Developing Models of Palliative Care for Patients in the Community with Advanced Non Malignant Respiratory Disease

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Project aims were to work with patients with advanced non-malignant respiratory disease to:
1) Introduce Advance Care Planning (ACP)
2) Improve quality of life
3) Establish effective communication of patients’ end of life wishes across health care settings

Methodology

Purpose

► Prospective study
► Convenience sample – all referrals from local NHS Respiratory Team using specific criteria adapted from the Gold Standard Framework Prognostic Indicator
► Intervention – 3 Home Visits which included holistic assessment of needs, symptom control, information giving, referral to other services and ACP

Results

Total Population

► 51 patients were referred to the service
► 96% (n=49) of patients referred met the criteria for inclusion
► 45 patients were assessed at home by a palliative care CNS, 3 patients died prior to initial visit and 1 patient refused to participate

Outcomes

► At point of referral 87% of patients understood that their illness was progressing, incurable and might lead to death
► At the end of the intervention:
  ► The ceiling of treatment was clarified for 82% of patients
  ► DNACPR was discussed with 69% of patients (a further 20% of patients had DNACPR form in place at point of referral)
  ► Preferred place of care was identified in 89% of patients
  ► 89% of patients had an Electronic Palliative Care Summary
  ► 87% of patients were on the Palliative Care Register

Referrals to other services | Frequency
---|---
Social work services | 24
Complementary therapy | 21
Macmillan money matters | 17
Hospice day care | 13

Patient experience

► 'you do not feel forgotten about'
► ‘The visits ‘helped me to cope better with my condition’

GP Feedback

► ‘Patients have found visits to be very helpful indeed’
► ‘better end of life care’
► 56.7 % of GPs agree that care patients receive is more equitable
► 70.3 % of GPs agree visits promote a more person centred approach to care

Recommendations for Service Development

1) Integrate this intervention as a substantive element of specialist palliative care
2) Review role of Palliative Respiratory Clinic
3) Maintain and develop care and collaboration with the respiratory team across care settings

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