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# **The effect of the coronavirus disease 2019 (COVID-19) pandemic on people with mesothelioma and their informal carers in the UK**

Why you should read this article:

- To gain insight into the impact of the covid-19 pandemic on mesothelioma patients and their families
- To understand how to better support mesothelioma patients and their families during the remainder of the pandemic

## Abstract

Mesothelioma is a rare, life limiting and aggressive cancer with a high symptom burden. This is the first article that explores the effect of the coronavirus disease 2019 (COVID-19) pandemic on the experiences of mesothelioma patients and carers. The charity Mesothelioma UK (MUK) conducted two surveys, one with mesothelioma patients and carers and one with mesothelioma UK clinical nurse specialists, to explore the effects of the COVID-19 pandemic. This article presents the findings from these surveys which suggest that mesothelioma patients and their carers have been disproportionately affected by the pandemic in a number of areas, including treatment and investigations, communication with healthcare teams, confusion about shielding and emotional and psychological burden. The article includes recommendations for practice to ensure patients and their families receive the best treatment and support during the remainder of the pandemic.

## **Background**

Mesothelioma is a rare, life limiting and aggressive cancer with a high symptom burden. The only known cause of mesothelioma is exposure to asbestos (MUK, 2020). The two main types; pleural (89%) and peritoneal (3%), affect the lining of the lungs and the abdomen respectively (CRUK, 2020). The UK has the highest incidence of mesothelioma globally with approximately 2,700 people diagnosed annually (CRUK, 2020).

In March 2020, covid-19 emerged as a global pandemic (WHO, 2020). The tremendous impact of covid-19 on health care systems worldwide carries significant implications for cancer patients across the care pathway (Richards et al, 2020). Initial evidence suggests that cancer patients with different tumour types may vary in their response to covid-19 (Lee et al, 2020). However, all cancer patients are considered to be at increased risk of serious complications of covid-19 (Gupta et al, 2021). This risk is believed to be even greater for patients following surgery (Dai et al, 2020) or undergoing active chemotherapy treatment (Liang et al, 2020).

People with mesothelioma also present with additional covid-19 risk factors. In the UK, approximately 83% of mesothelioma diagnoses are amongst men and 55% of diagnoses are of people aged 75 and older (CRUK, 2020). Both older age and male sex are associated with higher mortality for covid-19 (Docherty et al, 2020). In addition to increased covid-19 risk factors, changes to service provision in the UK pose further risk to cancer patients. NHS routine treatments and clinical trial recruitment were significantly disrupted. This was partly to divert resources to the immediate crisis of covid-19 but also because of the increased risks (e.g. immune-suppression) associated with some cancer treatments (Liang et al, 2020). Sadly, approximately 60% of mesothelioma patients do not survive the disease for beyond 12 months (RCP, 2020). This means that accessing diagnostic services, timely treatment and monitoring disease progression is exceptionally important for mesothelioma patients.

In general, people living with cancer are suffering due to the implications of social distancing and shielding measures (Tsamakis et al 2020). In March 2020 the UK government advised people who were ‘clinically extremely vulnerable’ to take additional precautions during the initial peak of the pandemic by ‘shielding’ (NHS Digital 2020). This meant not leaving home and avoiding close contact with anyone living outside of the home. Although mesothelioma is not listed as one of the conditions which automatically registers a person on the Shielded Patients List (SPL), the national charity, Mesothelioma UK, advised patients to seek registration according to point three of the criteria, ‘people with severe respiratory conditions’ (NHS Digital, 2020). The experience of shielding has been shown to increase risk of psychological stress, including overwhelming anxiety (Chen et al, 2020; Kemp et al, 2020), isolation and depression (Cancer 52, 2020). People living with a terminal illness during the pandemic have faced difficulties managing existing care needs with reduced support and expressed concerns about how restrictions may impact end of life experiences (Johnson et al, 2020). Informal carers have experienced increased caring responsibilities, worry about spreading the virus to the patient and extremely difficult bereavement circumstances (Johnson et al, 2020).

Mesothelioma UK is an independent national charity embedded in the NHS and dedicated to improving the care and treatment experiences of mesothelioma patients and their families. The charity funds 28 Mesothelioma Clinical Nurse Specialists (MCNSs) across UK NHS Trusts. To capture the impact of the pandemic on patients and informal carers, Mesothelioma UK conducted two national surveys, from the perspectives of MCNSs and patients/carers. The aim of this paper is to present a summary of key findings from the surveys. This can inform efforts to ensure patients and their carers receive the best possible treatment and support during the remainder of the covid-19 pandemic.

## Methods

Mesothelioma UK conducted a service development evaluation in order to capture the impact of the covid-19 pandemic on mesothelioma patients, their carers and MCNSs. This comprised two national on-line surveys, using the platform Survey Monkey. The first survey captured the experience of patients and informal carers' at the beginning of the pandemic. The patient and carer survey was launched on the 28th April 2020 and remained open for five days. This survey questionnaire consisted of 12 questions; six open ended and six closed questions with space for additional comments. Questions were developed by senior nurses and reviewed by patient representatives. The survey was anonymous. No demographic information or detail regarding disease status was requested, aside from confirming that all respondents either had mesothelioma or were informal carers for someone with mesothelioma. A convenience sample were recruited via the Mesothelioma UK website and social media platforms (Twitter and Facebook). Other social media and support groups circulated details about the survey. Information was posted with a request for potential eligible participants to complete the survey. A PDF version was available to download on request and responses could be returned by post. Sixty-four responses were received; 35 patients and 29 carers.

Mesothelioma UK designed a second survey to capture the insights of MCNSs concerning changes to mesothelioma services as a result of the pandemic, the impact of these on patients, and the challenges experienced by nurses and their clinical teams. The survey questionnaire consisted of 18 questions; five closed and 13 open ended. The survey was launched on 6th August. It was shared with the

MCNSs via email and completed by twenty of the 28 Mesothelioma UK MCNSs working across the UK. The survey was open for 10 days and nurses received two reminders during that time. Some nurses were on annual leave without access to their emails.

This service development evaluation did not require ethical approval. However, ethical principles were adopted (Somers et al, 2006). Completion and return of the survey were deemed consent to participate. Questions with closed responses were collated and analysed using descriptive statistics in Excel. Free text responses were analysed for each survey using the principles of thematic analysis as laid out by Braun and Clarke (2006). Themes and sub-themes were tabulated and areas of overlap between the two surveys were identified. Quantitative and qualitative data were triangulated through iterative analysis and discussion within the research team and with MUK.

## Findings

Responses were received from 35 patients, 29 carers, and 20 MCNSs. The findings presented here focus on a number of overlapping messages regarding the impact of the covid-19 pandemic on mesothelioma patients and their carers. Quotes are provided from across the respondents to illustrate the findings.

Table 1. Thematic framework

| Themes | Sub-themes |
|---|---|
| Provision and access to health services, care and advice | • Disruption to treatment schedules<br>• Disruption to CT scans<br>• Remote communication<br>• Vulnerability and Shielding |
| The psychological and emotional impact | • Negative impact on mental health and well-being<br>• Fears of catching covid-19<br>• Feeling forgotten and unworthy |

### Provision and access to health services, care and advice

### *Disruption to treatment schedules*

Thirty-two patients and carers (50%) reported that treatment schedules had been affected by the covid-19 pandemic. They identified the following specific impacts on treatment schedules: postponement of chemotherapy (16%; N=5), entry onto a clinical trial (13%; N=4) and cancellation of radiotherapy (6%; N=2). When asked about their 'worries due to covid-19', the most frequent concern was changes to treatment access and consequent disease progression (31%; N=20).

> *Patient: "Due to recommence treatment but all postponed. Quite daunting as it's such an aggressive disease"*

Similarly, 30% of MCNSs (N=6) commented on patient fears about disease progression due to reduced treatment availability and options.

> *MCNS: "With all clinical trials suspended during the pandemic people with advancing disease were blocked from accessing treatment which might have stabilised their disease. Patients have died who might be alive. They and their families were acutely aware of this barrier and expressed distress and helplessness."*

Forty-five percent of MCNSs (N=9) reported ongoing disruption to clinical trials. The most commonly cited priority for improving current cancer services was access to treatment and clinical trials (50%; N=10).

### *Disruption to routine monitoring*

Sixty-four percent (N=41) of patients and carers reported alterations to scans or outpatient appointments. Of these, 31.7% (N=13) commented that CT scans, used to monitor disease progression, had been cancelled or postponed.

> *Patient: "I get three monthly [CT] scans to keep track of progress. I'm in early stages so I'm worried about not having these scans"*

Four months later, 35% of MCNSs (N=7) reported there was ongoing disruption to accessing CT scans.

### *Remote communication*

At the time of the patient and carer survey, outpatient appointments were conducted via telephone or video call. Twenty of the 64 patient and carer respondents commented on this change which was generally well-received. However, some participants missed face-to-face interaction with their health care team. They recalled challenging experiences, for example receiving bad news over the phone. One person described adjusting to the necessary technology as a *'steep learning curve'*. Remote appointments also reduced communication opportunities for carers.

> *Patient: "Now having consultations by phone, I'm ok with it, it just means you miss the personal touch and forget about things you were going to ask but feel a bit rushed on the phone."*

MCNSs perceived numerous advantages to remote communication for patients; more frequent contact and greater continuity of care (20%; N=4), reduced travel time (25%; N=5), shorter waiting times (15%; N=3) and lower risk of exposure to covid-19 (10%; N=2). Nevertheless, when asked about the most challenging or saddest issue in recent months, 45% of MCNSs (N=9) said lack of face-to-face contact. This was because this reduced their ability to adequately assess patients, break bad news and build relationships with patients and carers.

> *MCNS: "It can be difficult to pick up on non-verbal cues via phone etc and examining people is obviously a problem. It's a good way of following up well patients though and I think it will continue into the future. the advantages are saving a trip to the hospital for people – they seem to like that especially if they are well."*

Generally, respondents to both surveys valued remote communication in health care but in some circumstances the costs outweighed the benefits.

### *Vulnerability and Shielding*

Both surveys revealed confusion regarding eligibility for, and how to register on to, the SPL. Only 52% (N=33) of patients and carers were informed automatically that they or the person they cared for were registered as 'clinically extremely vulnerable'. Others were left unsure as to their eligibility and independently registered, or assumed they were not eligible and did not need to shield.

> *Carer: “We were not aware he should have got a letter and presumed the doctors must think he was ok.”*

MCNS survey findings supported this and suggested that there remained a need for further clarity about shielding advice.

> *MCNS: “Should there be a second wave/lockdown we need more clarity on who should be shielding, this has been the biggest source of concern to patients.”*

Six MCNSs (30%) reported that patients were still struggling to understand shielding advice, complicated by variations across the UK and changes in the advice given.

## The psychological and emotional impact

### *Negative impact on mental health and well-being*

When asked about their mental health during the lockdown period, 11 (17.2 %) patients and carers reported increased feelings of depression and anxiety. Restrictions on spending time with loved ones was the most worrying issue for six respondents.

> *Patient: “I feel so shut in and very lonely. I hate not seeing my family.”*

MCNSs witnessed the impact that living through the pandemic had on patients’ emotional wellbeing. Thirteen MCNSs (65%) perceived patients experienced a loss of confidence and 14 (70%) identified low mood/ depression amongst patients. These figures are notably higher than those self-reported in the patient and carer survey. This may be because the MCNS survey was conducted later and therefore picked up longer term impacts of the pandemic. In line with this, MCNSs commented that the initial *‘Dunkirk spirit’* amongst patients had dwindled over time. Longer periods of isolation had therefore impacted significantly upon mental health for these participants who have a life-limiting diagnosis.

### *Fears of catching covid-19*

Some patients and carers (28% N=18) expressed worries about being exposed to and contracting covid-19. Some were relieved when appointments were conducted remotely or postponed because they considered the hospital environment high-risk. Likewise, when MCNSs were asked about fears or worries expressed by patients and carers, the most frequent response (65% N=13) was fear about contracting covid-19 and related worry about attending hospitals as these were considered high-risk.

### *Feeling forgotten and unworthy*

In addition to concerns about exposure, 11 (17%) patients and carers worried that mesothelioma patients would not receive equal treatment and care if they contracted covid-19.

> *Carer: "Only issue that has concerned us, is being told my husband (the mesothelioma sufferer) would not be treated with a ventilator if he caught covid-19."*

It is possible that these fears were more prevalent earlier on in the pandemic when the patient and carer survey was conducted, as only one MCNS identified this as an issue. Nevertheless, a more general concern was evident across the narrative comments of both survey responses. This concern was that mesothelioma patients and carers felt unworthy and forgotten at a time when they needed treatment, care and support the most.

> *Carer: "Probably mental health has been affected, and feel Coronavirus has taken precedence over cancer patients and their families"*

> *MCNS: "They felt forgotten and ignored once they were shielding"*

## Discussion

This article is the first to provide unique insights into the experiences of mesothelioma patients and informal carers during the covid-19 pandemic. These patients and their carers experienced significant disruptions to treatment schedules, investigations and communication with their health care team. Both surveys reported confusion about shielding and challenges to the mental health and well-being of mesothelioma patients and carers as a result of covid-19. Although some valuable and timely reports have been published (Cancer 52, 2020; Johnson et al, 2020; MUK, 2020b) currently, there is a limited number of peer-reviewed articles that present insights into the lived experiences of cancer patients during the pandemic (including Chen et al, 2020; De Joode et al, 2020; Frey et al, 2020; Tsamakis et al, 2020). There are even fewer focusing on UK health care (including Younger et al, 2020). This article therefore provides valuable insight into the experiences of people living with an incurable cancer diagnosis during the covid-19 pandemic in the UK.

Access to treatments and clinical trials is central to the provision of high quality healthcare for patients with mesothelioma, and a great source of hope (Bibby & Maskell, 2018). The reduced access reported in this study carries a profound impact on potential disease progression, and on psychological and emotional wellbeing. Poorly managed fear of cancer progression can adversely impact quality of life (Reb et al, 2020). Although the majority of cancer services are now being reinstated (as of Nov 2020), two additional remaining issues were highlighted across survey findings. These are inequitable access across the UK, particularly in relation to clinical trials and CT scans, and ongoing fear of exposure to covid-19 in relation to hospital attendance. These findings mirror those from a recent lung cancer survey which reported that 44% of CNSs believed patients fear of covid-19 exposure was restricting hospital attendance and therefore uptake of treatments (LCNUK, 2020). This reinforces the importance of routine cancer services being fully reinstated and maintained across the UK, but in a way that reassures patients that it is safe to attend hospital and receive treatments (Vrdoljak et al, 2020). This presents a real challenge to services already under pressure from covid-19. Covid-free wards, treatment hubs and home treatments look likely to prove valuable while the pandemic remains (Mayor, 2020; Richards et al, 2020).

Covid-19 has changed ways of working, not least the increased reliance on remote communication. This change is expected to remain an integrated component of future health services (Smith et al, 2020). Participants in this study welcomed the flexibility of remote communication, consistent with existing reports that patient’s communication with their health care team has improved through the use of remote appointments (Cancer 52, 2020). Nevertheless, some difficulties were identified including assessing patients, involving family members and breaking bad news. Again, this reflects the recent survey of lung cancer CNSs, that reported breaking bad news remotely may increase patient distress (LCNUK, 2020). This indicates one size does not fit all. Whilst some patients and carers will prefer virtual communication, others would value the option of face-to face communication. This may be particularly important for patients with incurable cancers, where the sensitive nature of discussions around disease progression or end of life, may necessitate face-to-face communication. Moving forward, investment is required to provide the option of face-to-face appointments alongside good quality remote communication.

Participant's experiences highlight inconsistency and confusion regarding eligibility and access to the SPL. This resonates with a lack of clarity about shielding across the wider UK population (Torjesen, 2020) and other patient groups (Cancer 52, 2020). A clearer and more consistent message regarding eligibility is therefore required, with specific consideration for people with peritoneal mesothelioma who are currently not automatically eligible under point three of the SPL, which includes 'People with severe respiratory conditions including all cystic fibrosis, severe asthma and severe chronic pulmonary disease (COPD)' NHS Digital, 2020). This study indicates the importance of improving understanding of viral risk for cancer patients and tailoring advice and services accordingly (Lee et al, 2020). This will facilitate informed decision making (Kemp et al, 2020) and reassure patients that they matter.

Survey findings show that the pandemic is having a negative effect on the mental health and well-being of patients and carers. Mesothelioma can cause psychological distress (Sherbourne et al, 2020) which may be exacerbated during the current pandemic (Tsamakis et al, 2020), as reported amongst other cancer patient groups (Frey et al, 2020). Our data have highlighted that the psychological impact of mesothelioma can be compounded by covid-19. These findings reinforce the recommendation made by Cancer 52 (2020) and Younger et al (2020), that patients with rare cancers would perhaps benefit from additional psychological support throughout the remainder of the pandemic.

Limitations of this study include the absence of information about the patient/carer participants, for example disease status, time since diagnosis and respondent demographics. This, and the size of the sample, make it difficult to conduct sub-group analysis. As a convenience sample, those who responded may not be representative of all patients and families living with a mesothelioma diagnosis. The patient/carer survey and MCNS survey were conducted four months apart and therefore provide slightly different insights.

Covid-19 presents an ongoing risk that will shape clinical practice for the foreseeable future. These study findings have informed the development of the following recommendations to outline ways in which the experiences of mesothelioma patients and carers can be improved during this pandemic. These recommendations potentially have relevance to other patients with rare and incurable cancers. Further research is required to better understand the impact across a range of conditions.

- As a priority, mesothelioma services across the care pathway, from diagnosis to end of life, need to be reinstated and sustained during the remainder of this pandemic.
- Where appropriate, patients and carers should be reassured that it is safe to attend hospital and receive treatment. For example, this can be facilitated by, increasing information and awareness of covid-free wards and treatment hubs.
- Where possible all mesothelioma patients should be offered the option of face-to-face appointments.
- Investment is required to ensure the provision of good quality remote communication, especially when breaking bad news. This includes access to necessary training and equipment.
- Care and support of patients and carers should remain person-centred. This includes providing reassurance that they will receive the best quality care and treatment if they contract covid-19. Regular communication with services and provision of up to date information and advice (from organisations such as Mesothelioma UK) can help achieve this.
- Clear and consistent messaging is required regarding SPL eligibility and requirements, with specific consideration for peritoneal patients.
- On-going emotional and psychological support is essential for mesothelioma patients and carers throughout the remainder of the pandemic. This can be facilitated through regular ‘check in’ calls from mesothelioma service

providers, including specialist nurses. Effective ways of running support groups during the pandemic also need to be explored.

## Conclusion

This article is the first to focus on the impacts of the covid-19 pandemic experienced by mesothelioma patients and carers. The findings suggest that mesothelioma patients and their carers have been disproportionately affected by the impact of the covid-19 pandemic. Our survey findings suggest patients with mesothelioma have faced significant disruptions to their health services and problems accessing care. Mesothelioma is a terminal condition. It is therefore essential that mesothelioma patients and their families receive the best quality care, treatments and support despite the ongoing pandemic. These insights have informed a number of recommendations to improve the experiences of mesothelioma patients and carers while the pandemic remains a public health emergency and continues to shape everyday lives.

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## Conflict of Interest

No conflicts of interest to declare.

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