Mesothelioma Patients' and Carers' Concerns about Their Diagnosis, Treatment, and Care

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The authors declare no conflicts of interest
• The James Lind Alliance (JLA) is a non-profit making organisation.

• Priority Setting Partnerships (PSP) with stakeholders (patients, carers, and their families) identify aspects of care that matter most to them.

• Mesothelioma PSP identified the top unanswered research questions.
  
  *Stephens RJ et al. Lung Cancer 2015;89;175-80*

• BUT many ‘out of scope’ issues also raised.....
Delays in diagnosis

‘My husband visited local medical practice about 8-9 times before being diagnosed. Never asked about family history (he had lost his brother to mesothelioma)’

• A timely and early diagnosis is important.

• It provides the best chance of longer survival and better quality of life.

• Late diagnosis might limit treatment options.
Empathy

‘You have mesothelioma and it will kill you within 2 years’. Those are the words used by my husband’s consultant without preamble’

- Few tasks are more difficult than breaking bad news.
- It requires skill, compassion and careful consideration.
- The way bad news is given to patients can have a significant impact on how patients and their families come to terms with and cope with their situation.
- Factors to consider:
  The people involved
  The communication process
  The environment
Information

‘No one outlined a core plan for my father or flagged up what stages there would be, or what triggers would be in place for different stages. It should not have to be a Magical Mystery Tour’

• Once diagnosed, patients and their families need information (or access to information as and when they want it).

• Once a care pathway is agreed they need a map of their likely journey, with information about the possible treatments, side effects and symptoms.
Continuity of Care

‘I am amazed to hear all the different stories of how patients are treated at various hospitals. The inconsistencies are unacceptable. Every mesothelioma patient deserves the best care and treatment’

• Care for mesothelioma may have multiple, different components.

• Seamless continuity of care requires timely and appropriate referrals, and smooth transitions between care providers.
Patient Input

‘I will always wonder if he might have had a little less time, but better quality, if he had declined chemotherapy’

• Patients need information and clear explanations to help them understand care and choose the best care pathway for them.

• Individual patients may value care in different ways.

• Patients’ preferences must be respected.
Pain

‘Although we were given all sorts of options, my husband was still in great pain for most of the time and this was extremely upsetting for us to witness’

• Many patients mentioned unrelenting chronic pain, related not only to symptoms, but also to treatment.

• Pain is an unmet need in this patient population.

• Pain relief was included as an unanswered research question in the JLA PSP but ranked surprisingly low.
Carers

‘At his last appointment the consultant said he would not benefit from any more chemo, and discharged him. We were sent away completely abandoned and lost, not knowing what our next step would be’

• Mesothelioma potentially places huge burdens and responsibilities on carers.

• Support networks can help some people.

• Community nurses with experience of mesothelioma and who are available at short notice are important.
Key messages

The remit of the JLA PSP was to generate and prioritise unanswered research questions but the survey highlighted many concerns with diagnosis, treatment and care.

These concerns cannot be ignored.

Innovations in care are important but we also need applied health research to reduce variations and improve care quality.

Research that leads to real changes in patient care is vital otherwise the outlook for patients who suffer from this devastating disease will remain bleak.

‘All he ever did to get sick, was go to work’