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Living beyond expectations: a qualitative study into the experience of long-term survivors with pleural mesothelioma and their carers

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ABSTRACT

Background Malignant pleural mesothelioma (MPM) is characterised by poor prognosis and limited treatment options. However, a minority of patients can survive well beyond these bleak estimates. Little is known about the specific experiences and needs of long-term survivors and families.

Study purpose The study aimed to gain in-depth understanding of the experiences of patients diagnosed with MPM 3 or more years, along with their main carer, and to determine the care and support needs of this group.

Participants and setting People diagnosed with MPM 3 or more years were recruited via asbestos and mesothelioma social media and support groups. Potential participants were asked to identify someone who acted as their main carer.

Method The study employed a cross-sectional qualitative interview design. A topic guide aided a conversational interview style, conducted remotely and recorded. Patient and carer pairs were interviewed jointly when possible, but were given an option for separate interviews if preferred. Fifteen patients, with 14 identifying a main carer, consented to participation.

Analysis Recorded interviews were transcribed verbatim, and then anonymised by the interviewer. Framework analysis was used to analyse the data iteratively and to develop final themes.

Findings Three themes were developed. Participants 'Living beyond expectations' remained acutely aware that MPM was incurable, but developed a range of coping strategies. Periods of disease stability were punctuated with crises of progression or treatment ending, straining coping. 'Accessing treatment' was important for patients and carers, despite the associated challenges. They were aware options were limited, and actively sought new treatments and clinical trials. 'Support needs' were met by healthcare professionals, voluntary groups and social media networks.

Conclusions Managing patients via regional MPM multidisciplinary teams, facilitating equal access to treatment and trials, could reduce patient and carer burden. Greater awareness and support around crisis points for this group could improve care.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Malignant pleural mesothelioma is incurable, with limited effective treatment options and high symptom burden, but a significant minority of patients can exceed estimated prognoses.

WHAT THIS STUDY ADDS

⇒ Patients who are long-term survivors and their carers are aware of the incurable nature of this condition, often characterised by periods of stability, punctuated by crises precipitated by disease progression. Patients or their carers recognise the limited therapeutic options and seek access to new treatments and clinical trials.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE AND/OR POLICY

⇒ Provision of nationally equitable access to current treatment and trials, greater awareness of support needs around crisis points in pathways would help to mitigate problems for patients and carers.

INTRODUCTION

Malignant pleural mesothelioma (MPM) is considered incurable and generally has a poor prognosis.[1] Many professionals consequently see the disease in nihilistic terms.[2] It is a relatively rare disease, linked to asbestos exposure usually decades earlier[3] and MPM predominantly affects older men. The proportion of patients who survive more than 1 year after diagnosis is around 40%, and 3 year survival is 10%.[4] Prognosis is affected by various factors, including general health and histological subtype of mesothelioma.[5] However, the clinical course of the disease is highly variable, with a small number of patients surviving for comparatively long periods after diagnosis, and some exceptional patients surviving 8 or more years.[1] Treatment options for MPM remain limited and are aimed at managing symptoms and offering modest improvements in survival.[6] Newer immunotherapy drugs appear to offer significant benefit; outside clinical trials, however, their availability on the National Health Service (NHS) has been limited.[5]

There is a small body of research that has explored the experiences of diagnosis and living with MPM from patient and carer perspectives.[7–12] Patients can struggle with the shock of coming to terms with a life-limiting condition,[13] the volume and complexity of information, and coping with difficult symptoms and treatments.[8 10] While many patients report feeling well supported, carers describe a lack of information and feeling isolated.[7 9 11] The poor prognosis associated with the condition is often openly discussed at diagnosis.[11] Existing studies have largely focused on recently diagnosed patients and there are no studies that specifically explore the experience of those who live with the diagnosis over longer periods.[14]

The aim of this study was to gain an in-depth understanding of the experience of living as a long-term survivor of MPM from the perspective of the people diagnosed with the condition and their primary carers. The specific study objectives were to understand the practical impact of living with MPM, undergoing treatment and coping with symptoms and side effects, and to explore the long-term emotional impact of the disease. Ultimately the project aimed to make recommendations on future service provision for this group.

METHODS

The study took an applied qualitative approach from a broadly interpretivist standpoint, in line with its aims.[15 16] Data collection was by in-depth interviews,[17] and analysis used the Framework method.[16] The study was undertaken in compliance with Good Clinical Practice.[18]

Patient and public involvement statement

Patient participant representatives were involved prior to study protocol development to determine the value of the study and give insight into design and recruitment. Initial findings were presented to a patient and public involvement board, helping to inform the analysis process. Participants were offered the opportunity to receive a report of findings, which will also be presented to the Mesothelioma UK patient and carers' group.

Sampling and recruitment

We defined a long-term survivor with MPM as anyone 3 or more years from diagnosis. Informal feedback from nurse specialists and patient advocates indicated this group provided a viable recruitment pool while also having significantly exceeded median survival (approximately 9 months for MPM overall[4]). We aimed to recruit 15 people diagnosed with MPM, along with their carer. This was felt to be sufficient to give a wide range of experiences from this relatively rare population.[19 20]

We publicised the study through mesothelioma and asbestos support groups, social media, websites and newsletters. Interested participants approached the Mesothelioma UK helpline and were put in contact with the research team. A researcher (MJ) screened potential participants using inclusion and exclusion criteria (see table 1). Responders were sent a participant information leaflet and asked to reply, at which time interviews were scheduled. Patients were asked to identify their main carer and whether they would be willing to have a joint interview. If either preferred individual interviews then these were arranged separately.

Data collection

Twenty people who met the criteria responded to the study publicity. Fifteen were recruited and undertook the study. Fourteen identified someone as his or her main carer (eg, spouse, partner, adult child or friend) willing to be interviewed as part of the study. One did not identify anyone as a main carer. Interviews were conducted between June and December 2021. We used a remote videoconference platform, chosen due to nationwide recruitment and coronavirus pandemic restrictions. Interviews were led by experienced qualitative researchers (MJ—a male senior nurse and PA—a male academic) who were previously unknown to participants. Interviews were conversational in nature following a topic guide (see box 1). This was reviewed and slightly modified after the first two interviews. These were recorded and formal consent established verbally at the start. Recordings were transcribed verbatim via a professional service and reviewed for accuracy and anonymised by the interviewer. Twelve interviews were conducted jointly with both patient and carer, with the remainder undertaken as separate interviews. Interviews lasted between 38 and 94 min (mean 68 min).

Data analysis

Data were analysed using the framework approach.[16] This involved familiarisation with all data. We developed a thematic framework from the published literature and

Table 1 Inclusion/exclusion criteria

Inclusion	Exclusion
Person diagnosed with malignant pleural mesothelioma	Participant under 18 years old
Primary carer of person diagnosed with malignant pleural mesothelioma	Primary carer of person with mesothelioma not taking part in the study
Diagnosis of mesothelioma 3 or more years prior to recruitment	Participant unable to converse fluently in English

Box 1 Interview topic guide

I'd like to start by asking a few things about you
⇒ Basic demographic and illness history from person diagnosed with mesothelioma and their carer.

I'd like to ask you a few questions about your initial diagnosis of mesothelioma.
⇒ How did the diagnosis come about?
⇒ Receiving the diagnosis.
⇒ Understanding the diagnosis.
⇒ Impact of the diagnosis on you/your relative and family.
⇒ Coping with the diagnosis.

Next I'd like to find out about the treatment you have had for your mesothelioma
⇒ What treatment (if any) did you have after your diagnosis?
⇒ After this, did you have further treatment?
⇒ Are you currently having treatment?
⇒ Have you received treatment you wanted or expected when you wanted it?
⇒ How has the pandemic affected the treatment you have received and the choices you and your team have made?

Next I'd like to talk to you about how you (and your carer) are now
⇒ What is your health like now?
⇒ What are your current physical care needs?
⇒ What are your support, emotional and information needs?
⇒ What are the support-needs of your primary carer/you as the primary carer?
⇒ What has been the key to coping with and living with a diagnosis of mesothelioma?
⇒ How has the COVID-19 pandemic affected you over the last year or so?
⇒ What are your hopes and concerns for the future?
⇒ Are there things that you know or understand now that you'd wished you'd known when you were first diagnosed?

Is there anything you would like to say that has not been covered in the interview?
⇒ Additional comments about mesothelioma and the diagnosis?
⇒ Questions about the study?

Ending
⇒ Clear reminder of how the information gathered at the interview will be used.
⇒ Ask them if they would like to receive a summary of what we find at the end of the patient experience study.
⇒ Thank participants for their participation with this research interview.
⇒ Suggest a debrief call with Meso UK.

related research questions. A computer-assisted qualitative data analysis system (NVivo V.1.5.1) was used to manage the data. The thematic framework was then used to code the data, iteratively refining and expanding it using emergent concepts from the interviews. Seven interviews were coded by two researchers for consistency. Final codes were summarised, grouped and a matrix constructed, allowing deeper latent themes and subthemes to be developed.

RESULTS

The median age of patient participants was 73 years (range 38–79 years). There were seven male and eight female patients and they had been diagnosed for a median of 4 years (3–12 years). Participants came from a wide geographical area; Scotland to Devon, with one couple living in continental Europe. All participating patients had received active treatment for MPM. Details of individual participant patients and carers are given in table 2.

Themes

Three overarching themes were developed from the data: 'Living beyond expectations', 'Accessing treatment', and 'Support Needs'. Sub-themes were identified within these major headings and are discussed in full below, with illustrative quotes given in box 2.

Living beyond expectations

Prognostication

Study participants vividly recalled the traumatic experience around diagnosis, often associated with poor, insensitive communication. All participants understood that this was an incurable disease, and most spoke about their shock at this change to life expectations. Others received the news pragmatically or stoically. Several participants were given a prognosis estimate at diagnosis, ranging from 3 to 18 months, sometimes without requesting it. Some specifically asked not to be told a timescale. Nevertheless, participants were still aware of average life expectancy, usually from Internet searches. Participants spoke about feelings of hopelessness following diagnosis and taking time to adjust to this devastating blow and loss of future. The process of claiming government benefits and pursuing a legal case often reinforced the poor outlook of the diagnosis. Medical forms sometimes starkly laid out the prognosis, and there were examples of humour in how participants coped with such information.

Participants had mixed feelings about having exceeded even the most optimistic estimates of survival. There was evident pride in having survived beyond expectations and relief that they had not succumbed to this disease. Some patients expressed survivorship guilt for living on beyond their prognosis while so many others had died. Others talked about managing the expectations of family and friends when they exceeded estimates, particularly those with young children, but ultimately knew the condition was terminal. Some patients and carers spoke about making life decisions, such as stopping work, which now seemed unnecessary.

Ways of coping

Participants drew on a wide range of coping strategies. Some avoided focusing on survival statistics and emphasised their own individual progress. Others saw themselves as exceptional, hoping they might be 'the one' who was cured. Many participants consciously tried to

Table 2 Participant characteristics

Patient	Gender/age group	Years diagnosed	Treatment	Clinical trial enrolment?	Carer	Relationship (Interview)
P1	Female 65–74	3–5	Surgery Chemotherapy	No	C1	Husband (Joint)
P2	Female Over 75	Over 5	Chemotherapy Immunotherapy	Yes	C2	Husband (Joint)
P3	Male Under 45	Over 5	Surgery Chemotherapy	No	C3	Wife (Joint)
P4	Male 65–74	3–5	Chemotherapy Immunotherapy	Yes	C4	Son (Joint)
P5	Female Under 45	3–5	Chemotherapy	No	C5	Husband (Joint)
P6	Male 45–54	3–5	Chemotherapy	No	C6	Wife (Joint)
P7	Male Over 75	3–5	Chemotherapy Immunotherapy Radiotherapy	Yes	C7	Daughter (Joint)
P8	Male 65–74	3–5	Immunotherapy	Yes	C8	Wife (Joint)
P9	Female 65–74	3–5	Chemotherapy Immunotherapy	Yes	C9	Female friend (Joint)
P10	Male 65–74	3–5	Surgery Chemotherapy Immunotherapy Radiotherapy	Yes	C10	Wife (Individual)
P11	Female 65–74	3–5	Chemotherapy surgery Immunotherapy Radiotherapy	Yes	C11	Female partner (Individual)
P12	Male Over 75	Over 5	Surgery	No	C12	Wife (Joint)
P13	Female Over 75	3–5	Chemotherapy Immunotherapy	No	C13	Husband (Joint)
P14	Female, 65–74	Over 5	Surgery Chemotherapy	No	C14	Husband (Joint)
P15	Female, Over 75,	3–5	Chemotherapy	No	N/A	N/A (Individual)

N/A, not applicable.

maintain a strong sense of positivity, adopting a glass-half-full approach. One admitted that sometimes this positivity was only a veneer. Many talked about taking things 'day-by-day' and not focusing on the long term, despite the restrictions this approach placed on family life.

Acquiring detailed knowledge about MPM treatment and future developments was important for many. In some cases the patient took on this role, in others the carer. Becoming an expert in the condition was a valued strategy for these participants, often involving trusted websites, while several were frequent attendees at both patient and clinical conferences.

Many participants wanted to work to help others with the condition and improve future care and treatment. Most felt lucky to have survived for as long as they had, and there was a sense of wanting to repay this in some way. Fundraising for research and support charities was important for many. Several participants engaged in campaigns to improve treatment of mesothelioma or asbestos regulations.

Reaching a crossroads

Most patient participants had periods where their disease or treatment was stable, in some cases for many years. Several participants had recently received news that had led them having to re-evaluate their position in a way that felt like reaching a crossroads in their journey with MPM. Unfavourable scan results, new symptoms or needing to stop treatment acted as disruptors bringing dramatic challenges to future assumptions. At these points the

Box 2 Interview quotations

Living beyond expectations

Prognostication

⇒ 'even though he'd mentioned 15 months my immediate reaction was right, well, I'd better get all my ducks in a row for my family when I depart'. P15

⇒ '[…]as soon as you get a diagnosis, the first thing you do is go on Mr Google, isn't it. And then they tell you things like average lifespan, one1 year or something I mean that puts the wind up you […].' P4

⇒ 'I actually had a report written […] to do with a compensation claim, which was to say I was going to die on June 19th of 2016. […] I know it was an average given and all that. It was quite funny actually to get to that date and just see, oh, am I still alive, you know, the next morning.' P11

⇒ 'the mere fact that you're still going is encouraging'. P4

⇒ 'We've always wanted to keep [the children] fully informed. Which was hard. And actually it's been difficult since, because obviously it's not panned out as we thought, which on the one hand is good, but it's still there, it hasn't run away.' P6

Ways of coping

⇒ '[Stephen J Gould] wrote a very good article [saying] you can read the statistics, but you must remember you're an individual. And personally I found that quite inspiring.'P11

⇒ 'I sort of live in hope that there'll be a miracle cure or I'll be the odd one out that doesn't succumb to meso.' P15

⇒ 'We don't know what's coming, so we live for today, tomorrow and next week and next year, until somebody tells you can't.' C13

⇒ 'Go to every conference and whenever they say, any questions, who pops up, it's me.' P2

Reaching a crossroads

⇒ 'there are moments when the scan goes wrong—it's happened to me twice, now—where I suddenly sort of think, oh I'm going to die, I guess.' P5

⇒ 'I went in thinking okay, I'll see [Oncologist] and he told me it wasn't working. […] So I said […], okay, is there anything else? Oh, he said, I don't know, I don't think there is.' P9

⇒ 'while someone is on treatment you just feel it is doing some good. When now suddenly off it, it is like, ugh, what is going to happen now? And is that other treatment going to be as effective as the one before? I think there is sort of underlying anxiety about where it's going.' C11

⇒ 'Have I got a future now, you know? I think, oh sometimes I give into it and think that this is it, I'm going to go now.' P2

Accessing treatment

Driving active treatment

⇒ '[…] one authority to the next, different things are offered, or it's a different system.' P1

⇒ 'there was no mucking about and we went straight on to the next oncologist.' C7

⇒ 'I think […] if [any hospital] can't actually come down with a diagnosis, they should be required to take it for a second opinion. Absolutely required to do it' P11

⇒ 'I'd say to the nurses, I'm sorry, I'm just a pushy woman. They said, that's how you've got where you are' P9

⇒ 'So my oncologist, to be fair to her, is extremely good at me […] coming along going, look at this, I found this, and I've researched this, you know what I mean. She knows how to deal with me.' P5

Continued

Box 2 Continued

⇒ 'I've had plenty of chemotherapy in my lifetime and it's horrible and I didn't want anymore. I thought, I'd rather feel well and get on with my life. And I was feeling quite well.' P6

The burden of treatment

⇒ 'We used to say, right, it's a ten day thing and we'd count it down. You know, the first day horrendous, second day still not great, and then it would start to ease and it seemed to be on the tenth day my dad was back to normal, and it was great.' C7

⇒ 'the first signs of it manifested themselves on my legs, on my back legs, which were horrendously… […] I mean, they were sort of horrible scabs and bleeding and what have you.' P13

⇒ 'I don't feel the bottoms of my feet when I'm walking, it feels like I'm on a padded cushion.' P2

⇒ 'He said, […] your autoimmune system is causing that to happen, it is attacking your cancer cells. So he looked so gleeful. Oh, great, you've got rheumatoid arthritis.' P11

Support needs

Support from HCPs

⇒ '[Meso CNS] was excellent, she was the centre of all the information if you needed additional information and things like that. So, that was a very good link for me.' P10

⇒ 'If [P11] had gone into palliative care five years ago that emotionally, psychologically, that would almost put a cap on our lives together.' C11

⇒ 'I don't want counselling. I mean I can't see what talking about it, from how I'm going to pop my clogs and stuff like that […] is going to change the diagnosis.' P1

Groups and voluntary sector support

⇒ 'I remember going, […] it was quite a big group when I first went. Then people asked why I was there, and I sort of told them. And I met so many fantastic people and they were just so welcoming'. P3

⇒ 'There were people there that were obviously very, very ill and who were going to die and there was a chap on our table, they were all very distressed and I was just appalled' P14

⇒ '[Asbestos support worker] went through everything. Yes, they were so amazing. And they get the finances sorted out and things like that' P10

⇒ 'I don't think you should turn [the Internet] on, and just expect to hear all glowing things. I think you do have to expect that some people don't make it, and some people have a hard journey.' P10

⇒ 'And someone said to me he went for the op because he saw how good I was, so I felt such a responsibility for it [after he died].' P1

Carers' support

⇒ 'I don't even look at myself as a carer. I'm just [P12]'s wife and I look after him like a wife would.' C12

⇒ 'Yes, I'm always aware of what she is doing, and I care for her desperately and deeply and just do everything for her, as I can. I'm always there.' C14

⇒ 'I think you just have to [cope]. You don't have a choice, do you? Just get on with it.' C10

fragile equilibrium of day-to-day coping was replaced with acute uncertainty about whether there would be alternative treatments, or if this was the beginning of the end. Having survived with MPM for a long time did not bring reassurance, but rather raised questions as to whether their luck would finally run out. While their disease was stable the coping strategies used by long-term survivors

appeared to mitigate the worst aspects of their situation. But this equilibrium was fragile and easily disrupted by developments.

Accessing treatment

Driving active treatment

Participants had different levels of confidence in the teams they were initially referred to regarding MPM. Approaches between treatment centres differed widely, seen as a 'postcode lottery' by one carer. Some participants were referred to, or managed jointly with, specialist mesothelioma centres. One participant particularly valued the coordination and access to comprehensive treatment afforded by an integrated multidisciplinary MPM network. Other participants felt a sense of nihilism from their initial team. Being offered a watch-and-wait approach, holding off active treatment following diagnosis, was hard for some participants. One patient felt that she 'couldn't sit back and do nothing', describing the timescale of her prognosis ticking away without starting any treatment. Where initial services did not offer what participants saw as best treatment, several sought referral to a specialist centre. Some made enquiries about getting treated privately, which on occasions acted as a route into specialist NHS treatment and clinical trials.

Many participants wanted to drive the quest for active treatment. In most patient/carer couples one or other led the search. Family members with a healthcare background could be important in navigating and accessing treatment. Participants became aware of treatment available across the UK and abroad via the Internet, support groups and on one occasion by meeting a lawyer specialising in MPM compensation. Treatment was viewed as highly specialised and evolving. Clinical trials were regarded as a route into new treatments and nearly half had been on a trial, with another three hoping to be recruited soon. Searching for trials and new treatments could take up considerable time and energy. There was often a sense of collaboration between patient and treating team regarding the search for the best treatments and clinical trials. Nevertheless, this search was not universal. One participant had received a lot of treatment for previous cancer diagnoses and wanted to enjoy the time he had left without pursuing further treatment.

The burden of treatment

The majority of patient participants had received multimodality treatments. While there were obvious benefits, such as disease response or stability and the reassurance of receiving active treatment, interviews also reflected the high level of treatment-related problems patients encountered. Those having radical surgery talked about slow recovery, long-term pain and breathlessness. While some undergoing chemotherapy tolerated it without major problems, others found it hard, often experiencing nausea or fatigue for long periods. Those having immunotherapy similarly had a range of experiences. Side effects could be severe, including allergy, hepatitis, or bowel changes, sometimes requiring treatment to stop. However, certain symptoms, such as an itch, or arthritis, were taken as a sign that treatment was working and regarded positively. Some appeared to want to downplay side effects for fear that it might delay or stop the treatment that they desperately wanted to have. Coming to the end of a planned course of treatment could bring relief, but also increased anxiety about the future. Long-term treatment effects, such as pain, neuropathy and skin reactions, were a problem for several participants; however, none identified any specific care aimed at addressing these symptoms.

Accessing treatment at a specialist centre often meant long travel times for participants and attendance for systemic therapies could become a significant burden, but participants prioritised treatment. Some felt isolated by the distance from the specialist centre when problems occurred and they needed to seek emergency care locally. One participant, who had his care directed by the specialist centre but delivered locally, reported instances of poor communication between teams leading to loss of confidence and anxiety.

Support needs

Support from healthcare professionals

The rare nature of this diagnosis meant that participants placed great faith in the specialist expertise of their medical team. Interviewees often reflected a sense of personal relationship with their consultant. All participants had access to a mesothelioma specialist nurse, even where they were not being treated in a specialist centre. More generalist lung cancer nurses were also important sources of support, but specialist MPM knowledge was particularly reassuring to participants. Those being treated at specialist centres reported the importance of the mesothelioma nurse specialist as a route into their clinical team and expert advice.

Participants reported big differences in the support they received from primary care. Some had proactive contact from their general practitioner, while others felt primary care lacked knowledge of MPM and consequently provided little support. Most participants had not received input from specialist palliative care services. Several patients and carers felt that such referrals could be damaging due to the association with end of life. However, one patient had discussed her future care with her general practitioner, including what specialist palliative care could offer. Another couple had met a specialist palliative care doctor during a support group meeting and subsequently had preliminary discussions about future care needs.

Groups and voluntary sector support

Most participants had attended a mesothelioma or asbestos support group since diagnosis. The greatest value was felt to be just after diagnosis, with several

participants advising newly diagnosed people to join a support group straightway. Groups gave access to others going through the same thing, information about treatment, legal advice, as well as being a social event. Those who had attended over several years felt it kept them aware of current developments and allowed them to offer their experience to newly diagnosed people. However, not all felt that the support group format was right for them, or had tried it and had a bad experience, such as encountering very sick individuals, or recently bereaved relatives.

Participants found the one-to-one support offered by asbestos support charities invaluable. As well as helping with financial and legal issues, they were also a source of information about accessing treatment and helped link up people willing to talk about their experiences of treatments. Participants also used Internet chat rooms, message boards, and Facebook groups to connect with others. Although often helpful, users understood they had to be realistic about the content. Relationships that developed with others affected were often extremely supportive, but several participants talked about the burden of getting too close to others who then died.

Carers' support

Several participating carers did not see themselves as being in a 'carer' role, as they were not giving physical care. Where patients had more physical problems carers identified more with this label. The importance of the network of wider family and friends in providing support to both the patient and the carer was clear. Participating pairs often presented their stories as a joint experience, with the impact of diagnosis and treatment affecting both parties. Patient participants frequently wanted to protect their carer, more explicitly so where interviews were undertaken separately. This included protecting them from the worst aspects of the emotional impact, as well as trying to ensure future financial security. Where participating carers had their own health needs, or where there were school-age children, the dynamic could be profoundly changed.

None of the participating carers had accessed specific support aimed at them, except one who particularly valued Internet carers' message boards. In this case the patient had significant physical needs and his daughter found linking in with others in a similar situation helpful. Most of the carer participants did not talk about their own needs, and prioritised those of the patient. Some patients recognised the need for emotional support for carers, although several carers and patients said they did not know where they could access services such as counselling for carers. One patient said that her attendance at a support group was primarily with the purpose of giving her carer the chance to meet and talk to others in a similar situation.

DISCUSSION

This is the first study explicitly focusing on the experiences of long-term survivors of MPM. As such it generates valuable insight into their needs, and the care and support received. Many of the issues identified around diagnostic problems, poor communication, and the shock of a life-limiting diagnosis, mirror those in all MPM patients.[7–11] Despite the considerable time since participants had received their MPM diagnosis, all had vivid recollections of how this happened, and remained acutely aware of the life-limiting nature of the diagnosis.[1] The difficulties participants experienced when given a prognosis without providing an opportunity for hope has been recognised previously.[21] This underlines the need to provide honest information at diagnosis that also provides an element of positivity, such as discussing treatment, trials or symptom support.[13]

Nevertheless, study participants exhibited hope for the future. Participants had a strong belief in their current clinicians and treatments, and avoided focusing on unfavourable statistics. Coping strategies were varied and included some patients delegating information seeking and decision-making to their carer, with others devoting much energy to becoming an expert in the disease. Other studies have described patients and carers being cautious and wanting to finely balance potential risks of clinical trial participation against their quality of life.[22 23] The proactive approach to treatment of the patients and carers in the current study was notable. It indicates motivation to seek active treatment is strong among MPM long-term survivors, particularly by accessing clinical trials as a route to treatment otherwise unavailable. However, this begs the question, what happens to people who lack the knowledge and health literacy to drive this quest? The study lends weight to the establishment of regional mesothelioma multidisciplinary teams (MDTs) where patients can be guaranteed access to equitable care regardless of location.[4 5]

While most participants actively wanted treatment, there were high levels of treatment related problems for many. Significant burden associated with MPM therapies has been recognised previously.[24] This study also highlighted the particular problem with long-term consequences of treatment that were poorly addressed, such as neuropathy. Nevertheless, these long-term survivors were willing to tolerate side effects and travel substantial distances in order to secure therapies that they viewed as essential to their survival.

This study has revealed how people affected long-term by MPM developed ways of coping with the day-to-day reality of living with an incurable disease, often with long periods of stability. However, we captured episodes of acute uncertainty for participants when they reached a disease 'crossroads'. Scans indicating progression, new symptoms or the end of a treatment course could suspend disbelief in the incurable nature of the disease. Unlike other conditions, such as metastatic breast cancer, MPM treatment options are limited and leave patients feeling they had few choices when their disease progresses. While many patients experience heightened anxiety around the time of routine scanning, a recent study has nonetheless

reinforced the importance of routine follow-up after treatment to monitor disease status.[25] Participants in this study tended to view scans and X-rays with equanimity; many emphasised the reassurance provided by a favourable result. However, patients and carers facing a 'crossroads' in their disease often appeared to be doing so alone, without specific recognition or support from their clinical teams. Key areas of support for study participants were their MPM team and their family and friends. Specialist psychological support had rarely been accessed by patients or their carers. This reflects findings from other studies,[9 26] and suggests improved access to tailored emotional support for patients and carers is important for long-term survivors.

In contrast to other findings, there was relatively little evidence of significant disease related symptoms in this group of long-term survivors,[11 27] reflecting a group with more indolent disease. Most participants had little appetite for specialist palliative care support around the time they were interviewed, although some had begun to make links. Other studies indicate that specialist lung and MPM nursing teams may be providing non-specialist palliative care.[28 29] Variability in support for participants from primary care was evident. The need for better collaboration between primary, secondary and tertiary care has been recognised elsewhere.[25 30] Work to address this would benefit long-term survivors. Support groups, charities and social media linking people affected by MPM together played a huge role. Little literature exists on these resources for people with MPM,[31] and this study identifies both the benefits, as well as problems, such as deaths of other MPM patients with whom they had become close, leading to existential questioning and survivor guilt.[32]

The strengths of this study are that it is the first to specifically explore the experiences of those living with MPM for 3 years or more and identifies the distinct needs of those with more indolent disease.[14] Participants lived and were treated in diverse locations, providing a snapshot of experiences and practices across local services, as well as at specialist MPM centres. However, the study also has a number of limitations. Recruitment using social medial and support groups does not allow a view across all long-term survivors. Only participants with some link to these organisations and who proactively responded were included. Therefore, the study is heavily weighted towards those who seek online resources, or who are support group attendees. This excludes those who are not using these forms of support, thus limiting the wider applicability of the findings. While the participants were reflective of the population MPM age group, participants were over-represented by female patients. Females are more likely to use support resources,[33] which may both help to explain to some extent the gender bias but also influence the findings. The study also attempted to look at the needs of both patients and their carers by undertaking joint interviews. Relatively few carer-specific issues were discussed. Future studies should focus explicitly on the needs of carers of people with MPM.[12]

Conclusion

Long-term survivors with MPM and their carers remain acutely aware of their original prognosis. Key ways of coping with this include seeking others in a similar situation, helping others and becoming knowledgeable about the condition. In the face of this rare and incurable disease, many feel the need to proactively seek the best treatments or access clinical trials. Routine involvement of regional MPM MDTs would help to address the perceived postcode lottery around MPM treatment. Long-term survival is often characterised by long periods of disease stability, punctuated by bad news associated with new symptoms, or scan results where the next treatment option is uncertain or lacking. Further research should address the support patients need around these crucial time points, and more generally the support needs of the carers of people with MPM.

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Contributors MJ conceived the idea for the study and was supported in developing the protocol by AT. MJ and PA conducted the interviews. Data analysis and interpretation was led by MJ, with the assistance of PA. Final themes were developed by MJ and PA, with the support of AT. MJ drafted the manuscript, with critical review and comment by PA and AT. All authors gave final approval for publication and have agreed that they are accountable for all aspects of the work, and in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. MJ acts as guarantor and accepts full responsibility for the finished work and the conduct of the study, had access to the data, and controlled the decision to publish.

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Patient consent for publication Not applicable.

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