DEVELOPMENT OF A HOSPICE REFERRAL PATHWAY FOR PATIENTS WITH ADVANCED INTERSTITIAL LUNG DISEASE

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Background:
Patients with interstitial lung disease (ILD) have a poor overall prognosis, with limited therapies to halt disease progression or extend life.1 2 The disease experience comprises significant physical symptoms and a profound psychological burden.3 4 NICE (2013)5 recommend early integration of tailored supportive care. Rapidly progressive disease and breathlessness at rest being possible triggers for referral to specialist palliative care (SPC).

Aim:
To develop collaborative working practices between the hospice/SPC team and the local respiratory physicians to produce a seamless pathway for ILD patients as their condition advances. Such a pathway could be modified to improve the care of patients with other advanced non-malignant respiratory diseases.

Method:
A retrospective survey of hospital notes for patients with advanced ILD admitted to the acute hospital allowed us to identify a cohort of patients who had sub-optimal symptom control and might ideally have been cared for in the non-hospital setting. A pathway was then developed in collaboration with the lead ILD physician aimed at earlier identification of such patients via the hospital MDT or clinic setting, to encourage timely referral to the hospice/SPC team.

Results:
- Identified patients were assessed for non-pharmacological and pharmacological interventions to improve breathlessness mastery and alleviation of other symptoms via the hospice multi-professional team. The significant associated psychological distress and social impact were also addressed and engagement in advanced care planning was encouraged.
- Of the 35 patients referred 18 have subsequently died; 2 before assessment (<3 weeks from referral), 1 in hospital, 9 in the hospice, 2 in a care home and 4 supported at home.
- 9/15 had one or more hospice in-patient admissions prior to their final admission/death. Three patients required hospital admission prior to death and one patient died in hospital. Placement in a care home (2/15) was facilitated via the hospice. 2/15 attended day therapy. 13/15 had input regarding non-pharmacological management of breathlessness 11/15 had an advanced care plan (ACP) in place. 13/15 expressed a preferred place of care (PPC), which was achieved in 11/13.
- Of the other 17 referrals, 4 declined on-going support, 2 improved and were discharged (comorbidities treated), 1 was admitted to a care home, 11 patients have on-going support in the form of day therapy (2), family support (1) hospice admission (3) and hospice out-patient clinic (6). 7/11 have engaged in advanced care planning.

Conclusion:
With appropriate collaboration it is possible to develop services to produce a major improvement in the care for patients with advanced ILD. Although death from ILD can be distressing for all involved we have shown that such patients do get a significant benefit from specialist palliative care involvement. We have allowed a high percentage of patients to have a supported death in the place of their choice, aided by early involvement in advanced care planning. Our aim going forward is to improve the referral rate of such patients from the specialist respiratory team and to explore ways of further developing the psychological support available to them.

References:

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