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Patient experience of Extended Pleurectomy Decortication (EPD) and chemotherapy in the MARS 2 feasibility trial: findings from a longitudinal qualitative sub-study

Lord K, Warnock C, Allmark P, Taylor B, Tod AM,

Background

Little robust, evidence exists regarding patient experience of new interventions for mesothelioma (Cao et al 2014, The et al (2011)). The Mesothelioma and Radical Surgery 2 (MARS 2) Trial, will evaluate clinical and cost-effectiveness of Extended Pleurectomy Decortication (EPD) plus chemotherapy in mesothelioma versus chemotherapy alone.

This paper presents findings from a longitudinal qualitative patient experience sub-study within MARS 2 feasibility. It investigated patient experience of the study interventions.

Methods

An in-depth longitudinal qualitative study with interviews of 16 participants (7 chemotherapy, 7 chemotherapy + surgery, 1 declined participation and 1 declined randomisation). Interviews were conducted prior to randomisation, and at 6 and 12 months post randomisation. Surgery patients had an additional interview at the time of surgery. Framework analysis methods were used (Ritchie and Lewis, 2014).

Results

Participant's expectations of treatments (chemotherapy and surgery) did not always match the reality of their experience. Both interventions had profound impacts on participants, with many being more severe than anticipated. Chemotherapy patients experienced Nausea, fatigue, mouth ulcers, rash, constipation and fatigue. Whilst surgery patients suffered problems with pain, breathing, fatigue and, in addition, anxiety and discomfort due to the drains, especially if left in situ following discharge. Self-management and coping strategies are presented. These included pacing, testing out, managing expectations, 'playing things down', 'manning up' and goal setting. Factors that facilitated symptom management, recovery and coping are discussed including continuity of care, and clarity of information.

Conclusion

This is the first study that follows the progress of people with mesothelioma through a trial evaluating a radical treatment (EPD plus chemotherapy) against standard treatment (chemotherapy alone). It therefore provides valuable insight into the nature and extent of the impact of both treatments. Related patient care needs are identified to inform future care provision.

References

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