Double pneumonia and other infections

P201 LIVING YOUR LIFE WITH BRONCHIECTASIS: AN EXPLORATION OF PATIENTS AND CARERS INFORMATION NEEDS INFORMING DEVELOPMENT OF A NOVEL INFORMATION RESOURCE

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10.1136/thoraxjnl-2015-207770.338

Introduction/background Bronchiectasis is a chronic lung condition, causing breathlessness and chronic productive cough, with intermittent infective exacerbations. Patients often have recurrent hospital admissions, poorer quality of life, and significant fatigue. Treatment concordance can be problematic. There is little patient information currently available, yet information and education could support patients to self-manage, improve understanding and optimise engagement with treatment. Previous exploratory interviews with patients suggested that a lack of credible patient information was available and that having information could help patients learn to live with and manage their condition.

Aims/objectives

1. To further identify, explore and understand the information needs of patients with bronchiectasis and their carers.
2. To co-develop, with the user group, a novel patient information resource.

Methods In-depth interviews were conducted with 17 people who have bronchiectasis and 9 carers. Three focus group style workshops were subsequently held with 11 patients and 3 carers in total. All were recruited from respiratory clinics in the North of England. Interviews and workshops were audio-recorded and transcribed and thematic analysis was undertaken to identify common themes.

Results Ages ranged from 33 to 78 years, including both newly diagnosed and longstanding patients. The focus of the interviews was to identify, explore and understand information needs. A core mediating issue emerged, however: what it means to learn to live your life with bronchiectasis. Embedded in this journey are issues around developing support and coping mechanisms, how people learn to connect with information and how they start to take back control and develop new, active, partnerships with the medical team.

Using these qualitative data in the workshops, we co-developed a novel online and paper-based information resource for patients and their families. This resource is currently being piloted in a feasibility study comparing use of the resource to usual care.

Conclusions Understanding patient and carer experiences of living with bronchiectasis, the biographical disruption (s) that it imposes and the ways in which patients and carers connect with health information over time, has enhanced our understanding of their information needs and how these could be met. The outcomes of the feasibility study are expected in March 2016.

P202 ASSESSMENT OF BRONCHIECTASIS SCORING SYSTEMS: A LONG TERM COHORT STUDY

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10.1136/thoraxjnl-2015-207770.339

Introduction Bronchiectasis is a chronic, disabling illness with an unpredictable clinical course. Two multidimensional scores have been developed to predict mortality in bronchiectasis: the bronchiectasis severity index (BSI) and the FACED score.^{1,2} This study is a retrospective cohort study aiming to compare these scores and test their ability to predict long-term mortality in bronchiectasis.

Methods Data was obtained for 74 subjects with bronchiectasis who had previously taken part in research at our centre. BSI and FACED scores were calculated and outcomes were ascertained after a median of 18.8 years follow-up. Receiver operator characteristic (ROC) curves for mortality were generated and survival between groups compared using univariate Cox proportional hazards analysis.

Results Both scoring systems had similarly excellent predictive power for 5-year mortality, with area under the ROC curve (AUC) 0.79 for BSI and 0.8 for FACED. Both scores were also able to predict 15-year mortality (Figure 1), with the FACED score showing superior predictive power (AUC 0.82 vs 0.69 $P = 0.0495$). For both scores subjects with high scores had an increased risk of death compared to the low scoring group (hazard ratio (HR) for death 3.6 for BSI $P = 0.02$, 12.5 for FACED $P < 0.001$). The intermediate scoring FACED group was also at an increased risk of death (HR 5.9 $P < 0.001$), whereas the intermediate BSI group was not (HR 1.4 $P = 0.58$). The BSI tended to assign higher scores; accordingly the high BSI group was larger (33 vs 6 subjects) with a lower mortality (57% vs 83%) than the equivalent FACED group.

Abstract P202 Figure 1

Conclusion This study demonstrates the ability of the BSI and FACED score to predict mortality in bronchiectasis over a far longer period than previously described. Such tools will be