

Marie Curie Cancer Care Research Programme - Project Grant

Project details
<p>Dr Anthony Byrne (PI), Cardiff University</p> <p>A study of quality of care needs for patients with idiopathic pulmonary fibrosis, and their carers, across disease trajectory</p> <p>Duration of project: 24 months Start date: Summer 2012 (TBC) Budget: £111k</p>

Abstract
<p>Background</p> <p>Idiopathic pulmonary fibrosis (IPF) is a progressive life-limiting condition characterised by chronic inflammation and progressive lung fibrosis. This results in worsening breathlessness, functional decline and eventual death, with a highly variable clinical course. There are approximately 4000 new cases of IPF diagnosed each year in the UK, an incidence which exceeds that of cervical cancer and of the acute leukaemias combined. Average survival is less than three years. Despite awareness that patients with IPF have specific palliative care needs, there is very little primary research to guide delivery. Differing disease trajectories also present specific barriers to intervention and challenges for coordination of care. There remains considerable uncertainty regarding the timing of palliative care interventions, the service configuration needed to support patients and carers and their information needs in negotiating optimal management. These key elements must be addressed in order to define clinically effective patterns of care.</p> <p>Aims</p> <ul style="list-style-type: none"> • identify changes in patients' and carers' perceived palliative care needs over the progression of the disease in order to improve future service interventions • identify time-points or triggers at which palliative care services might effectively be introduced • define the specific information needs of patients and carers • evaluate specifically the experiences and roles of the carer <p>Methods</p> <ol style="list-style-type: none"> 1. Qualitative interviews with patients and carers will be undertaken at time-points chosen to reflect patient and carer experience across different disease trajectories. Data will be analysed using Interpretative Phenomenological Analysis (IPA). This approach involves trying to understand the experiences of individuals, and how they make sense of them. 2. Objective data will also be captured on demographic variables, symptom severity and service use and correlated with perceived care needs. <p>A complementary analysis of the quantitative and qualitative data will help define time points or symptom/physiological triggers for palliative care involvement. Definition of interventions and outcomes meaningful to patients and carers will be identified to inform design and evaluation of service provision.</p> <p>How the results of this study will be used</p> <p>This study will address uncertainties in relation to the palliative care needs of patients with IPF, and their carers. Capturing experience across the disease trajectory will provide key information for the development and evaluation of future service models. In particular, it will inform the definition of interventions and of meaningful outcomes.</p>