

Experiences of care and variability in patient pathways in peritoneal mesothelioma - qualitative findings from a UK study

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INTRODUCTION

There is an increasing awareness that those living with peritoneal mesothelioma may have different experiences to those living with pleural mesothelioma.

This study presents qualitative findings from a larger mixed-methods, longitudinal study exploring variability and patient experience of the care pathway of people with peritoneal mesothelioma.

Initial evidence suggests variability in experiences and access to care in patients living with peritoneal mesothelioma in the UK.



Image taken in-house

METHODS

A longitudinal multiple case study design was used. Data was collected between February 2022 and December 2022.

Semi-structured interview schedules were used which focused on the experience of living with peritoneal mesothelioma, the care pathway and how that experience changed over time.

Seven patients were recruited via respondents from a survey circulated in an earlier phase of the study. Each case study consisted of one patient, one carer identified by the patient and one professional identified by the patient.

Interviews (up to three each) were undertaken with patients over a one year period. Carers and professionals were interviewed once each.



RESULTS

Patients and carers reported:

- Journey to diagnosis challenging partly due to non-specific symptoms

“I’d been complaining of stomach pains and general symptoms of tiredness”

- Heavy symptom burden
- Multiple specialties involved in diagnosis and care
- Access to and decision-making around treatments often relied on them educating themselves about all available options

“No discussion about the type of treatment, it was, you’re having chemotherapy”

- Need for more information specifically for people living with peritoneal mesothelioma
- Specialist multidisciplinary peritoneal mesothelioma services highly valued and supported a more co-ordinated care pathway

“Patient clearly has had a long and frustrating route to diagnosis as often occurs in patients with rare tumours” Oncologist

- Asbestos support groups and legal professionals alleviated administrative burden of seeking benefits and financial compensation

Health and support professionals:

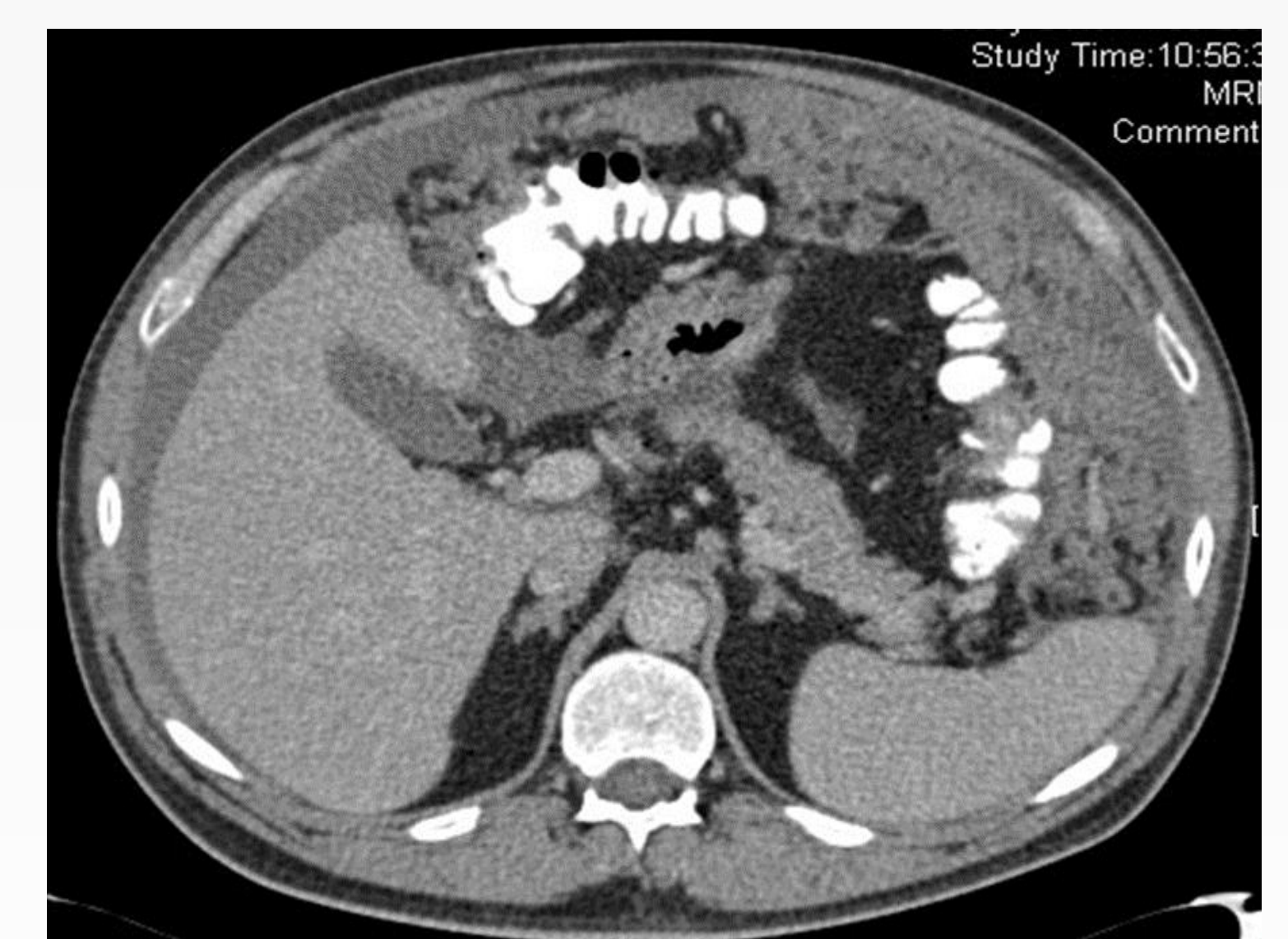
- Were key to patient journeys and navigating the healthcare systems
- Identified challenges such as access to treatments, specialist services and impact of living with a rare cancer.

CONCLUSIONS

This study suggests that patients with peritoneal mesothelioma experience significant variability in diagnosis, treatment and care.

The study provides valuable insight into the experience of living with peritoneal mesothelioma and highlights the value of joint decision making for treatment options, and the inclusion of specialist mesothelioma multidisciplinary team support.

Recommendations for practice are being developed.



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