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

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Purpose

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

- 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

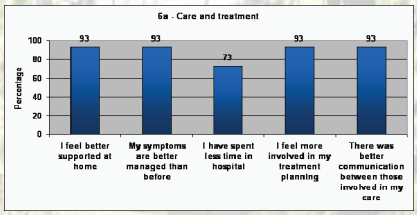
Data collection is ongoing regarding the number of hospital admissions within a year of referral to the service, and the extent to which ACP wishes were adhered to in hospital.

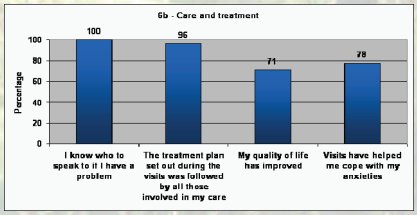
Patient experience

*76% response rate

'you do not feel forgotten about'

'The visits 'helped me to cope better with my condition'



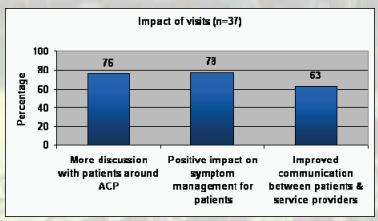


GP Feedback

*82% response rate

'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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