Patient’s experiences of radical treatment for mesothelioma: the MARS 2 trial

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Background
Malignant pleural mesothelioma is an aggressive cancer predominantly affecting the lining of the chest wall and lung. With over 2,500 people diagnosed each year, the UK has the highest incidence of mesothelioma in the world. Response to current treatments are variable and mortality remains high (in the UK half of patients die within 8.5 months of diagnosis) [HSCIC 2015]. Research to improve survival is a priority and the Mesothelioma and Radical Surgery 2 (MARS 2) Trial was established in the UK to compare chemotherapy and surgery to chemotherapy alone. The trial includes a nested qualitative sub-study to explore patient’s experiences of trial interventions.

Method
The study utilised an in-depth longitudinal qualitative approach. 14 participants were interviewed following randomisation to chemotherapy (n=7) or chemotherapy and surgery (n=7). Additional interviews were conducted post treatment (surgical patients) and at 6 and 12 months after the initial interview (all participants). Data was collected between August 2015 and March 2017 and analysed using Framework analysis (Ritchie et al 2013).

Findings

Challenges
- Chemotherapy and surgery had significant troubling physical effects and recovery was slow and prolonged. Fatigue that impacted on daily living was experienced by all.
- Participants struggled to cope with the effect of treatment whilst trying to come to terms with their illness. Some felt unprepared for the full extent of the problems they experienced during and post treatment.
- Uncertainty was expressed in relation to treatment plans, severity and duration of side effects, rehabilitation and treatment outcomes.
- Information overload was reported due to the range of subjects covered in multiple consultations with different healthcare staff from distinct specialist services (e.g. surgical, chemotherapy, oncology, community) which may have been exacerbated by trial participation.
- There was evidence of a degree of fragmentation in communication and treatment plans between services at key points in the pathway.

Facilitators
- Participants were positive about the care received and recounted excellent team work, feeling safe, valued and “cared for”.
- Most recalled receiving clear and comprehensive information about specific subjects such as the details of the surgical procedure and the side effects of chemotherapy. The demanding nature of treatment had been spelled out clearly beforehand and this was seen as positive.
- Interventions to manage side effects had been provided and chemotherapy patients have a point of contact to access advice between cycles.
- All had developed adaptive approaches to coping with their diagnosis and treatment. Many strategies facilitated staying positive, maintaining hope and finding comfort which was important to participants.
- Family members played a key role in providing physical, practical and emotional support.

Discussion/Conclusion
Patient’s perspectives on the experience of radical treatment for mesothelioma increase understanding of the significant challenges they face. The contribution of healthcare staff to supporting coping was appraised positively. However, we identified aspects of treatment that were not anticipated by patients and fragmentation in services where there was no single point of contact or co-ordination. Interventions to reduce uncertainty have been identified as a priority for service improvement. Conducting a qualitative study within a clinical trial has provided valuable insights into patient’s experiences of trial procedures and treatments.

References