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Evaluation of the Healthcare Burden of Idiopathic Pulmonary Fibrosis (IPF) in Fife, Scotland

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Abstract Body

RATIONALE

Idiopathic Pulmonary Fibrosis (IPF) carries a poor prognosis with median survival less than 3 years, and poses several challenges in diagnosis, management and healthcare planning. With complexities in diagnosis, the prevalence remains highly variable in studies across the world. Healthcare planning requires an estimate of the burden IPF disease on the community, and we sought to provide a more accurate assessment of this burden and cost in our region within Scotland.

METHODS

This was a retrospective study using electronic patient records and pathology/imaging systems, both local and national, alongside case notes, pharmacy records and admission data from January 1st to December 31st 2014 to assess the burden of IPF in our region of Fife with a population of 367,260. The emphasis was on secondary care healthcare burden. Admission data were also reviewed in the preceding 5 years. With review of the clinical, pathological and imaging data, we assigned cases into ‘definite/probable IPF’, ‘possible IPF’ and ‘other’ diagnoses.

RESULTS

An average of 166 patients with an initial coded diagnosis of IPF took up 437 admissions per year from 2010-2014, inclusive. Of the patients admitted in 2014, 54 (29%) had a final diagnosis of ‘definite/probable IPF’, 29 (16%) ‘possible’ and 110 (55%) ‘other’ diagnosis. The estimated hospital cost for the duration of stay covering those with a definite/probable or possible diagnosis of IPF during 2014 was £200,718. Primary care coding and CT report analysis provided additional cases not identified through conventional data related to admission, standard electronic systems and IPF-specific treatment data. The majority of cases initially coded by any modality did not have a final diagnosis of IPF. CT-related data with a search term of ‘honeycombing’ enabled an increased yield in IPF diagnoses.

CONCLUSIONS

The existing coding system is inadequate, inconsistent and poorly identifies those with definite/probable IPF. An estimate of the burden of IPF disease in a region can be obtained using several different streams of data. We suggest that IPF requires governmental recognition and to be afforded clear and early referral pathways, with diagnostic standards linked to and supported in primary care. With improved and early recognition, consistent coding and prompt referral

to secondary care, we would expect earlier diagnoses and therefore improved care. A consistent approach to coding and diagnosis would allow more informed local and national public health policy. Finally, admission likely identifies those at most risk of severe and complicating disease.

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