

HotPick October 2005

The healthcare needs of chronic obstructive pulmonary disease patients in the last year of life

Elkington H, White P, Addington-Hall J, Higgs R and Edmonds P.

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This article provides much needed evidence about the latter stages of chronic obstructive pulmonary disease (COPD). COPD causes almost as many deaths as lung cancer in England and Wales, yet surprisingly little is known about the latter stages of this debilitating condition. The study uses a retrospective survey of family informants of COPD deaths to assess symptoms, day to day functioning, information about health and social service use and place of death.

While the retrospective post-bereavement design (using proxies for the deceased experience) may be limited in some respects, given the difficulties of conducting a prospective study with COPD patients with a high risk of dying, this proved a sound approach. COPD questions were developed to provide a disease specific version of the well-respected VOICES (Views of Informal Carers – Evaluation of Services) questionnaire. In the case of the COPD study this cost effective and practical methodology has provided some clinically and policy oriented useful information. For example, almost all of the deceased were reported to have breathlessness, weakness or fatigue all the time or sometimes in the last year of life. In addition, insomnia, low mood and anxiety and panic attacks were prominent symptoms reported by most respondents. The heavy symptom load is particularly notable. However, perhaps the low rate of contact with health professionals and the extreme confinement of housebound patients debilitated by the severity of their disease are of even greater concern.

The authors quite rightly argue that the need for palliative care in many of the subjects in the study is clear. Nearly half of the informants in the study were unaware that the deceased person might die. Although the difficulties of making a prognosis in advanced COPD are noted, there is still a very pointed role for palliative care providers. While this is a UK study the implications for Australia are also compelling. In the period July 2000 to June 2002 five per cent of all deaths in Western Australia were from COPD and of these only nine per cent received a palliative care service (McNamara, B. et. al. *Who receives palliative care in Western Australia - and who misses out*). Given that the needs of people in the advanced stages of COPD are so similar to those in the advanced stages of lung cancer, as demonstrated so pointedly in Elkington et al.'s study, more should be done to address this inequity.

Reviewer

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Dr Beverley McNamara is a medical anthropologist with ten years extensive research experience in Palliative Care (PC) including a three year ethnographic study of Western Australian Palliative Care services that investigated both organisational and ideological challenges in Palliative Care provision. She is a chief investigator on two NHMRC Palliative Care Grants where she has collaborated with researchers in population health and medicine at the University of Western Australia. These projects describe the services that people receive in the last year of life and focuses specifically on discovering why people who potentially should receive palliative care miss out.