

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 has 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.

Treatment effects

Surgery: prolonged chest drainage, pain, breathlessness, constipation (exacerbated by analgesia), fatigue, difficulty sleeping, numbness at operation site

"Every time you done something like cough, you'd get this pain....where the tube was, oh it was murder"

"getting out of breath...I could walk anywhere ...before I went in, I could do all these things, but now I can't do them. It's frustrating."

"I've been in pain, I've cried over it and stuff like that but at the end of the day it's just a bit of pain."

Challenges

Treatment effects

Uncertainty

Information overload

Fragmented care

Facilitators

Care interventions

Coping strategies

Being prepared

Access to support

Treatment effects

Chemotherapy : nausea and vomiting, anorexia, constipation, anorexia, taste changes, fatigue, infection, sore mouth

"I go downhill for 7 to 10 days then pick up and you just feel as though you got back to where you started when it's time for another dose"

"the sickness, the tinny taste in your mouth, and how tired it makes you. I mean, the first day after the chemo I just felt absolutely knackered."

"I couldn't eat, I couldn't drink and I had to go into hospital for nine daysI was very low and dehydrated."

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

Health and Social Care Information Centre (HSCIC) (2015) *National Lung Cancer Audit Report Mesothelioma 2014*
Riche, J and Lewis J (2013) *Qualitative research practice: a guide for social science students and researchers*. 2nd Edition. London: Sage.

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