

taking oxygen therapy. Patients may be left with feelings of anger at missed opportunities and concern for lost years of intervention and appropriate palliative care support.

Conclusions The diagnosis of IPF is a devastating one, which can be challenging to manage. Carers, patient groups and expert support at diagnosis were found to be invaluable to patients during this time.

M269 THE EMOTIONAL TURMOIL OF IPF

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Background Our aim was to understand the emotions patients experience in IPF, from initial symptoms to IPF specialist management.

Methods Market research was conducted with an independent agency. Patients with IPF were asked to record a personal account of their experience on a hand-held camera. Face to face interviews with patients were conducted in their home. Carers were also interviewed to add an alternative perspective.

Results The sample included 13 male and 3 female patients with IPF. Patients with lung function impairment of all severities were included, five patients were treated with oxygen therapy and another had received a lung transplant.

Many patients had a very active lifestyle before developing IPF, leading to a high degree of frustration with the limitations imposed on their physical ability. A protracted time to diagnosis of a rare lung disease while symptoms progressed often led to distrust with their primary healthcare physician. Lack of expert knowledge about the condition often resulted in variable handling of the situation, with patients often finding themselves involved in a type of 'role-reversal' whereby they informed their primary healthcare physician about their own condition.

IPF specialists were perceived as their "guardian angels". Despite being given a terminal diagnosis, patients felt reassured that they were receiving appropriate management for their condition. This stemmed from the perception that specialists treating them had appropriate knowledge and a feeling they were supported by the specialist team.

Conclusions As with other rare diseases, patients appear to gain most reassurance from HCP's with a clear understanding of their condition. This highlights the benefit of expert multidisciplinary teams for IPF.

M270 OBTAINING INFORMATION WHEN YOU HAVE A RARE DISEASE – THE POTENTIAL FOR IPF SUPPORT GROUPS

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Background The aim was to explore the ways in which patients with IPF obtain information about their condition.

Methods Market research was conducted with an independent agency. Patients with IPF were asked to record a personal account of their experience on a hand-held camera. Face to face interviews with patients were conducted in their home. Carers were also interviewed to add an alternative perspective.

Results The sample included 13 male and 3 female patients with IPF. Patients with lung function impairment of all severities were included, five patients were treated with oxygen therapy and another had received a lung transplant.

Patients reported finding information from a variety of sources, including primary healthcare professionals, patient information leaflets, the internet, district nurses and support groups. Most valued sources of information were IPF physicians, nurse specialists and patient support groups.

Gaps identified by patients were the need for high quality information including, 1) accurate and complete information about IPF, 2) clarity on the difficulty of predicting life expectancy, 3) how to access services and benefits, 4) how palliative care can help, 5) why support groups are beneficial, 6) how to modify lifestyle as capabilities change, 7) how to live and travel with oxygen and 8) how to explain oxygen to others.

Conclusions Support groups are under-developed, with great potential to help patients and their carers. Support groups are well placed to provide advice for everyday living that the healthcare community may be unable to offer. There is also a need to improve the standard of written information currently available for patients with IPF.

M271 A SURVEY OF TRAINEE EXPERIENCES IN INTERSTITIAL LUNG DISEASE

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Interstitial lung disease (ILD) is a major area of respiratory medicine. It is important that trainees gain competence and confidence in this area.

Methods A survey of BTS trainee members was conducted in November 2013 to examine training provision in ILD, including trainee's opportunities, experience and confidence in aspects of ILD.

Results There were 104 respondents out of a possible 574.

33% of respondents were not expecting any subspecialty clinics in ILD in the course of their training. 42% of trainees expect to spend 3 months or less attending specialist clinics. Trainee attendance at MDTs is far from guaranteed, with 45% expecting to attend less than half during their period in these hospitals.

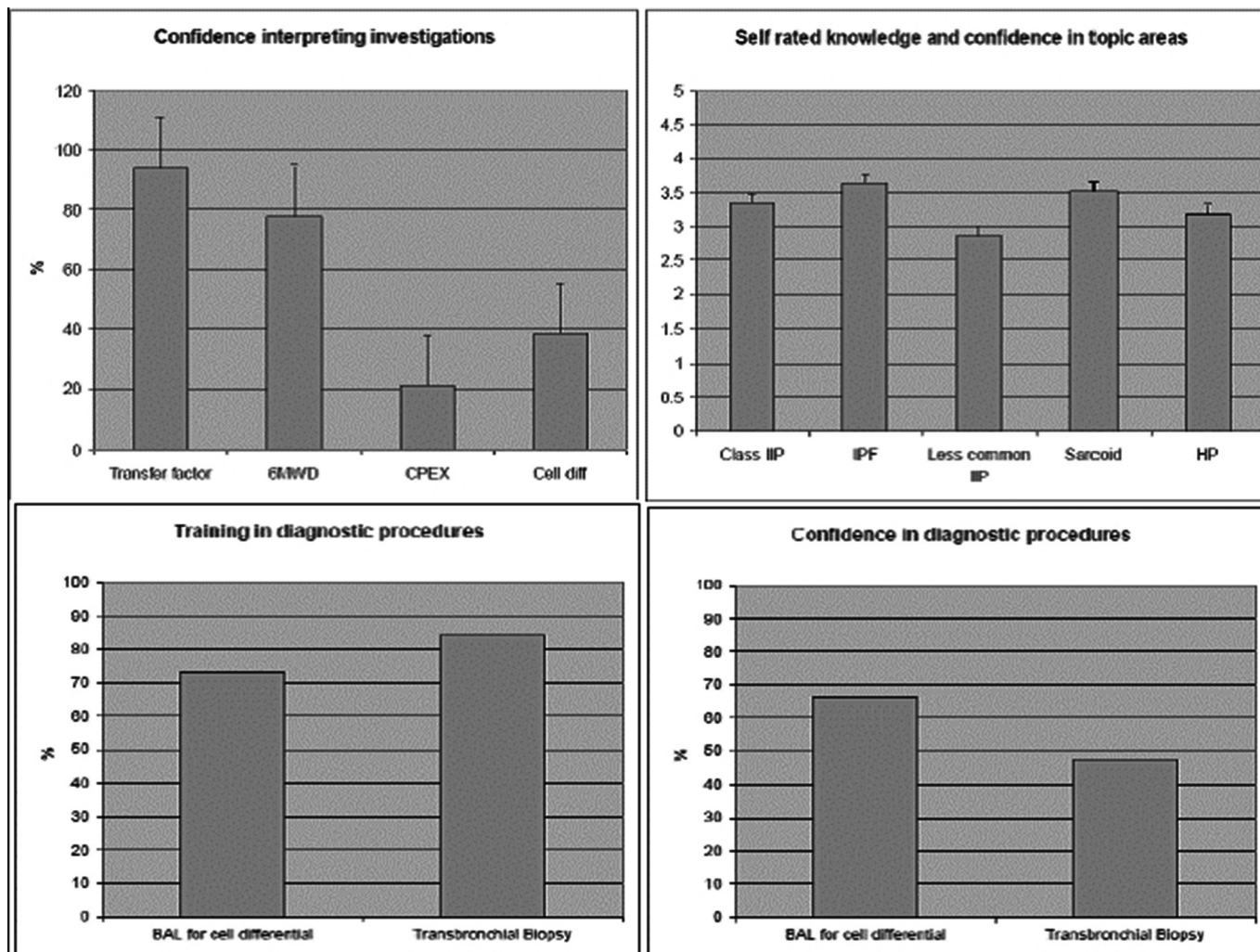
The majority of trainees are trained in performing BAL for cell differential analysis (73%) and transbronchial biopsies (84%), however only 48% are confident performing transbronchial biopsies. Confidence interpreting investigation results increases with the frequency these are performed.

The self rated knowledge in a range of subject areas was also assessed and demonstrated that most areas were moderately well understood, however knowledge of the less frequently encountered IIPs was rated lower.

54% of trainees felt their ILD training was inadequate for SCE preparation. 94% would value a BTS Short Course on ILD to improve their knowledge and confidence.

Discussion This survey highlights areas where there are clear opportunities to enhance the training of registrars in ILDs. It is worth noting that some of the data is in conflict with previous BTS surveys in this area and there is the possibility of self-selection bias in the response population.

Whilst most trainees are trained in performing relevant procedures, their confidence interpreting the results of common investigations in ILD is low. To give evidence of training and



Abstract M271 Figure 1

competence in this area, deaneries may wish to consider requesting logbook evidence of procedures related to ILD, in addition to evidence of ILD MDT attendance. There is undoubtedly a need for a BTS short course on ILD for trainees.

M272 ESTIMATED COST AND PAYMENT BY RESULTS (PBR) TARIFF REIMBURSEMENT FOR IDIOPATHIC PULMONARY FIBROSIS SERVICES ACROSS 14 SPECIALIST PROVIDERS IN ENGLAND

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Background Idiopathic Pulmonary Fibrosis (IPF) is an increasingly important respiratory illness in the UK. Rising prevalence of disease, emerging treatments, development of clinical guidelines for diagnosis and management and a NHS England service specification¹ increase demands on healthcare providers who are

required to enhance capacity or reconfigure services to manage patients.

Aims Estimate the patient care pathways across service providers in England compared with pathways recommended by NICE guidelines² and the NHS England Service Specification; in terms of time and cost per patient by 'diagnosis', 'management' and 'monitoring', and then levels of reimbursement to providers for current levels of care and those recommended.

Methods Structured interviews with clinicians and coders ascertained current levels of service provision, excluding drug costs, by 14 NHS specialist ILD providers. Data were analysed utilising a bottom-up costing approach to estimate the total pathway costs. Comparison with services and costs as recommended by NICE guidelines and service specification allowed estimation of NHS providers' profit or loss.

Results The estimated mean cost per patient for the first year of diagnosis, management and monitoring was £1,414, which is approximately £418 (42%) more than is reimbursed by the PBR tariff.³ By comparison, the equivalent cost of the NICE/service specification pathway is approximately £477 (41%) more than reimbursed by the tariff. In particular, it was noted that significant staff time is required for MDT discussion, but that this is not reimbursed.

Conclusions Results suggest that current NHS tariffs for ILD are insufficient to support current service provision. This is true for current levels of care as well as for the levels of care