Generalist and specialist palliative care for patients with non-malignant respiratory disease: an all-Ireland qualitative study

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Introduction

Non-Malignant Respiratory Disease (NMRD) is an umbrella term that includes Interstitial Lung Disease (ILD), bronchiectasis and Chronic Obstructive Pulmonary Disease (COPD). Two hundred and ten million people worldwide have a diagnosis of COPD and, although the exact amount is not known, it is estimated that millions of others have other chronic respiratory diseases. Key national and international respiratory guidelines have highlighted the role of palliative care for patients with NMRD. The American Thoracic Society (ATS) published an official clinical policy statement regarding palliative care for patients with respiratory conditions emphasising the importance of palliative care being made available to patients with a respiratory illness from diagnosis, and also recommended that specialist palliative care should be involved when the patient’s needs go beyond healthcare professionals (HCPs) level of competency. Although palliative care is recommended for people with NMRD, there is limited evidence regarding the integration of palliative care for people with interstitial lung disease, bronchiectasis and COPD.

AIM

This study aimed to explore specialist and generalist palliative care provision for people with non-malignant respiratory disease and their carers, in rural and urban areas in the North and Republic of Ireland.

Methods

• Qualitative study with a broad interpretivist approach to explore the individual interpretations the participants associated with the phenomenon being investigated.
• Semi-structured interviews with 17 bereaved caregivers of patients that had died from NMRD.
• 4 focus groups with 18 multidisciplinary HCPs.
• Data was analysed using thematic analysis.
• All participants were recruited across 2 rural and 2 urban sites in the North and Republic of Ireland.
• Eligible participants for the semi-structured interviews included bereaved carers, identified by a respiratory nurse specialist as the main carer, of people with NMRD who had died three to eighteen months previously.
• Eligible participants for the focus groups included members of the multi-disciplinary team that were involved in the palliative care of patients with NMRD.

Results

We weren’t expecting them to die
Lack of consistency in palliative care delivery
Role Ambiguity
Barriers to providing appropriate palliative care
The future direction of palliative care for NMRD patients

Interview Themes

Focus Group Themes

References


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Discussion

Findings highlighted that inequalities in the provision of palliative care were influenced by a patient’s geographic location, not only due to rurality but also health jurisdiction. Additionally, healthcare professionals identified with the interview participants in highlighting their lack of prognostic certainty in relation to NMRD. Healthcare professionals also perceived there to be a lack of consensus regarding when specialist and generalist palliative care is appropriate for patients with NMRD. Findings illuminated that HCPs would have benefited from a model of care to guide the provision of palliative care for patients with NMRD that emphasised the importance of introducing palliative care early in the disease trajectory, and ensuring this care was needed based. Figure 1 demonstrates a model of palliative care for patients with NMRD, and their carers, derived from the findings of the present study. This model advocates the continued holistic assessment of the patient and the carer’s needs, and proposes three levels of palliative care for patients with ILD, COPD and bronchiectasis:

- **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.

Throughout the trajectory of NMRD, the identification of growing complexities must be facilitated by the early and continued assessment of the patient’s holistic care needs. The patient may move between levels at different points within their trajectory and this will be based on the assessment of their needs and symptom complexities.

Conclusions

The management of patients with non-malignant respiratory disease is complex and challenging with a clear need for a more integrative model of practice, incorporating palliative care in a responsive and dynamic way. This research informed a potential model of care which may help healthcare professionals introduce palliative care, and specialist respiratory care, early in the disease trajectory, whilst also encouraging the involvement of specialist palliative care for complex symptom management. Future research is needed to explore the feasibility of this proposed model of palliative care for patients with ILD, COPD and bronchiectasis.