European Respiratory Society Annual Congress 2012

Abstract Number: 2570

Publication Number: P1506

Abstract Group: 4.3. Pulmonary Circulation and Pulmonary Vascular Disease

Keyword 1: Pulmonary hypertension Keyword 2: Quality of life Keyword 3: No keyword

Title: The imPAHct of diagnosis delay in pulmonary arterial hypertension

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Body: Introduction: With the availability of effective therapy, early diagnosis of pulmonary arterial hypertension (PAH) is important; yet, early diagnosis remains difficult. Aim: To investigate patients' experiences of the trajectory to receiving a diagnosis of PAH. Mixed-methods: UK national patient survey and in-depth interviews. Results: 514 surveys analysed (most (83%) had been diagnosed with PAH from 2001 onwards. Interviews were conducted with 30 patients. Results are presented in 3 themes: 1) Symptom appraisal: 43% of survey respondents experienced symptoms (e.g. breathlessness) for more than one year before consulting a doctor. A process of appraising symptoms was apparent. As time progressed this period was punctuated by critical events that triggered seeking medical advice. 2) Process of elimination: Nearly half of the survey respondents (47%) were seen by four or more doctors before being diagnosed with PAH, a process taking on average more than 2 years. Once medical contact had been made patients described a period of 'elimination' and convoluted contact with the medical profession. Misdiagnosis was common until in young and older patients. 3) Being diagnosed: Receiving a diagnosis of PAH was described as 'a whirl of good and bad' and relief that it was 'not psychological'. Diagnosis disclosure often lacked empathy. Survey respondents noted quality of life and life expectancy as major concerns (60% and 55%, respectively). Conclusion: The PAH diagnosis trajectory remains lengthy and burdensome. Our results emphasise the importance of an increasing awareness of this disease, to expedite the process of correct diagnosis and the referral of patients with PAH to specialised centres.