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26 September ES07 Beyond the diagnosis: collaboration for change

ES07.06 Research update: Patient's perspective on living with malignant pleural mesothelioma - Angela Mary Tod

Malignant pleural mesothelioma (MPM) is an aggressive rare cancer due, in the main, to exposure to and inhalation of asbestos (Odgerel et al 2017). Incidence is higher in certain occupational groups including asbestos mining (e.g. Australia) and construction industries (Rake et al 2009). Rates vary within and across countries. The UK has one of the largest rates of mesothelioma with approximately 2700 new diagnosis a year. Rates of MPM show no signs of reducing and global incidence and burden is likely to be underreported due to poor data capture in some countries. Whilst asbestos use has drastically reduced in developed countries, significant amounts of asbestos are still used in India, China, Russia, and some developing countries (Frank&Joshi 2016)

The latency period for MPM varies from 30 and 50 years with an average of 40. Occasionally exposure to diagnosis can be 10 years or less, but this is uncommon.

MPM is an incurable cancer but there are new treatments offering promise in terms of length of life and palliation of symptoms. New radical surgical procedures are being performed and novel drug treatments provide better patient outcomes. In addition there are new procedures for the consequences of MPM such as trapped lung and malignant pleural effusion (MPE).

Although showing no signs of the global burden reducing, and the increase of new treatment and procedures, there is little research exploring the experience of living with mesothelioma from the perspective of the person with the disease and their family. This presentation will shine a light on existing research, and provides us with an understanding of the experiences of living with MPM. It will draw on the wider literature as well as recent and current studies being conducted by the author and colleagues. International literature will be included but many references will be to the UK context.

The journey of the person with MPM will provide the structure for the presentation. Starting with the long road to diagnosis, the experiences of coming to terms with and understanding the diagnosis will be considered. This will be followed by research on people's experiences of treatment and trials and care related to end of life. An underpinning theme will be balancing the bleak with the positive.

The diagnostic process is a challenging experience for patients. Many people describe it as a long and winding road, full of dead ends and false trails, as other possible diagnosis are offered prior to confirmation of MPM. For others whose first symptom is a MPE the distress of the symptoms are compounded by the shock of being delivered a terminal diagnosis. Although challenging, for some actually getting a diagnosis confirmed has the benefit of the end of uncertainty.

Understanding and coming to terms with a MPM diagnosis is fraught and perplexing. Not only is the diagnosis life limiting, it was due to exposure to asbestos many years ago. The extent to which people remember and expected consequences of this exposure will impact upon ability to accept the diagnosis.

It is not uncommon for people to have never heard of MPM and people can struggle to understand the nature of the tumour and their prognosis. Many people see cancer as a solid tumour or lump, so a diffuse cancer such as MPM is difficult for people to understand. Balancing the needs of patients and family members can be difficult especially if they conflict in terms of the nature of information and the time in the pathway it is requested. Prognostic facts are an example as patients and family carers may differ when and if they want such information.

For those with a MPE, there is an urgency to have that treated. Unless the MPE and related symptoms are addresses, people are unable to assimilate information about the underlying diagnosis of MPM. This highlights the importance of timing related to information delivery.

As new treatments become available, this will increase the information burden for patients. Whilst they offer promises in terms of outcomes for patients, there are challenges regarding decision making and tolerating the burden of treatments and interventions (Hughes&Arber 2008, Clayson et al 2005). People will have to understand procedures required to assess eligibility for new surgery or drug treatments and face the consequences of being eligible or not eligible. Finding themselves not eligible can be experienced as a 'failure' as well as a loss of hope. For those proceeding to new treatments they will have to endure additional information burden as well as any potential side effects and consequences.

Legal and compensation processes that run parallel with treatment add additional challenges to the patient journey. Again there may be a time pressure for people to resolve this for family members before the person with MPM dies (Hughes&Arber 2008).

Finally research findings regarding end of life are considered, including the access to timely palliative care, pressures on family members in coping with MPM as an industrial disease requiring post-mortem and coroner involvement.

Psychosocial impacts emerge across the pathway as patients ad carers deal with stress, shock, changes to identify, relationships and the demands of managing uncertainty.

Throughout the pathway, research indicates the need for people with MPM to balance out the bleak with the positive (Taylor 2018). Understanding this can help health professionals better meet the needs of patients and family.

Much of the research on MPM experience highlights the enormity and range of information people have to take on board. Some of this has a time pressure as it is linked to treatment or trial decisions.

In conclusion, the contribution of Relationship-centred care' (RCC) will be considered. This expands on and enhances the notion of person-centred care. The proposition is that RCC will help address the complex and challenging nature of improving the MPM patient and carer experiences.

The experience of patient and family carers experiences of MPM is relatively unexplored. We need more evidence to help us understand what is important to them and how care priorities can best be met. At the impact of increased asbestos use in developing countries emerges, with an increase in asbestos related diseases, research to illuminate patients perspectives and experiences in those nations will be required.

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