CareSearch Project Research Studies Register: Registration Proforma	0037

Study Title: A very public death – exploring the needs of a person dying of mesothelioma or asbestos related lung disease

Brief description of the study:

This descriptive exploratory study will highlight the particular needs of people dying of mesothelioma and their families and carers. An initial literature search of the issues involved for a person dying of mesothelioma, indicates that while this issue receives a lot of (often emotive) attention in the media (mainly focusing on compensation issues), there is little information to highlight whether there are different care needs at the end of life for people dying of mesothelioma. It is anticipated that cases of mesothelioma will continue to rise significantly over the next fifteen years (Leigh, Davidson, Hendrie, & Berry, 2001) with power station workers having a risk second only to asbestos mill workers. Because most cases of mesothelioma are related to work exposure to asbestos, cases are often a part of local and regional epidemics (Walker & LaMontagne, 2004). Sufferers often have had past experience of close family, friends and colleagues dying of the same disease. This and the consequent battles for compensation results in victims of the disease having very public profiles. Significant work in Australia by the Australian Mesothelioma Register (National Occupational Health and Safety Commission, 2004) has documented epidemiological factors related to the disease and others have studied the diagnosis (Henderson et al., 2004) and the clinical features of the disease (Baker et al., 1991). Despite the increasing incidence of Mesothelioma and the acknowledgment that Mesothelioma responds poorly to treatment and is always fatal (The Australian Lung Foundation, 2000), there have been no Australian studies related to the palliative care needs of this diagnostic group.

Methodology

As there is little research informing the palliative care needs of people with Mesothelioma / asbestos related lung cancer and their families, this will be a descriptive case study. The case study method (Yin, 2003) enables a detailed study of a group using multiple data sources. Data sources will include in-depth interviews with people suffering from asbestos related diseases, their carers and key stakeholders. In addition, media reports related to asbestos will be gathered and the content analyzed. Reports from local authorities and employers and historical data will also used to inform the case. Data will be analysed using the constant comparative method (Strauss & Corbin, 1990) to identify common themes and issues.

From the data collected, a consensus picture will emerge of the common issues that arise for a person dying of mesothelioma and their clinical needs in terms of seeking a good death. We anticipate that this project will form the basis for further research, in developing clinical guidelines for practitioners in palliative care. In addition, the interviews with families and other carers, together with the involvement of the support group, will indicate their particular care needs.

Study Methodology: (Please mark with an x which type of study methodology)

	Epidemiology
x	**Health Services / Health Economics / Quality Improvement**
x	**Qualitative, Observational or Descriptive**
	Mixed Method
	Systematic Review
	Intervention: RCT
	Intervention: Comparative or cohort study
	Intervention: Case series

Project details:						
Funding source (Optional): Affinity Health						
Has the study received ethics approval?	**x**	Yes		No		Not applicable
Project starting date: 26.10.06						
Project completion date: 31.10.07						
Multi site:	**x**	Yes		No		Not applicable
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Associated publications / reports:						
Topics: Cancer, General assessment issues and goals of care, caregiver						