OP 035 AN INTEGRATED MODEL OF SPECIALIST PALLIATIVE CARE (SPC) FOR CYSTIC FIBROSIS (CF)

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Background Specialist palliative care (SPC) for patients with Cystic Fibrosis (CF) is complex as they have severe symptoms requiring active CF treatment and some die on a transplant waiting list, which may be a barrier to referral for SPC. We describe a model of care whereby the SPC team is part of the CF team providing SPC alongside CF care.

Results Of 270 CF patients, 20 (9 male; mean age 32.3 (19–47) years) had SPC input over 2 years. They had advanced CF (mean FEV_1 25%; BMI 19.7); 9 patients died, 3 underwent successful transplantation and 9 are in ongoing care (2 on active transplant list). Prominent symptoms on assessment were dyspnoea (85%), cough (80%), pain (75%), nausea or vomiting (75%), fatigue (55%) anxiety (50%) and low mood (30%). SPC interventions included drug advice, non-drug measures for management of symptoms (relaxation, massage, acupuncture), practical provision of equipment, activity based therapy, financial advice, and psychosocial and spiritual support. Deaths were in hospital after a short final exacerbation. SPC have been involved in the end of life care of all that died. Evaluation showed that all of the CF team felt that SPC should be a part of the team, and rated SPC highly (mean score 4.1 on a 5 point scale). The CF Team perceived that all patients had found SPC helpful or very helpful. Only one patient awaiting transplant declined SPC input.

Conclusions This model is successful in overcoming barriers to SPC and is highly rated by the CF team. The SPC team have developed their knowledge of CF, and find it helpful to meet patients and families earlier. This integrated model of SPC is applicable to other specialist diseases.