

The provision of generalist and specialist palliative care for patients with non-malignant respiratory disease in the north and Republic of Ireland: a qualitative study

Dr Clare Mc Veigh RN
Lecturer (Education) in Adult Health

PhD Supervisory Team
Professor Peter Hudson
Dr. Joanne Reid
Professor Philip Larkin
Professor Sam Porter



@ClareVeigh



Overview

- Background
 - Methods
 - Findings
 - Discussion
- Model of care

Background

- Umbrella term: Chronic obstructive pulmonary disease (COPD), Interstitial lung disease (ILD) and Bronchiectasis.
- Chronic, non-curable progressive disease
- Over 200 million people worldwide have a diagnosis of COPD and while confirmability data are not available, it is estimated that the extent of other chronic respiratory diseases is a growing global health problem ¹

Why was this research needed?

- Internationally, palliative care is recommended for people with non- malignant respiratory disease (NMRD) ^{2 3 4 5 6}
- Patients with NMRD and their carers do not receive the same standards of generalist and specialist palliative care as patients with malignant respiratory disease ^{7 8 9 10 11}
- However, there is limited evidence regarding palliative care for patients with interstitial lung disease or Bronchiectasis, alongside COPD.
- Limited research regarding the influence of geographical location on the provision of palliative care for patients with NMRD.

All- Ireland Study

Aim

To explore specialist and generalist palliative care provision for people with non-malignant respiratory disease, in rural and urban areas in the North and Republic of Ireland.



Methods

- Broad Interpretivist Approach
- Convenience sample of 17 bereaved carers and 18 HCPs
- Recruited from 2 rural and 2 urban sites on the Island of Ireland.
- Data were collected throughout 2012 and 2013 through semi-structured interviews with carers of patients with COPD (n=12), ILD (n=4) or bronchiectasis (n=1) who had died 3-18 months previously
- Focus groups (n=4) with HCPs.
- Data were analysed using a thematic analysis framework.

Participants of the semi-structured interviews	
Gender	Women: 14 bereaved carers Men: 3 bereaved carers
Age	Mean: 58.2 years Median: 55 years Range: 41 – 81 years
Relation to patient	Daughter (n=5) Son (n=2) Wife (n=7) Partner (n=1) Daughter in-law (n=1) Nephew (n=1)
Patient and carer living together	Yes (n=10) No (n=7)
Occupation	Residential home manager (n=1) Unemployed (n=3) Retired (n=6) Classroom Assistant (n=1) Housewife (n=3) Probation Officer (n=1) Porter (n=1) Health and Safety Officer (n=1)
Time post bereavement	Mean: 7 months Median: 6 months Range: 4 – 17 months
Area	Northern Ireland (n=10), Republic of Ireland (n=7), Rural (n=8), Urban (n=9)
Diagnosis	COPD (n=12), Interstitial Lung Disease (n= 4), Bronchiectasis (n=1)
Interview Type	Face to Face (n= 10), Telephone (n=7)

Participants of the Focus Groups

Occupation

- Specialist Palliative Care Occupational Therapist (n=1)
- Respiratory Nurse Specialist (n= 6)
- Palliative Care Nurse Specialist (n= 3)
- Consultant in Palliative Medicine (n= 1)
- Specialist Palliative Care Nurse Consultant (n= 1)
- Respiratory Consultant (n=2)
- Respiratory Ward Manager (n= 1)
- Respiratory Deputy Ward Manager (n= 1)
- Palliative Care Inpatient Unit Deputy Ward manager (n=1)
- Physiotherapist (n= 1)

Area

- Northern Ireland (n=11)
- Republic of Ireland (n= 7)
- Rural (n= 8)
- Urban (n= 10)

Interview Findings

Lack of consistency in palliative care delivery

Specialist palliative care was only introduced when the patient was nearing the end of life, and carers felt that the patient could have benefited from earlier integration

“We would have liked to have had more of the [specialist] palliative care side of things earlier on rather than just before he died.”

(BC15, p3).

Carers within the ROI perceived that patients with NMRD received adequate specialist respiratory care for their palliative needs when in hospital, but this care was not continued when the patient was discharged back into the community:

“Well she didn’t really have any care at home apart from when she took sick and went into hospital. Then she was seen by doctors and nurses but nothing at home. She would have seen the respiratory nurse but that was only up at the hospital.” (BC10, p1).

In contrast to the views expressed by carers in the ROI, in NI perceptions were that patients with NMRD had sufficient input from the RNS in the primary care setting:

“Like if it was anytime during the day I would have just rang up the respiratory nurse and there was always someone there to help me.” (BC14, p4).

Focus Group Findings

Barriers to providing palliative care in NMRD

Healthcare professionals' perceived that specialist palliative care was often still only associated with malignant disease, and therefore HCPs did not recognise the important role it had in NMRD:

“You know awareness is improving but there still are professionals who are surprised and will say, “That patient is respiratory they haven’t got cancer so why are you seeing them?” So there is still a gap in the awareness even among professionals.” (PCN4, Palliative Care Nurse Specialist, p5).

The views expressed by HCPs in the ROI additionally indicated an inequality of generalist and specialist palliative care service provision for patients with ILD or bronchiectasis, in comparison to COPD:

“Bronchiectasis patients are left to self-manage at home and I would say that the COPD patients are getting a better [specialist and generalist] palliative care service than the other cohorts [ILD and bronchiectasis].” (RN7, Respiratory Nurse Specialist, p9).

Focus Group Findings

Future direction of palliative care for NMRD

Participants from the varying healthcare professions conveyed that specialist palliative care involvement was necessary when a patient with NMRD developed complex symptom needs:

“I know my limitations in terms of symptomatically what can the girls [specialist palliative care nurses] bring in that we [RNS] perhaps wouldn't even consider and therefore I think that specialist palliative care is required on that account.” (RN7, Respiratory Nurse Specialist, p8).

However HCPs additionally illuminated that the delivery of holistic care to patients with NMRD was part of the role of all generalist palliative care providers:

“I think that in some of these NMRD patients the fact that they have a chronic disease may not mean that they need specialist palliative care but certainly a palliative approach is needed and is all our responsibilities regardless of our qualifications.” (PCN4, Palliative Care Nurse Specialist, p5).

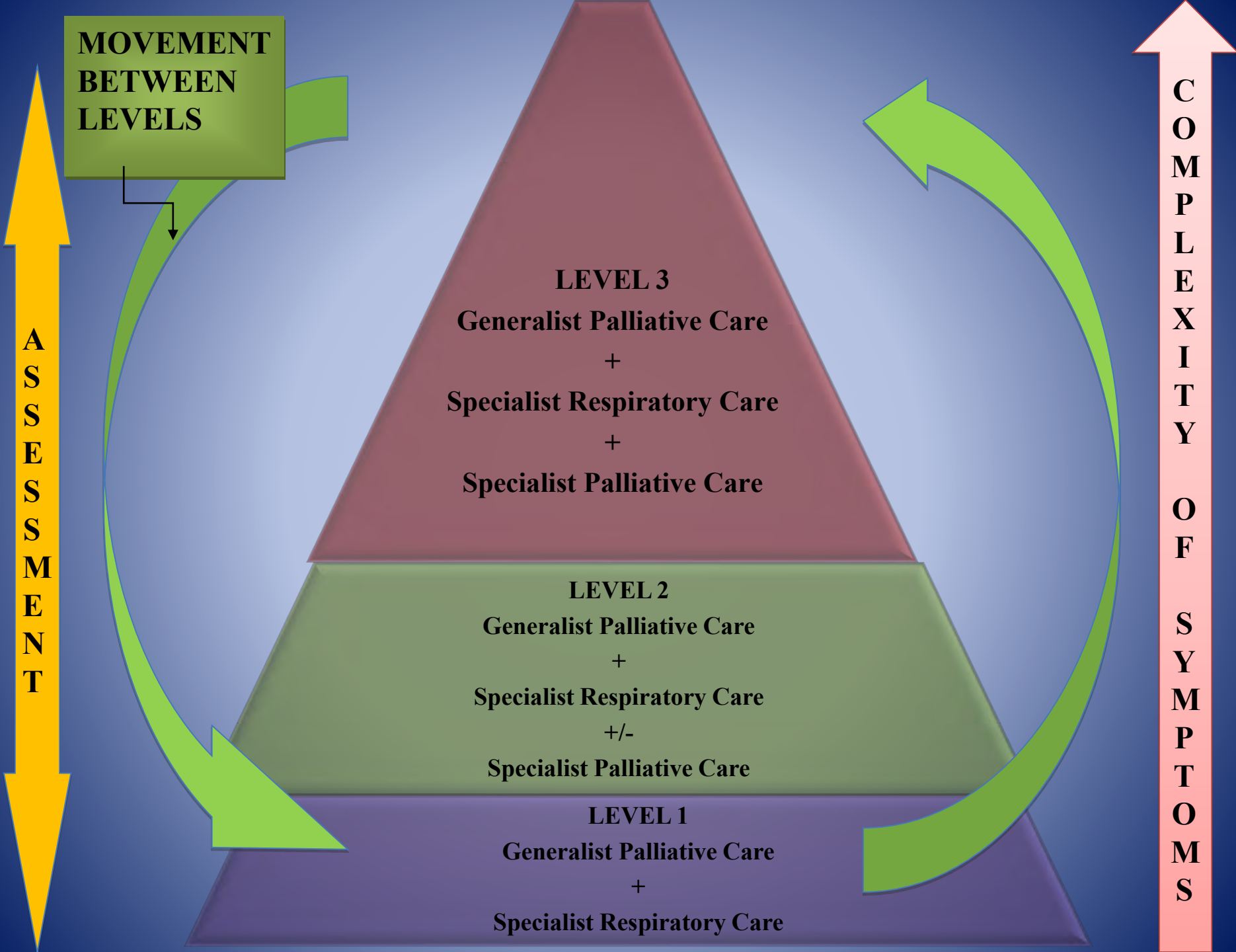
Within the ROI however participants highlighted that there was not a regional model for palliative care that could help to guide the delivery of palliative care to patients with NMRD:

“We don’t have a model for either delivering palliative care or respiratory care and I suppose we should.” (RN5, Respiratory Nurse Specialist, p8).

Discussion

- Findings highlighted that HCPs may have benefited from a model of care to guide the provision for palliative care for patients with NMRD that emphasised the importance of introducing holistic care early in the disease trajectory, and ensuring it is needs based.
- Potential model of palliative care for patients with NMRD derived from the findings of the present study

McVeigh, C, Reid, J, Larkin, P, Porter, S & Hudson, P 2017, 'The provision of generalist and specialist palliative care for patients with non-malignant respiratory disease in the North and Republic of Ireland: a qualitative study' *BMC Palliative Care*, 17 (6) DOI: 10.1186/s12904-017-0220-1



**MOVEMENT
BETWEEN
LEVELS**

**A
S
S
E
S
S
M
E
N
T**

**C
O
M
P
L
E
X
I
T
Y

O
F

S
Y
M
P
T
O
M
S**

LEVEL 3

**Generalist Palliative Care
+
Specialist Respiratory Care
+
Specialist Palliative Care**

LEVEL 2

**Generalist Palliative Care
+
Specialist Respiratory Care
+/-
Specialist Palliative Care**

LEVEL 1

**Generalist Palliative Care
+
Specialist Respiratory Care**

Level 1	A holistic approach to care should be introduced from diagnosis, and delivered by both generalist palliative care and specialist respiratory care providers.
Level 2	As symptom complexities increase, generalist palliative care and specialist respiratory care providers must continue to provide holistic care. However, they must also assess the need for referral to specialist palliative care providers if they feel they need support or guidance in managing the patient's symptoms.
Level 3	If the patient develops complex symptoms that generalist palliative care and specialist respiratory care providers perceive they are no longer able to effectively manage, then timely referral to specialist palliative care services is required.

Limitations

- Eighteen HCPs were recruited into the study however the majority who participated in the focus groups were nursing staff (n=13). Increased numbers of allied HCPs and medical staff may have provided more diverse perspectives.
- The majority of bereaved carers who participated in the study (n=17) had cared for someone with COPD (n=12) and only a small number of participants had cared for someone with a diagnosis of ILD (n=4) or bronchiectasis (n=1).

Key Implications

- Enhanced availability of specialist respiratory and palliative care services would enhance generalists access to specialist support for NMRD
- Services need to also filter down to patients with bronchiectasis and ILD
- Future research explore the feasibility of a service development model to enhance availability of services

THANK YOU!

- Contact email: clare.mcveigh@qub.ac.uk
- Tweet me @ClareVeigh



Publications

McVeigh, C, Reid, J, Hudson, P, Larkin, P, Porter, S & Marley, AM 2014, 'The experiences of palliative care health service provision for people with non-malignant respiratory disease and their caregivers: an all-Ireland study' *Journal of Advanced Nursing*, vol 70, no. 3, pp. 687-697. DOI: 10.1111/jan.12240

McVeigh, C, Reid, J, Larkin, P, Porter, S & Hudson, P 2017, 'The provision of generalist and specialist palliative care for patients with non-malignant respiratory disease in the North and Republic of Ireland: a qualitative study' *BMC Palliative Care*, vol 17, no. 6. DOI: 10.1186/s12904-017-0220-1

McVeigh, C, Reid, J, Larkin, P, Porter, S & Hudson, P 2018, 'The experience of palliative care service provision for people with non-malignant respiratory disease and their family carers: an all-Ireland qualitative study' *Journal of Advanced Nursing*, 74 (2) pp. 383-394. DOI: 10.1111/jan.13453

References

1. World Health Organisation (2008) *Global Alliance against Chronic Respiratory Disease Action Plan 2008–2013*. WHO, Italy.
2. Bradley B., Branley H.M., Egan J.J, Greaves M.S., Hansell D.M., Harrison N.K. & Wilsher M.L. (2008) British Thoracic Society Interstitial Lung Disease Guideline Group, British Thoracic Society Standards of Care Committee; Thoracic Society of Australia; New Zealand Thoracic Society; Irish Thoracic Society. Interstitial lung disease guideline: the British Thoracic Society in collaboration with the Thoracic Society of Australia and New Zealand and the Irish Thoracic Society. *Thorax* **63**(Suppl 5), 1-58.
3. Lanken P.N., Terry P.B., DeLisser H.M., Fahy B.F., Hansen-Flaschen J., Heffner J.E., Levy M., Mularski R.A., Osborne M.L., Prendergast T.J. & Rucker G. (2008) An official American Thoracic Society clinical policy statement: palliative care for patients with respiratory diseases and critical illnesses. *American journal of respiratory and critical care medicine* **177**(8), 912-927.
4. National Institute for Health and Care Excellence (2010) *Chronic obstructive pulmonary disease Management of chronic obstructive pulmonary disease in adults in primary and secondary care (partial update)*. NICE, UK.
5. Raghu G., Collard H.R., Egan J.J., Martinez F.J., Behr J., Brown K.K. & Schünemann H.J. (2011) An official ATS/ERS/JRS/ALAT statement: idiopathic pulmonary fibrosis: evidence-based guidelines for diagnosis and management. *American Journal of Respiratory and Critical Care Medicine* **183**(6), 788-824.
6. National Institute for Health and Care Excellence (2013) *Idiopathic pulmonary fibrosis: The diagnosis and management of suspected idiopathic pulmonary fibrosis*. NICE, UK.
7. Goodridge D., Lawson J., Duggleby W., Marciniuk D., Rennie D. & Stang M. (2008) Health care utilization of patients with chronic obstructive pulmonary disease and lung cancer in the last 12 months of life. *Respiratory Medicine* **102**(6), 885- 891.
8. Partridge M.R., Khatri A., Sutton L., Welham S. & Afmedzai S.H. (2009) Palliative care services for those with chronic lung disease. *Chronic Respiratory Disease* **6**, 13- 17.
9. Bajwah, S., Koffman, J. Higginson, I. J., Ross, J. R., Wells, A. U., Birring, S. S. and Riley, J. (2012) ‘“I wish I knew more...” the end-of-life planning and information needs for end-stage fibrotic interstitial lung disease: views of patients, carers and health professionals.’ *BMJ supportive & palliative care*. 3 (1), p.p. 84-90.
10. Beernaert K., Cohen J., Deliens L., Devroey D., Vanthomme K., Pardon K. & Van den Block L. (2013) Referral to palliative care in COPD and other chronic disease: A population-based study. *Respiratory Medicine* **107**(11), 1731-1739.
11. Lindell K.O., Liang Z., Hoffman L.A., Rosenzweig M.Q., Saul M.I., Pilewski J.M., Gibson K.F. & Kaminski N. (2014) Palliative Care and Location of Death in Decedents with Idiopathic Pulmonary Fibrosis. *Chest* **147**(2), 423-429.