & HIPEC and this expertise makes important contributions to the management of patients with PM. Specialist MDT meeting pitfalls should also be acknowledged, such as individual clinicians not following MDT advice (Bibby 2016). There is insufficient evidence for the effectiveness of patient outcomes and MDT meetings.

Patient preferences and experiences

Patient participants also expressed they wanted their HCP to acknowledge the prognosis differences between pleural and peritoneal mesothelioma, however evidence is lacking on differential prognoses. Most published studies including pleural and PM patients do not differentiate between the two, and many studies only include pleural patients e.g. Baas 2021. There is a scarcity of information available for people living with peritoneal mesothelioma and those that care for them, and further research specifically focusing on PM is required to address this gap in the evidence.

Significant variability was noted in the route to diagnosis, treatment and management options, referral to specialist MDT and the overall care pathway. This is likely to be due, in part, to the rarity of the disease which many health care professionals will only encounter once or twice in their careers. Nonetheless, there is considerably capacity to improve the consistency and experience of the care pathway through seeking specialist input and advice, particularly from mesothelioma specialist nurses and the NMDT. In addition specialist advice can be sought from the wider community including Mesothelioma UK and Asbestos Support Groups.

Limitations

To our knowledge, this is the largest experience study of PM in the UK examining the diagnostic and treatment pathway. While this is the largest sample of PM surveyed, due to the rare nature of PM, our sample size was small and may not be representative, and interpretation should be considered cautiously.

Recommendations

Recommendations for practice were co-produced by a stakeholder group including health care professionals, researchers, patients and advocacy workers (Box 1). The recommendations have emerged directly from the findings of the study and are intended to enhance the experience of the PM pathway, reduce variability in care and treatment, and provide equity of care for PM patients across the UK.

Box 1: Recommendations for clinical practice

- **Improve compassionate and timely delivery of diagnosis**
    - ✓ Consider asbestos exposure outside of the 'typical' industries; higher index of suspicion for those who may have had secondary exposure
    - ✓ Forward planning before delivering a PM diagnosis to ensure diagnosis is given sensitively
    - ✓ Give accurate disease-specific information, at the right time
    - ✓ Take care around prognosis and differentiate between pleural and PM prognoses
    - ✓ Signpost to support services including Mesothelioma UK and asbestos support groups
- **Reduce variability in treatment and management pathways**
    - ✓ Provide good partnership working and communication between different health professionals across disciplines
    - ✓ Refer all patients diagnosed with PM to a mesothelioma clinical nurse specialist
    - ✓ Support patients and carers to look after their mental health and well-being
- **Refer all PM patients to specialist MDT's**
    - ✓ All PM patients should be referred for discussion at a mesothelioma MDT and should be considered for referral to the NMDT
    - ✓ Referral to the NMDT can be considered for non-surgical patients, particularly to address complex needs.

  - ✓ Engage patients in decision making throughout the treatment pathway, not just regarding surgery
- ➢ **Share accurate information about the pros and cons of seeking compensation**
  - Signpost to asbestos support services, for support, benefit and compensation advice, seeking compensation
- ➢ **Support**
  - Ensure patient has a local Clinical Nurse Specialist, and Mesothelioma UK CNS if available
  - Support for patients and carers to look after their mental health and wellbeing

Conclusions

This study provides valuable insights into the care pathway experiences of PM patients, their carers and professionals. The experiences described variation, delays and uncertainty across the whole care pathway from initial investigations, to diagnosis, to treatments and information and support. Multiple specialities were involved in diagnosis and care. Lung oncology was favoured as the preferred speciality for treating PM. Specialist peritoneal mesothelioma MDT services were highly valued and supported a more coordinated care pathway. Examples of excellent and positive experiences illustrate possible foundations for improving care. We hope our study recommendations will help improve the experience of the PM pathway.

Footnote

Since completing this study, first line SACT has been changed from chemotherapy using a platinum-based agent and pemetrexed to immunotherapy using ipilimumab and nivolumab. The Checkmate 743 clinical trial (Baas 2021) included pleural mesothelioma only, and it is important to note immunotherapy research is limited in PM. PM patients can receive first line ipilimumab and nivolumab.

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