Mesothelioma UK Research Centre: Patient and carer experience research
Mesothelioma UK Research Centre - Sheffield

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https://www.sheffield.ac.uk/murc
The Vision

• The Mesothelioma UK Research Centre conducts a portfolio of robust and rigorous research with a reputation for excellence nationally and internationally and that is:
  
  • of benefit the care of people diagnosed with mesothelioma and their families,
  
  • relevant and in tune with scientific and general cancer research progress, service development and patient and carer need.
  
  • able to build research capacity within the field of mesothelioma patient care, clinical practice and relevant professions
  
  • of relevance and able to inform policy
  
  • able to demonstrate a pathway to impact
Patient and Public Involvement (PPI) Panel

- Gives advice and guidance to the Mesothelioma UK Research Centre.
- Improves the design, implementation and dissemination of our research
- Open to other UK researchers in mesothelioma

Who can join?
- Anyone with personal experience of mesothelioma can join. This includes patients, family members and friends, and interested members of the public.
Current projects

- Rapid review of evidence: patient/family experiences of mesothelioma
- Research Prioritization Exercise
- MEWS (Mesothelioma in Education Workers)
- Impact of COVID-19 on mesothelioma
- Palliative care needs in mesothelioma & role of Clinical Nurse Specialist
- Experience of long-term survival in pleural mesothelioma
- MINNOW – Mental health in mesothelioma
- Care and treatment variability in peritoneal mesothelioma
Rapid review of evidence: patient/family experiences of mesothelioma

• Aimed to identify what is known about the experience of living with mesothelioma, from the perspective of patients and their informal carers.

• A narrative synthesis identified eight themes:
  • experience of diagnosis
  • physical impact of mesothelioma
  • psychological impact of mesothelioma
  • impact on informal carers, carers and relationships
  • self-management
  • health care professionals and systems
  • treatment and trials
  • asbestos exposure and compensation

**Aim:** to identify unanswered questions about the mesothelioma patient and carer experience and then to prioritise these areas, through consultation, to identify research areas of most importance.

**Timeline:**
- Nov 20 - Jul
- Mar - Jul
- Jul - Sept
- Sept - Nov 21
Mesothelioma patient and carer experience research priority statement

Conducted by the Mesothelioma UK Research Centre, Sheffield in 2021

Five research priorities relating to mesothelioma patient and carer experience were identified as the most urgent. These are as follows (in no particular order):

- Symptom management (support for patients and carers to manage symptoms, management of physical symptoms e.g. cough, breathlessness, and management of psychological symptoms e.g. stress)
- Receiving a mesothelioma diagnosis (patient experience immediately after diagnosis, barriers and facilitators to early diagnosis, occupational history taking at diagnosis)
- Palliative and end of life care (supporting quality of life across the patient pathway, from diagnosis to the end of life and bereavement)
- Experience of treatments (the physical impact of treatments (including side effects), factors influencing treatment decisions)
- Barriers and facilitators to joined-up service provision (access to services; how different health, care, and other services are brought together to meet the needs; choices and aspirations of the individual; geographical variation across the UK)

A further six research priorities relating to mesothelioma patient and carer experience were also identified as important. These are as follows (in no particular order):

- Care delivery (the role of different professionals in supporting patients and their families, maintaining hope, preferences for the delivery of information about mesothelioma, the role of support groups)
- Living with peritoneal mesothelioma (all aspects of the peritoneal mesothelioma experience need further research). Research recognising the experiences of peritoneal mesothelioma patients and carers may be integrated into the other research priorities.
- Mental health and wellbeing (the link between physical and psychological wellbeing, exploring mental health and wellbeing (positive and negative) across the mesothelioma journey)
- Experience of clinical trials (factors influencing clinical trial participation, costs and benefits of taking part in a clinical trial)
- Experience of caregivers (supporting and communicating with families and caregivers from diagnosis to bereavement, positive and negative impacts of informal caregiving, the impact of mesothelioma on family and intimate relationships)
- Compensation (barriers and facilitators to seeking compensation)
MEWS (Mesothelioma in Education Workers)

• Scoping review on presentation, diagnosis, treatment and care for school-based education workers with mesothelioma:
• No primary research studies were found.
• Grey material covering 84 individual cases in the UK were found; 19 were ancillary staff, the remainder, teachers.
• Experience of education workers may differ from the wider mesothelioma patient group. The differences centre on:
  • Causation
  • Lack of knowledge or training,
  • Anger and surprise at exposure and poor management of the problem,
  • Concern for others at risk, particularly pupils.
Impact of COVID-19 on mesothelioma

Patients with mesothelioma and their carers have been disproportionately affected by the COVID-19 pandemic in various areas. These include:

- Disruption to treatment schedules, scans and investigations
- Communication with healthcare teams, challenges with remote communication (esp bad news)
- Confusion concerning shielding
- Emotional and psychological burden of the pandemic including fear of contracting COVID, negative effects on mental health, feeling ‘forgotten’
- Impacts on healthcare staff
Palliative care needs in mesothelioma & role of Clinical Nurse Specialist

1. Significant palliative care needs in mesothelioma
2. Mesothelioma UK clinical nurse specialists highly skilled at providing palliative care; majority have received training in palliative care
3. Important distinction between ‘specialist’ palliative care and ‘generalist’ palliative care.
4. Good partnership working between Mesothelioma UK CNS’s and specialist palliative care is crucial
5. A co-ordinated approach to care is crucial
6. Patients with mesothelioma and their families can be reluctant to accept palliative care due to preconceptions about the term ‘palliative’
7. COVID-19 has presented significant challenges.
Living beyond expectations: a qualitative study into the experience of long-term survivors with pleural mesothelioma and their carers

- Paper submitted for peer review
- Three themes were identified:
  - 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.
MINNOW – Investigating the Mental health Implications of a mesothelioma diagnosis and developing resources to Optimise Wellbeing

- Aims to generate understanding of the impact of mesothelioma on the mental health of patients, their families and close friends
- Stage 1: Systematic review of the literature
- Stage 2: Quantitative data collection and analysis
- Stage 3: Qualitative interviews with patients and informal carers
- Stage 4: Co-production workshops
Aim: To explore variability in care pathway of people with peritoneal mesothelioma, and to explore the impact on quality of life and patient outcomes based on their care pathway.

This mixed-methods study using survey and in-depth case-study methods.

1) Cross-sectional survey of 48 PM patients and 22 family members to explore demographic characteristics; patient pathway; experiences of treatment and care.

2) A longitudinal, exploratory case study series of up to 7 individual patients, their family members and professionals, representing up to five patients with a diagnosis of PM.
Supporting Our Supporters (SOS): improving the experience of family and caregivers of people with mesothelioma

• Aim: to explore the impact on the family carer, of caring for or supporting a person with mesothelioma and consider changes over time.

• The study will involve three workstreams
  • A survey of around 50 family carers, to ask about the impact of being a carer.
  • Individual interviews and surveys with around 20 carers every 3 months for 9 months, to get a picture of how experiences change over time.
  • Two workshops for carers and other people with expertise in mesothelioma. At these workshops we will use the data from the study and work together to come up with solutions, and develop new strategies for helping support family carers of people with mesothelioma.
Publications

2022

- Couchman E, Gardiner C, Ejegi-Memeh S, Mitchell S. Facilitators of and barriers to continuity with GPs in primary palliative cancer care: A mixed-methods systematic review. *Progress in Palliative Care* 2022

2021

Thank you

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