

Marie Curie Cancer Care Research Programme - Project Grant

Project details
<p>Professor Miriam Johnson, The University of Hull</p> <p>The adaptation and validation of an assessment tool to identify the palliative care needs of people with irreversible idiopathic interstitial lung disease for use in every day clinical practice</p> <p>Duration of project: 24 months Start date: 01/06/2014 (TBC) Budget: £119k (TBC)</p>

Abstract
<p>Purpose To adapt and validate a needs assessment tool that is fit for purpose in every day clinical practice, able to facilitate the identification of palliative needs of people with interstitial lung disease (ILD), and to triage those requiring referral to specialist palliative care (SPC) services.</p> <p>Background ILD is a group of conditions resulting in lung fibrosis. Many patients experience a progressive loss of functional ability and, ultimately, die from acute respiratory failure. Severe and distressing breathlessness, cough, fatigue and pain are experienced by most in the last year of life in conjunction with psycho-social, financial and spiritual distress. Despite this, patients and carers often have poor understanding of their illness and what to expect as the disease advances. In addition there is poor communication and coordination of care, with vast unmet information needs. National guidelines relating to the most common type of lung fibrosis, (interstitial pulmonary fibrosis) recognise that patients have specific palliative care needs. Despite this, routine assessments of such needs are not part of everyday clinical practice, and palliative care services are rarely accessed by this group of people. The needs assessment tool-progressive disease (NAT:PD-C), developed for use in the oncology setting, is an "aide-memoire" designed to help a busy clinician identify patients with palliative needs in daily practice. Use of the NAT:PD-C has been shown to reduce unmet palliative care needs and has been adapted for heart failure patients. A clinician-rated tool, for use in the clinic or ward round and which can identify patients likely to have palliative care needs, is currently missing in ILD management.</p> <p>Aim We aim to adapt and validate the NAT:PD-C for use in ILD.</p> <p>Methods We are a three site collaborative (Hull, London, Manchester). All members of the research group will contribute to the project as a whole, with each centre leading one stage to allow a time and cost-efficient approach. This will be a four stage project: 1. Adapt the NAT:PD-C using the information from our published systematic literature review and qualitative interviews with patients, carers and health care staff. 2. Test the adapted NAT (NAT:PD-ILD) for face validity. 3. Test the NAT:PD-ILD for inter-rater and test-retest reliability using videorecorded patient consultations. 4. Test the construct validity of the NAT:PD-ILD against agreed comparator constructs using health related quality of life instruments in use for people with interstitial pulmonary fibrosis.</p>