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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

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Abstract

Background: Previous research and key guidelines have suggested potential models of palliative care for patients with COPD and interstitial lung disease. However, these recommendations are often not effectively implemented in clinical practice and are void of guidance regarding palliative care for patients with bronchiectasis, another form of non-malignant respiratory disease. The aim of this research was to explore generalist and specialist palliative care service provision for people with non-malignant respiratory disease in the North and Republic of Ireland.

Methods: Qualitative study involving a convenience sample of 17 bereaved carers and 18 healthcare professionals recruited from 2 rural and 2 urban sites on the Island of Ireland. Data collection consisted of semi-structured interviews with carers of patients with COPD, interstitial lung disease or bronchiectasis who had died 3–18 months previously; and 4 focus groups with healthcare professionals. Data analysed using thematic analysis.

Results: Findings highlighted the lack of a clear model of holistic care delivery for patients with non-malignant respiratory disease and illuminated the varying levels of palliative care provision this client group experienced. Additionally, ambiguity amongst healthcare professionals regarding prognostication illuminated the importance of the provision of palliative care being based on patient need, not prognosis. This research developed a potential model of palliative care which may help healthcare professionals introduce palliative care, and specialist respiratory care, early in the disease trajectory of non-malignant respiratory disease, whilst also encouraging the involvement of specialist palliative care for complex symptom management.

Conclusion: This research provides an important insight into a potential model of palliative care for people with non-malignant respiratory disease, inclusive of bronchiectasis. However, the feasibility of integrating this model into clinical practice requires further exploration.

Keywords: Palliative care, Non-malignant respiratory disease, COPD, Interstitial lung disease, Bronchiectasis, Healthcare Professionals, Qualitative research and bereaved carers

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Background
The World Health Organisation [1] highlighted that in 2012 more than 3 million people died of COPD, which globally represented 6% of all deaths that year. Although confirmability data are not available it is estimated that the extent of other non-malignant respiratory diseases (NMRDs), such as interstitial lung disease (ILD) and bronchiectasis, are a growing global health problem [2]. Within Europe, it is estimated that mortality rates of ILD are approximately 2.5 per 100,000 people per year [3]. In the United Kingdom (UK) it was highlighted that there were 1.68 deaths from bronchiectasis per 100,000 population in 2007, with the mortality rate increasing by approximately 3% per year [4]. Patients with NMRD should receive a palliative approach to their care, even if they are still actively receiving treatment to slow or stabilise their illness [5]. Although NMRD is on the increase internationally and nationally evidence suggested that patients with NMRD often do not receive optimum holistic care [6], or the same standards of palliative care as patients with malignant respiratory disease [7, 8]. However this research [7, 8] focused on patients with a diagnosis of COPD and their carers, and not those with ILD or Bronchiectasis.

The palliative care provided by healthcare professionals (HCPs) that specialise in this area is known as specialist palliative care, and these professionals provide palliative expertise, services and resources [9]. Palliative care delivered by HCPs who are not classified as specialist palliative care providers is known as generalist palliative care [10]. There are several key strategic drivers within Northern Ireland (NI) [11, 12] and the Republic of Ireland (ROI) [13–15] that have highlighted the need for generalist and specialist palliative care provision for patients with NMRD. However, there is a lack of consensus amongst national [16] and international [17–22] guidelines regarding palliative care for patients with NMRD and their carers. These strategic documents are also void of guidance regarding palliative care for patients with bronchiectasis. Specialist respiratory HCPs also have a key role in the provision of generalist palliative care to patients with NMRD [16]. Specialist respiratory services for patients with a malignant or non-malignant respiratory condition consist of HCPs specialised in respiratory care that include respiratory nurse specialists, respiratory consultants and allied health professionals. The provision of specialist respiratory services for patients with NMRD varies throughout the North and Republic of Ireland, with these services being more readily available in the primary care setting in NI [11] in comparison to the ROI [23]. The majority of specialist respiratory services in the ROI are based in the secondary care setting. The coordination and availability of specialist respiratory, specialist palliative care and generalist palliative care services differ across the North and Republic of Ireland, especially within the primary care setting.

Aim
The aim was to explore generalist and specialist palliative care service provision for people with NMRD in the North and Republic of Ireland.

Methods
Design
The design of this study involved two methods of data collection: semi-structured interviews with bereaved carers of patients with NMRD, and focus groups with HCPs involved in their care. Due to the exploratory nature of this research a broad interpretivist approach was utilised by the researcher. Interpretivist researchers believe that by interacting with the world around them people attach their own meanings and values to their experiences, therefore broad interpretivism attempts to explore this to provide a deeper understanding of the topic being researched [24]. Something that must be considered in qualitative research when discussing the research process is reflexivity. The main researcher (C.V) was a registered nurse with 10 years experience caring for patients with palliative care needs.

Settings and participants
A total of 17 bereaved carers and 18 HCPs were recruited from 1 rural and 1 urban site in NI, and 1 rural and 1 urban site in the ROI using convenience sampling. In NI, the research involved bereaved carers and HCPs in the Northern Health and Social Care Trust (NHSCT) and the Belfast Health and Social Care Trust (BHSCT). In the ROI, bereaved carers and HCPs were recruited from Letterkenny, Co. Donegal and Dublin. Belfast is acknowledged as an urban area in NI [25] and Dublin is recognised as an urban location in the ROI [26]. The NHSCT covers a large rural area in NI [27] and Letterkenny is part of a rural county in the ROI [28]. Figures 1 and 2 illustrate the recruitment process. Tables 1 and 2 provide the sociodemographic details of interview and focus group participants. As noted within Table 1, the majority of carers were female (n = 14) and all carers were family members. Eligibility criteria for participation in the semi-structured interviews identified bereaved carers, ascertained by a respiratory nurse specialist (RNS) as the main carer, of people with NMRD who had died 3 to 18 months previously. Bereaved carers were identified from the patients’ documentation, and recruited, by the RNS in both the secondary and primary care setting. This group of participants were chosen as the researcher felt they would not only give an insight into the patient’s palliative care throughout their illness,
but also their own experiences as a carer. Bereaved carers were also used as proxies for the patient as they were able to provide a post-death account that also took into consideration the palliative care that was provided to the patient at the end of life [29]. The period of time was chosen as although it was not straight after the death of the participant’s relative, it was within a time frame that allowed them to remember their experience and also reduced trauma to the participant. Carers under 18 years of age, who did not speak English or were too distressed to take part in a research study, were excluded. Eligibility criteria for the focus groups included HCPs involved in the generalist and specialist palliative care of patients with NMRD, in the primary and secondary care setting. Permission to access staff was sought from the various relevant heads of each department e.g. director of nursing, respiratory consultant etc., in the areas involved in the study and they also aided recruitment.

**Data collection**

Semi-structured interviews (Additional file 1: Box 1) were conducted in bereaved carers’ homes (n = 10), or over the telephone (n = 7). The choice of telephone or face-to-face was offered to participants to allow them to choose an interview method that was most convenient for them. Research has previously highlighted that bereaved family members interviewed over the telephone did not report any concerns or limitations associated with this data collection method [30, 31]. Interviews ranged from 22 to 80 min in length, with an average of
50 min. Healthcare professional focus groups (n = 4) (Additional file 2: Box 2) were conducted with participants from the primary and secondary care setting at each area involved in the study. Focus groups ranged from 68 to 81 min in length, with an average of 74 min. All interviews and focus groups were digitally recorded and transcribed verbatim. Interviews and focus groups were conducted by one author (C.V) who had appropriate training on conducting qualitative research. In order to aid the accurate recording of the focus groups, an additional member of the research team fulfilled the role of note taker (J.R). Data collection was completed when it was noted by the researcher that no new themes or information were emerging from the data.

Analysis
Data were analysed by adopting King and Horrock’s [32] approach to thematic analysis. The qualitative research software package NVivo was used to allow for the management of the dataset, whilst also facilitating an increased focus on effectively analysing the data [33]. Initial data analysis consisted of the exploration of each interview and focus group to develop descriptive themes. Descriptive themes generate a list of emerging categories, or topics, from the data but do not offer an interpretation of their meanings [34]. Analysis then progressed to focusing on the interpretation of the meaning of the data [32] through grouping together the descriptive themes to highlight emerging interpretative themes. Finally, overarching themes were developed by linking all the interpretative themes that had been established. Each transcription was initially analysed by C.V and then reviewed separately by the remaining authors (P.H, J.R, P.L and S.P). All themes and transcripts were then discussed collaboratively by the research team for verification of the themes generated, and agreement was
reached regarding the final themes. Preliminary findings were also presented at various academic conferences and clinical meetings which provided further opportunities for feedback and critical discussions.

Ethics
All participation was voluntary with full written, and verbal, informed consent. Ethical approval was received from the Office of Research and Ethics Committee Northern Ireland (ORECNI, Reference: 11/NI/0166) and governance permission from the Northern Health and Social Care Trust (Reference: NRP11–0264/09), Belfast Health and Social Care Trust (Reference:11080JR-AS), Letterkenny and Dublin.

Semi-structured interviews findings
Analysis of the carers’ interviews identified the key overarching theme: lack of consistency in palliative care delivery, developed from the interpretative themes outlined below and illustrated through participants’ quotes.

Lack of consistency in palliative care delivery
The overarching theme of lack of consistency in palliative care delivery identified interpretative themes of ‘variations in the delivery of specialist palliative care’ and
Variations in the delivery of specialist palliative care

Amongst the 17 carers that were interviewed, 6 stated that the patient they cared for had received specialist palliative care input. Specialist palliative care was viewed by participants as care being delivered by HCPs who identified themselves as being specifically trained in delivering palliative care. The remaining 11 carers stated that, to the best of their knowledge, the patient had not received input from a specialist palliative care provider. Out of the 6 who perceived that the patient had received specialist palliative care, 2 had a diagnosis of ILD and 4 had a diagnosis of COPD. Carers who reported the patient as having received specialist palliative care expressed that these services were only introduced when the patient was nearing the end of their life:

“[Specialist] Palliative care was only introduced the week he died so that didn't even really get off the ground.” (BC17, p4).

The absence of specialist palliative care providers was also recognised and discussed by some carers who highlighted that they would have preferred these services to be involved in patients’ care:

“We would have liked palliative care were you would have a qualified nurse coming in who knew exactly what was happening here. I feel we would have benefited greatly from that. But we didn't have that.” (BC1, p13).

Carers’ experiences highlighted their perceptions that the early introduction of specialist palliative care may have been of benefit to the patient with NMRD.

Variations in the delivery of palliative care from specialist respiratory services

The provision of palliative care to patients with NMRD by specialist respiratory services was also illuminated by carers. In the ROI services from a RNS were available in the secondary care setting and not the primary care setting. Carers in the ROI perceived that patients with NMRD had sufficient input from the RNS in the primary care setting:

“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).

Variance in the provision of specialist respiratory care services for patients with NMRD were therefore indicated by the accounts provided by carers.

Focus group findings

Two overarching themes emerged from analysis of the HCPs’ interviews: barriers to providing appropriate palliative care and future direction of palliative care for patients with NMRD. Overarching themes originated from the interpretative themes outlined below and illustrated through participants’ quotes.

Barriers to providing appropriate palliative care

The overarching theme of barriers to providing appropriate palliative care identified interpretative themes of 'lack of prognostic certainty' and 'Lack of understanding of the role of palliative care in relation to patients with NMRD.'

Lack of prognostic certainty

Across the North and ROI, varying HCPs perceived that uncertainty regarding the trajectory of NMRD inhibited the timely provision of palliative care to this client group:

“I think the disease [NMRD] can be palliative from a much earlier stage and I am not sure how good we are at that, I think someone could be palliative from their first referral to the clinic and they might take five years to die. Prediction is often difficult; it is a little bit easier with pulmonary fibrosis as the line of trajectory tends to be more acute. And very difficult in Bronchiectasis, it's only after several runs of treatment that you
realise that this isn’t working. I think we often kind of
look back and think could I have spotted something six
months ago? I always ask myself are we late into the
game of palliation?” (RC1, Respiratory Consultant, p4).

“With lung cancer patients you can give a rough prog-
nosis and know when to introduce palliative care. With
patients with COPD there is no definitive timeline and
they can be up and down so there is no obvious point
where you know to definitely involve palliative care so
that is the big issue really.” (RN8, Respiratory Deputy
Ward Manager, p8).

Difficulties regarding prognostication due to the
clinical manifestations of NMRD, particularly COPD and
bronchiectasis, were highlighted as resulting in the
delayed introduction of palliative care in the disease
trajectory.

Lack of understanding of the role of palliative care in
relation to patients with NMRD
Healthcare professionals’ perceived that specialist
palliative care was often still only associated with mali-
gnant 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).

Participants in NI and the ROI additionally suggested
that specialist palliative care providers viewed patients
with a malignant diagnosis as having priority over those
with NMRD:

“You know I have had fights and struggles with the spe-
cialist palliative care team because they see cancer as a
priority and not respiratory and they don’t understand
that these people have palliative needs too and therefore
they wouldn’t prioritise them as much for the Marie Curie
sit in service.” (RN2, Respiratory Nurse Specialist, p4).

The views expressed by HCPs in the ROI additionally
indicated an inequality of generalist and specialist pallia-
tive 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).

“I suppose from what I have seen it is mostly NMRD
patients with COPD that get seen by specialist palliative
care and I haven’t had any bronchiectasis patients that
have been seen or referred to specialist palliative care
that I am aware of.” (PH, Physiotherapist, p8).

Healthcare professionals’ accounts illuminated how a
perceived lack of understanding amongst HCPs in
relation to the role of palliative care for patients with
NMRD, created a barrier to optimal service provision.

Future direction of palliative care for patients with NMRD
The overarching theme of future direction of palliative
care for patients with NMRD identified interpretative
themes of ‘who will provide palliative care?’ and ‘the
presence of a model for palliative care delivery in
NMRD.’

Who will provide palliative care?
When discussing the future provision of palliative care
to patients with NMRD in the North and ROI, HCPs
presented varied views on who should be involved in the
delivery of palliative care to this client group. Some
medical and nursing HCPs expressed that the involve-
ment of specialist palliative care providers was a neces-
sity for patients with NMRD:

“I would rather if I had a condition like NMRD I
would probably prefer to have a specialist palliative care
consultant than a generalist respiratory physician that
has had some experience in palliative care.” (RC2,
Respiratory Consultant, p12).

Allied and nursing HCPs perceived that increased in-
volve ment of specialist palliative care services equated in
reduced numbers of emergency admissions for patients
with NMRD:

“And I know it is far and few between but the [NMRD]
patients who have seen specialist palliative care maybe
coming in as much to accident and emergency as
they are not panicking and so therefore specialist
palliative care can make a big difference.” (PH, Physio-
therapist, p6).

“I think nursing homes sometimes send (NMRD)
patients in (to hospital) without really getting someone to
see why they need to be sent into hospital because they
do tend to sit in accident and emergency for hours un-
necessarily. You know I think if the hospice nurse did go
in to have a look then a lot of the admissions could be
avoided.” (PCN3, Palliative Care Inpatient Unit Deputy Ward Manager, p10).

Participants from the varying healthcare professions additionally 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).

Healthcare professionals’ accounts highlighted mixed perspectives on the specific role of specialist palliative care services, and when they should be introduced for patients with NMRD.

The presence of a model for palliative care delivery in NMRD
A model of palliative care for patients with NMRD can help to ensure they receive appropriate palliative care when it is needed. This was perceived by participants in NI:

“Well there is the ELCOS (End of Life Care Operational System) Model for palliative care used for respiratory palliative care and that is regional and it moves from early to late phase and tells you what the patient should be getting at each stage. And I suppose with the model everything is there and you know what's available and what you should be doing and us a team can look and see what we need to be doing.” (RN2, Respiratory Nurse Specialist, p14).

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
The present study highlighted carers’ perceptions that patients with NMRD wanted access to specialist palliative care services however service availability was often uncoordinated and varied. Research has highlighted this previously amongst patients with ILD [35–37] and COPD [38]. The present study however additionally discovered that patients with bronchiectasis also experienced a lack of involvement from specialist palliative care providers. The integration of early specialist palliative care can help alleviate the symptoms experienced by patients with COPD and ILD [39].

Prognostic uncertainty experienced by HCPs impacted on the referral of patients with NMRD to specialist palliative care services. Crawford et al. [40] discovered that often referrals to specialist palliative care services were linked to how long a patient with COPD had left to live, rather than their holistic symptom needs. This implies that HCPs may be reluctant to refer patients for specialist palliative care input if they are unsure how their disease is progressing. Healthcare professionals must make referrals to specialist palliative care based on a needs assessment of the patient’s bio-psychosocial symptoms. This should not just be based on when the patient will die, to ensure optimal management of their holistic needs. By predicting needs instead of prognosis, patients with NMRD could be delivered more proactive palliative care [14, 41].

Research comparing access to specialist palliative care services between patients with NMRD and lung cancer, internationally and within the UK, indicated that patients with COPD and ILD have less access to specialist palliative care services than patients with lung cancer [7, 8, 42]. It has been previously suggested that this may be a result of HCPs associating palliative care with malignant disease [7, 8]. Present findings added a novel perspective by further highlighting that this is also a misconception associated with bronchiectasis, not just COPD and ILD. If HCPs are unaware of the role palliative care has in the care of patients with NMRD then this will impact on the services this client group receives.

Healthcare professionals additionally indicated that patients with COPD may more commonly receive generalist and specialist palliative care than those with a diagnosis of ILD or bronchiectasis. Previous literature acknowledged the importance of palliative care for patients with bronchiectasis [43, 44] and ILD [35, 36]. Baj-wah et al. [35] also highlighted that the important role of palliative care in ILD was not always recognised in the UK as it was not a malignant disease. Within the present study however, it was additionally evidenced that inequalities related to the recognition of the role of palliative care may also be seen amongst different types of
non-malignant disease, and not just between cancer and non-cancer diagnoses. Patients with COPD are less likely
to get referred for specialist palliative care than patients
with other non-malignant disease such as heart failure
and severe dementia [38]. It is important that HCPs rec-
ognise that the provision of palliative care to patients
with NMRD must be based on need [14], to ensure the
effective provision of palliative care that is responsive to
the patient’s symptom complexities.

Focus group findings presented various views on how
future palliative care should be delivered to patients with
NMRD. Some HCPs highlighted that specialist palliative
care should be provided to all patients with NMRD.
International guidance has recognised that palliative care
should be delivered by generalist HCPs, and specialist
palliative care providers should be involved in a patients
care when their symptoms become increasingly complex
[21]. However research conducted in the UK advocated
the integration of early specialist palliative care for pa-
ients with ILD and COPD, and provided evidence that
it helped improve the mastery of breathlessness experi-
ted by these patients [39]. Guidelines within the UK
have also recommended the introduction of specialist
palliative care services for patients with ILD from the
point of diagnosis [18]. Policies specific to bronchiectasis
however do not provide guidance on the introduction of
these services [18, 22].

In line with international views [45], and previous re-
search [46], many HCPs expressed that specialist pallia-
tive care should only be introduced when generalists
find it difficult to manage the bio-psychosocial symp-
toms of patients with NMRD. Policy [19], research [47]
and international guidelines [21, 48] have advocated the
efficacy of specialist palliative care services for patients with ILD from the
point of diagnosis [18]. Policies specific to bronchiectasis
however do not provide guidance on the introduction of
these services [18, 22].

For some HCPs, within the present study, the reason-
ning behind championing the role of specialist palliative
care for patients with NMRD was due to its perceived
impact on reducing unplanned hospital admissions. Pre-
vious research highlighted that significant decline in ad-
missions for COPD exacerbations may have been
aligned with specialist palliative care services providing
palliative care to this client group [49]. The present
study concurs with these findings as some HCPs felt that
patients with NMRD who received specialist palliative
care were less likely to attend accident and emergency
departments, or have unplanned admissions to hospital.
This may be due to perceptions that patients with
NMRD who have specialist palliative care teams involved
in their care will have more effective symptom
management [39], and can therefore be effectively man-
aged within their preferred place of care.

Previous research has identified varying potential
models of palliative care for patients with ILD and COPD
[19, 20, 39, 46]. However, previous policy documents and
research have been void of guidance regarding a model of
palliative care for patients with bronchiectasis. Addition-
ally, if patients’ holistic symptom needs were treated rather
than their prognosis or diagnoses anyone with a life
limiting illness would get help when needed e.g. patients
with bronchiectasis or other rare diseases that will rarely
be thought of as needing palliative care. Findings from the
present study highlighted that HCPs might have benefited
from a model of care to guide the provision for palliative
care for patients with NMRD that emphasised the import-
ance of introducing holistic care early in the disease
trajectory, and ensuring it is needs based. Figure 3 demon-
strates a potential model of palliative care for patients with
NMRD derived from the findings of the present study.
This model proposes three levels of palliative care for
patients with ILD, COPD and bronchiectasis whilst
advocating the continued holistic assessment of pa-
tient need. Level one advocates a holistic approach to
care which is introduced from diagnosis of NMRD.
This care should be delivered by both generalist pal-
liative care and specialist respiratory care providers.
As symptom complexities increase, level two suggests
that HCPs must additionally assess the need for the
introduction of specialist palliative care services. The
proposed model indicates that this decision should be
based on HCPs feeling they need further support or
guidance to manage the patient’s symptoms. 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 level three of the model proposes that timely
referral to specialist palliative care services is neces-
sary. The patient may move between levels at
different points within their trajectory and this should
be based on the assessment of their needs and
symptom complexities.

With regard to future research, an interesting exten-
sion of this study would be adopting the Medical
Research Council (MRC) framework for complex inter-
ventions [50] in order to develop and ratify the potential
model of palliative care derived from the findings of this
study. This would initially involve conducting a feasibil-
ity study with respiratory teams to explore the practic-
alities of implementing the proposed model of palliative
care for patients with ILD, COPD and bronchiectasis.
The next stage would be interventional research to pro-
vide in depth information regarding the implications of
introducing a model of care into the palliative care of
patients with NMRD. This stage would focus on testing
the intervention based on the data gained from the feasibility study. This intervention study could be modelled on previous research that has explored the implementation of models of palliative care for patients with breathlessness [51], ILD and COPD [39] and lung cancer [52].

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. Only a small number of participants had cared for someone with a diagnosis of ILD \((n = 4)\) or bronchiectasis \((n = 1)\). Recruiting greater numbers from these disease groups may have provided further perspectives. Findings also only represented the perspectives of carers and HCPs and not the patient’s own perspective. It is also recognised that bereaved carers were recruited through the RNS which makes the sample less representative of patients with NMRD who do not receive RNS care.

Conclusions
The management of patients with NMRD is complex and challenging with a clear need for a stronger and more integrative model of practice, which incorporates palliative care in a responsive and dynamic way. This study has reinforced the importance of proactive palliative care that identifies the needs of the individual patient and is not influenced by their prognosis. Future care to patients with NMRD must also acknowledge the important role of palliative care and generalist palliative care providers must have access to specialist input and advice when needed. This

![Fig. 3 Model of palliative care for patients with non-malignant respiratory disease](image-url)
study also adds a novel perspective in identifying a potential model of palliative care for NMRD that may enhance future holistic care for this client group. The feasibility of integrating this model into clinical practice requires further exploration.

Additional files

**Additional file 1:** Box 1. Interview Guide. (DOCX 12 kb)

**Additional file 2:** Box 2. Focus Group Guide. (DOCX 12 kb)

**Abbreviations**

COPD: Chronic obstructive pulmonary disease; HCP: Healthcare professional; ILD: Interstitial lung disease; MDT: Multidisciplinary team; MRC: Medical Research Council; NI: Northern Ireland; NMRD: Non-malignant respiratory disease; RNS: Respiratory nurse specialist; ROI: Republic of Ireland; UK: United Kingdom; WHO: World Health Organisation

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**Availability of data and materials**

In adherence with ethical approval, data will not be shared.

**Authors’ contributions**

CV was the lead researcher and was involved in all aspects of the study, including planning, data collection, data analysis and drafting the article. JR, PL, SP and PH were involved in planning the study, data analysis and drafting the article. All authors reviewed and approved the final manuscript.

**Ethics approval and consent to participate**

All participation was voluntary with full written, and verbal, informed consent. Ethical approval was received from the Office of Research and Ethics Committee Northern Ireland (ORECNI, Reference: 11/NI/0166) and governance permission from the Northern Health and Social Care Trust (Reference: NRP11-0264/09), Belfast Health and Social Care Trust (Reference:11080JR-AS), Letterkenny and Dublin.

**Consent for publication**

Not applicable.

**Competing interest**

The authors declare that they have no competing interests.

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