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Abstract 6465

Supporting Patients Undergoing Radical Treatments EPD – MARS Study

Type: Invited Speaker Abstracts

Topic: 17. Nurses

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Abstract

Background

Malignant pleural mesothelioma (MPM) is an aggressive cancer of the lining of the chest wall and lung, its aetiology lies in asbestos exposure. With over 2,500 people diagnosed each year, the UK has the highest incidence of mesothelioma in the world. Chemotherapy is an established treatment for MPM but response rates are variable, evidence is lacking in new drug therapies and mortality remains high (in the UK half of patients die within 8.5 months of diagnosis) (Maggioni 2016, HSCIC 2015). Surgery is therefore an important option.

Very little robust, randomised controlled trial evidence (RCT) exists regarding surgical interventions for mesothelioma and many studies are observational (Cao et al 2014). This has prompted global variations in surgical approaches (Mclean 2013). Extended Pleurectomy Decortication (EPD) is a surgery for patients considered to have resectable MPM. EPD involves the removal of the lining of the chest wall, lining of the lung, with the sac of the heart and / or diaphragm (as required to achieve complete tumour removal) but leaving the lung in-situ. However, evidence on survival or symptom improvement benefits of this surgery is limited (Cao et al 2014, Teh et al 2011).

Challenges in surgical research are the lack of clinical trials and few patients choosing to enter RCTs for surgery (Treasure & Morton, 2012, Horton 1996). Potential explanations for this include restrictive trial regulation, patients declining randomisation, and difficulties in recruitment practice such as presenting trial arm options neutrally (Treasure & Morton 2012).

The Mesothelioma and Radical Surgery 2 (MARS 2) Trial, a UK based study, will evaluate whether EPD can improve the length and / or quality of life in patients with surgically treatable disease and its cost-effectiveness. It will randomise participants to chemotherapy or chemotherapy plus surgery. The feasibility stage has demonstrated the ability to recruit and randomise to this study and the plan is to proceed to full trial.

This paper presents findings from a nested qualitative patient experience sub-study within MARS 2 that investigated patient experience of the study interventions. It more specifically identifies the support and information needs for people regarding i) the interventions (surgery and chemotherapy) and ii) trial recruitment, consent and participation. This paper focuses on the findings related to support needs of the trial interventions. A summary of results will be provided along with reflections on the implications for future practice.

Methods

An in-depth longitudinal qualitative study with interviews of 16 participants randomised to chemotherapy (n=8) and chemotherapy + surgery (n=8). Interviews were conducted after randomisation (but before surgery in the surgical cohort). Surgical patients had an additional interview post-surgery. Framework analysis methods were used (Ritchie and Lewis, 2014). Follow-up interviews were at 6 and 12 months post-randomisation. This paper presents findings up to and including the 6 months follow-up.

Results

Participants reported being well informed about their illness, but had struggled to absorb and understand the extent of information delivered at diagnosis. This was influenced by the range of significant subjects that were covered in a number of consultations with different healthcare staff providing distinct specialist services. The topics discussed included diagnostic information about mesothelioma, treatment options and consequences, trials processes and logistics, and legal and financial information regarding classification of MPM as an industrial disease.

Despite feeling well informed about their treatment some participants reported not being prepared for the full extent of the problems they experienced. Both chemotherapy and surgery were challenging treatments although they were associated with different physical effects. Adverse consequences of treatment were described including neutropenic sepsis and dehydration post chemotherapy, and bleeding, prolonged pneumothorax and infection post-surgery. For most participants pain and breathlessness were experienced post-surgery while nausea, anorexia, taste changes and constipation were associated with chemotherapy. Fatigue that impacted on daily living was experienced by both groups. Interventions to manage the consequences of treatment were recounted; some had been recommended by healthcare staff while others had been developed by patients from their own initiative.

Participants reported struggling to cope with the effect of treatment whilst trying to deal with the broader context of coming to terms with their illness. Uncertainty was expressed in relation to treatment plans (exacerbated by the logistics surrounding participation in a clinical trial), severity and duration of side effects, rehabilitation and recovery and treatment outcomes.

Participants employed a number of strategies to help with coping. These included 'playing things down', 'weighing the balance', 'managing expectations', 'taking control' 'manning up' and 'trust in the doctor and/or treatment'. Many of these strategies facilitated staying positive, maintaining hope and finding comfort which was important to participants. Family members played a key role in coping. A diverse range of healthcare staff provided information, advice and practical interventions across the care pathway from community, surgical, respiratory and oncology services.

Discussion

Patient's perspectives on the experience of receiving radical surgery and/or chemotherapy for mesothelioma were identified by the study. This provided valuable insights into their impact on patient's feelings about their illness and treatment and how they coped with the challenges they were presented with. Multiple sources of uncertainty were expressed by participants.

The contribution of healthcare staff to supporting coping and providing information and advice was appraised positively by participants. However, we identified that fragmentation could occur due to the diverse services involved in providing care with no single point of contact or co-ordination.

Conclusion

Understanding the patient's perspective of the challenges associated with treatment, alongside their strategies for coping, provides insights for the services that can support patients undergoing arduous treatments for mesothelioma. The study reveals ways to facilitate strategies to help patients manage the condition, as well as treatment side-effects. Interventions to reduce uncertainty have been identified as a priority for service improvement.

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