



**QUEEN'S
UNIVERSITY
BELFAST**

The experience of palliative care service provision for people with non-malignant respiratory disease and their family carers: an all-Ireland qualitative study

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), 383-394. <https://doi.org/10.1111/jan.13453>

Published in:

Journal of Advanced Nursing

Document Version:

Peer reviewed version

Queen's University Belfast - Research Portal:

[Link to publication record in Queen's University Belfast Research Portal](#)

Publisher rights

Copyright 2017 Wiley.

This work is made available online in accordance with the publisher's policies. Please refer to any applicable terms of use of the publisher.

General rights

Copyright for the publications made accessible via the Queen's University Belfast Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The Research Portal is Queen's institutional repository that provides access to Queen's research output. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact openaccess@qub.ac.uk.

The experience of palliative care service provision for people with non-malignant respiratory disease and their family carers: an all-Ireland qualitative study

Running head

Palliative care for people with non-malignant respiratory disease

Authors

Dr Clare MC VEIGH PhD MSc RN

Lecturer in Adult Health

School of Nursing and Midwifery, Queen's University Belfast, Belfast, Northern Ireland

Email: clare.mcveigh@qub.ac.uk

Twitter: @ClareVeigh

Dr Joanne REID PhD RN RNT

Reader: Cancer Nursing

School of Nursing and Midwifery, Queen's University Belfast, Belfast, Northern Ireland

Email: j.reid@qub.ac.uk

Professor Philip LARKIN PhD RN RNT

Professor of Clinical Nursing (Palliative Care)

School of Nursing, Midwifery and Health Systems, University College Dublin, Dublin, Ireland

■

Professor Sam PORTER BSSC PhD RN

Professor and Head of Department

Department of Social Sciences and Social Work, Bournemouth University, Poole, UK

Professor Peter HUDSON PhD RN RNT

Professor of Palliative Care

School of Nursing and Midwifery, Queen's University Belfast, Belfast, Northern Ireland and Director of Centre for Palliative Care, c/o St Vincent's University Hospital and University of Melbourne, Melbourne, Australia

Acknowledgements

We wish to acknowledge the contribution and guidance of staff within the Belfast Health and Social Care Trust; Northern Health and social Care Trust; Letterkenny General Hospital; Letterkenny; St. Vincent's University Hospital Dublin; Irish Hospice Foundation and All Ireland Institute of Hospice and Palliative Care. We also wish to acknowledge the Department for Employment and Learning (DEL) in Northern Ireland for funding this research project.

Conflict of Interest

The authors declare that they have no competing interests.

Funding

This research received funding from the Department of Employment and Learning, Northern Ireland.

ABSTRACT

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.

Background. Globally, palliative care is recommended as an appropriate healthcare option for people with advanced non-malignant lung disease. Yet, there is limited evidence regarding the integration of palliative care for this client group.

Design. Qualitative study.

Methods. Convenience sample of 17 bereaved carers and 18 healthcare professionals recruited from two rural and two urban sites on the Island of Ireland. Data were collected throughout 2012 and 2013 through semi-structured interviews with carers of patients with Chronic Obstructive Pulmonary Disease (N=12), interstitial lung disease (N=4) or bronchiectasis (N=1) who had died 3-18 months previously; and 4 focus groups with healthcare professionals. Data were analysed using a thematic analysis framework.

Results. Carers' interviews yielded three overarching themes: 1) Lack of preparedness for death, due to ambiguity regarding disease trajectory; 2) Lack of consistency in palliative care delivery, in relation to the receipt of generalist and specialist palliative care; and 3) Role ambiguity, related to their caregiving role. Focus groups identified two overarching themes: 1) Barriers to appropriate palliative care; and 2) The future direction of palliative care for patient with non-malignant respiratory disease.

Conclusion. The uncertain disease trajectory was not only experienced by carers but also healthcare professionals. Although referral to specialist palliative care services was perceived as increasing, the availability and coordination of generalist and specialist palliative care services were fragmented and varied dependent on geographical location.

Keywords

non-malignant respiratory disease, COPD, chronic obstructive pulmonary disease, bronchiectasis, interstitial lung disease, palliative care, family carers, qualitative research, nursing and healthcare professionals

Summary Statement

Why is this research needed?

- Internationally, palliative care is recommended for people with non- malignant respiratory disease, yet the integration of palliative care for this client group is unclear.
- There is limited evidence regarding palliative care for patients with interstitial lung disease or Bronchiectasis, alongside Chronic Obstructive Pulmonary Disease.
- There is limited research regarding the influence of geographical location on the provision of palliative care for patients with non- malignant respiratory disease.

What are the key findings?

- The uncertain disease trajectory associated with non- malignant respiratory disease and a lack of prognostic information from healthcare professionals, resulted in a lack of preparedness for death.
- The availability and coordination of generalist and specialist palliative care services were fragmented and varied dependent on geographical location, this was not just isolated to rurality but also health jurisdiction.
- Specialist and generalist palliative care services are appropriate for patients with other forms of non- malignant respiratory disease such as bronchiectasis and interstitial lung disease, not just Chronic Obstructive Pulmonary Disease.

How should the findings be used to influence policy/practice/research/education?

- Future respiratory and palliative care policies should reinforce amongst healthcare professionals the importance of providing information regarding prognosis to this client group and be effectively implemented in clinical practice.
- Enhanced access to specialist and generalist palliative care services is needed in areas with fewer services to improve local palliative service provision.
- Palliative service provision should be inclusive of all forms of non-malignant respiratory disease to address the needs of patients with interstitial lung disease and bronchiectasis, alongside Chronic Obstructive Pulmonary Disease.

Introduction

Non- Malignant Respiratory Disease (NMRD) is an umbrella term that includes Interstitial Lung Disease (ILD), bronchiectasis and Chronic Obstructive Pulmonary Disease (COPD) (National End of Life Care Intelligence Network 2011). 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 (World Health Organisation (WHO) 2008). International guidelines emphasise the importance of generalist and specialist palliative care being made available to patients with a respiratory illness (Bradley *et al.* 2008, Lanken *et al.* 2008, NICE 2010, Raghu *et al.* 2011, NICE 2013). Research suggests however that patients with NMRD do not receive the same standards of palliative care as patients with lung cancer (Goodridge *et al.* 2008, Partridge *et al.* 2009).

Background

In 2014, the WHO and the Worldwide Palliative Care Alliance (WPCA) published an atlas highlighting the global need for palliative care. This atlas highlighted that although palliative care programs have mainly focused on the needs of people with a malignant disease in the past, the majority of those worldwide needing palliative care have a non-malignant diagnosis. A key recommendation from the WHO and WPCA was that palliative care should be integrated into relevant national health and disease-specific policies, a concept mirrored in the Palliative Care 2020 (2014) European Declaration on Palliative Care. Palliative Care 2020 additionally declared that new policies specific to palliative care must include referral criteria to facilitate timely access to palliative care based on the persons holistic needs, regardless of diagnosis or prognosis.

There is clear symptom burden experienced by patients with NMRD, such as dyspnoea, hypercapnia and anxiety, therefore palliative care may mitigate against increased burden by the judicious use of analgesics, antibiotics, O₂ therapy and comfort care measures as appropriate. Generalist and specialist palliative service provision for patients with NMRD in

the North and Republic of Ireland (ROI) has been previously described (Mc Veigh *et al.* 2017). In NI, patients with COPD and their carers expressed concerns about a variety of unmet holistic needs (Hasson *et al.* 2008). Hasson *et al.* additionally highlighted that patients with COPD experienced uncertainty regarding the trajectory of their disease. Further evidence also depicted that carers of patients with COPD had a range of unmet needs and can receive inadequate support from the healthcare profession (Spence *et al.* 2008). There is limited evidence however regarding palliative care for patients with ILD or Bronchiectasis, alongside COPD. Given this background the research question guiding this study was: What are the perceptions of bereaved carers and healthcare professionals (HCPs) of the generalist and specialist palliative care service provision for people with NMRD, in rural and urban areas in the North and ROI.

The study

Aim

The aim of this study was to explore specialist and generalist palliative care provision for people with NMRD from the perspectives of bereaved family carers and healthcare staff, in rural and urban areas in the North and ROI.

Design

This study employed a broad interpretivist qualitative enquiry to facilitate an in-depth exploration of the intricacies of the topic being investigated and to appropriately access the meanings and values study participants applied to their experiences (Lapan *et al.* 2011).

Participants

Recruitment for the interviews and focus groups has been previously highlighted (Mc Veigh *et al.* 2017). Convenience sampling was employed in this study. Sociodemographic details about participants of the interviews and focus groups are conveyed in Table 1. All participants were recruited across two rural and two urban sites in the NI and the ROI

(Figures 1 & 2). Eligible participants targeted for the semi-structured interviews were bereaved family carers, identified by a respiratory nurse specialist as the main carer, of people with NMRD who had died three to eighteen months previously. Participants were excluded if they were under 18 years old, did not speak English or were too distressed to take part in a research study. Eligible participants for the focus groups included members of the multi-disciplinary team that were involved in the generalist and specialist palliative care of patients with NMRD and identified by relevant heads of each department.

Data Collection

Data were collected throughout 2012 and 2013. Semi-structured interviews with caregivers (see supplementary information table 1) were conducted in participants' homes (N=10), or over the telephone (N=7) to allow them to choose an interview method that was most convenient. Interviews ranged from 22 – 80 minutes in length, with an average of 50 minutes. Focus groups (n=4) with HCPs were conducted at each site involved in the study (see supplementary information Table 2). The focus groups ranged from 68 – 81 minutes in length, with an average of 74 minutes. All interviews and focus groups were digitally recorded and transcribed verbatim. Interviews and focus groups were conducted by the lead author who had appropriate training on conducting qualitative research. To aid accurate recording of focus groups, an additional member of the research team fulfilled the role of note taker. Data collection was completed when it was noted by the researcher that no new themes or information were emerging from the data.

Data Analysis

Data were analysed by adopting a thematic analysis framework described by King & Horrocks (2010). To assist with managing the data the qualitative research software package NVivo (Jupp 2006) was used to provide the tools to support the management and categorisation of the qualitative data. Stage one of analysis was the assignment of descriptive themes to sections of the data to describe their meaning. Stage two encompassed grouping

together descriptive themes to generate interpretative themes and highlight emerging patterns in the data. The third stage of the framework required the identification of a number of overarching themes developed by pulling together and linking all the interpretative themes that had been established. The overarching and interpretative themes are outlined in supplementary information Table 3.

Ethical considerations

The ethical considerations of the study have been previously described (Mc Veigh *et al.* 2014). Ethical approval was received from the Office of Research and Ethics Committee NI (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. Written and verbal informed consent was obtained at the time of interview or focus group.

Rigour

Rigour of the study has been described previously (Mc Veigh *et al.* 2014). Each transcription was initially analysed by the lead author and then reviewed by the remaining research team to verify the themes generated from the data collected.

Findings

Quotes are used as best exemplars from each theme. The anonymous participant codes and transcript page numbers for each quote are also included.

Semi-structured Interviews Findings

Analysis of the carers' interviews identified three key overarching themes: 1) lack of preparedness for death; 2) lack of consistency in palliative care delivery; and 3) role ambiguity.

Overarching theme 1) Lack of preparedness for death

Participants expressed feelings of ambiguity in relation to the life limiting nature of NMRD due to unpredictable disease trajectory. The unpredictable nature of ILD, explained by a carer of a patient with idiopathic pulmonary fibrosis (IPF), highlighted how quickly the patient's condition progressed and recalled their shock at this rapid decline:

“She deteriorated very quickly when she went into the hospice I have to say. From going in and being able to walk and look after herself very quickly it got to the stage where she couldn't walk and didn't get dressed or anything. She had gone downhill very rapidly when she went home and then went back into the hospice.” (BC4, p5).

Carers of patients with COPD or Bronchiectasis expressed that the patient's condition appeared to deteriorate and then improve, leading them to believe that the patient would always get better again after becoming unwell:

You know a few Christmases ago he was rushed into hospital on Christmas Eve and was really unwell and I saw the wires and everything and thought this is serious. But he pulled through. So it was a case of every time he went into hospital the whole village just thought, ‘aw there he goes back into hospital again he will be out by the weekend.’ So we never expected him to die, to not come home. Nobody expected it at all, my friends, nobody. (BC9, p4).

Carers additionally highlighted feelings of uncertainty about the patient's condition associated with a lack of information from HCPs about the life-limiting nature of NMRD:

You know nobody ever told me how long he had left or how long this was going to go on for and I feel now I could have done with more information. Nobody ever tells you, you are just left to your own imagination and they just expect you to know but people don't know. Now I know a doctor can't just turn around and tell you the exact date he is going to last too but they could have given me an indication that he wasn't going to get better and that it would only go on so long. They are bound to know by the symptoms how long it is likely to go on for. (BC14, p7).

Due to difficulties in gauging how the patient's condition was going to progress, participants were left feeling uncertain about the staging of the patient's illness. This led to feelings of unpreparedness amongst participants when the patient's condition deteriorated.

Overarching theme 2) Lack of consistency in palliative care delivery

Carers' accounts demonstrated a lack of consistency in the timing of palliative care delivered to this client group. Carers expressed that specialist palliative care was only introduced when the patient was nearing the end of life and felt patients' could have benefited from it being introduced earlier:

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).

In the ROI, results confirmed that patients with NMRD received adequate support for their palliative needs in hospital. However, this care was not continued when the patient was discharged back into the community:

Well we felt that he could have definitely done with more support at home to help him. But now when he went into hospital the support he got there was brilliant, the respiratory nurses and all were just brilliant. But when he was discharged home the

care just stopped, it tapered off when he was discharged home from hospital. (BC15, p2)

Carers additionally reported that the majority of patients with NMRD in the ROI (n=7) died in hospital (n=6), rather than their preferred place of death:

My partner would have ideally liked to come home but...he did die in hospital.

(BC16, p13)

In contrast to the views expressed by participants in the ROI, findings highlighted that patients with NMRD in NI had sufficient generalist palliative care to deal with their palliative needs in the primary care setting:

As her illness progressed they were there for her. You know and obviously somebody was assessing to make sure that was happening. And then they brought in the machine for during the night and it was a very noisy machine, so they put that in that it was upstairs in the bedroom and also downstairs in the living room and so you could tell as the illness progressed all the services were being put in that she needed. (BC4, p4).

However, participants perceived that there was still insufficient palliative care service provision experienced at home to facilitate preferred place of death:

She did die in hospital, she did indeed and that's part of my hurt, calling the ambulance and letting her die in there. She would have loved to have died at home. I think that if we had have had more support at home she could have died at home.

(BC1, p10)

Overarching theme 3) Role Ambiguity

Results illuminated carers' feelings of ambiguity related to their caregiving role. Participants felt confused as to why they were not allowed to be involved in some conversations that took place between the patient and the HCP:

Any of the other doctors didn't mind when I stayed with my husband to explain to him what they were saying but she [the doctor] wouldn't let me stay. And it was always, 'you wait out in the corridor and I will speak to you in a few minutes. (BC3, p4).

Carers' expressed that the knowledge they acquired whilst caring for a patient at home was not acknowledged in the inpatient setting:

When I went to refill the machine [non-invasive ventilation machine] with water there was a nurse practitioner there and she went through me for touching the machine and I was very angry as I knew just as much about operating the bloody machine as she did. (BC2, p8)

Role ambiguity was also exemplified by participants' conclusions that they had a lack of support from the healthcare profession and therefore had no choice but to take up the role of carer:

You know it ended up being me and my sister that would have went up a lot to see him and help him out because we didn't have any other support. A lot of the pressure was put on ourselves to look after him. (BC15, p3).

Carers additionally revealed that certain HCPs depended on them to provide guidance on how to deliver certain elements of care to the patient, such as non-invasive ventilation:

I went to for a holiday on the Wednesday and I had no sooner arrived than I got a phone call saying 'this is the nursing home here something is wrong with the nippy machine can you come and fix it?' I then had to spend the next couple of hours

sending texts to the nippy rep and she actually went to the nursing home to sort it out.
(BC2, p3)

Focus Group Findings

Analysis of the HCP focus groups yielded two key overarching themes: 1) barriers to providing appropriate palliative care and 2) the future direction of palliative care for patients with NMRD.

Overarching theme 1) Barriers to providing appropriate palliative care

Participants across NI and the ROI described an inability to provide timely palliative care to patients with NMRD due to difficulties in identifying the patient's prognosis. For patients with COPD and bronchiectasis, findings indicated that prognostic uncertainty was related to the patient having multiple episodes of becoming very unwell and then their condition improving:

With lung cancer patients you can give a rough prognosis 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).

Healthcare professionals expressed that with a diagnosis of IPF it was easier to identify when the patient's condition was deteriorating:

Certainly in pulmonary fibrosis (ILD) it is fairly clear as there is a clearly defined decline and there is a life expectancy attached to the diagnosis. So I think we are better at recognising they are palliative than we were certainly but there are some improvements still to be made. (RC2, Respiratory Consultant, p14)

However, participants also recognised that an inadequate understanding amongst HCPs of the role of palliative care in NMRD created barriers to providing appropriate palliative care:

Well there are people who won't refer to palliative care and you will find it has a lot to do with their own hang ups about what palliative care really is and their own lack of understanding. (PCN5, Palliative Care Nurse Specialist, p7).

Participants in NI held the view that specialist palliative care was available equally to patients with COPD, bronchiectasis and ILD. However HCPs in the ROI indicated an inequality in the provision of specialist palliative care to patients with ILD or bronchiectasis, comparative to those with COPD:

I suppose from what I have seen it is mostly COPD patients 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)

Throughout NI and the ROI, the lack of availability of generalist and specialist palliative care services in rural areas to patients with NMRD, in comparison to those in urban settings, was highlighted:

In particular in the really rural areas they are particularly bad spots and we have major issues getting packages of care for anywhere around really rural areas. You just cringe when you hear someone's address is there and you just hope that they don't need a package because it is very, very difficult to get one. Even if they are end of life care it's still extremely difficult because the services are just not available. (PCN3, Palliative Care Inpatient Unit Deputy Ward Manager, p13).

I think as well with the specialist palliative care services there maybe aren't as many available to NMRD patients in the more rural areas as there are in urban areas. (PCN5, Palliative Care Nurse Specialist, p10).

Overarching theme 2) The future direction of palliative care for patients with NMRD

Throughout NI and the ROI, HCPs conveyed that the presence of specialist palliative care providers in the care of patients with NMRD was increasing:

The balance has changed because with our post [specialist palliative care OT] about 7 years ago there would have been the expectation that it would 90:10 malignant versus non-malignant disease but it has changed and I would say we are fast approaching a 75% caseload for malignant and the rest are non-malignant just made up of neurology or respiratory. (OT1, Specialist Palliative Care Occupational Therapist, p3).

The increased referrals to specialist palliative care services were perceived as being a result of specialist palliative care providers being more accepting of patients who have a non-malignant diagnosis:

Now all hospices are open to take non-malignant referrals which are great and they are much more eager to fill that role than they were previously. (PCN5, Palliative Care Nurse Specialist, p4).

In NI the presence of a regional model to guide the implementation of palliative care, dependant on stage of illness, was used by HCPs caring for patients with NMRD to ensure they received optimal palliative care:

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)

In the ROI however, participants acknowledged the lack of a regional model for palliative care that could help to guide the delivery of 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).

The role of the carer was acknowledged and great emphasis was placed on the importance of meeting the carer's information needs regarding the patient's condition:

Carers are slightly different, carers are different from patients. I think that quite often the carer has to have a clear picture of what is going on ... if you have a carer you would often say, you know, 'It is very, very severe lung disease and they may not survive this illness.' And that is a conversation that I often have very frequently with people. The carers are very keen to know how severe their relative is and the relative will be told that they have severe lung disease and let them ask what they want to know after that. There can be people [patients] who are devastated and don't want to know and yet the relatives have to know a little bit more of the gritty reality of, 'This is really tough stuff here and they are really unwell. (RC1, Respiratory Consultant, p21).

The wellbeing of the carer had an impact on the patient's experience as for patients with NMRD to be successfully cared for at home the carer needed adequately supported:

I think you have to have the carers on board as well because a lot of home management systems fail not because of the patient but because of the carer. You know trying to get someone home because 'Transforming Your Care' [2011 review of health and social care in NI] says that more people should have the chance to die at home but often it is the carer that you see totally wide eyed with fear when their loved one says that they want to go home and they sort of think 'how do I manage this?' So I think the support to the carer is hugely important, although you focus on the patient

you have to give just as much support to the carer. (RC2, Respiratory Consultant, p22).

DISCUSSION

Carers' accounts concurred with previous research as they highlighted how the uncertain COPD trajectory resulted in ambiguity regarding disease progression amongst patients and carers (Pinnock *et al.* 2011, Hynes *et al.* 2012). Similarly, bronchiectasis caused uncertainty regarding the disease trajectory due to the patient's fluctuation between periods of illness and wellness. However, ILD caused prognostic uncertainty through displaying a trajectory where the patient's condition was perceived as being stable and then rapidly deteriorating after experiencing no exacerbations to their condition. Previous research suggested that the deterioration in patients with ILD helped patients and carers understand that the condition was palliative (Bajwah *et al.* 2012). Conversely, our study reported that patients with ILD and their carers were unprepared for this rapid deterioration and it did not provide further clarity into the life-limiting nature of the disease. Carers perceived a lack of awareness regarding the patient's prognosis was also caused by a lack of information from HCPs regarding the palliative nature of NMRD. This adds to previous research which has highlighted that patients with COPD often get to the stage in their illness where they require regular oxygen therapy and are still unaware they have a palliative illness, due to a lack of information about the life limiting nature of their disease (Gott *et al.* 2009, Lowey *et al.* 2013). The present study highlighted a lack of death preparedness (Pincombe *et al.* 2000) amongst not only patients with COPD and their carers, but also those with bronchiectasis and ILD. Death preparedness can be defined as the readiness for death (Hebert *et al.* 2006) experienced by the patient and their carer. A contributing factor to being prepared for death is also an awareness of dying (McLeod-Sordjan 2014), however the present study highlighted how, alongside COPD, patients with bronchiectasis and ILD were unaware of the life limiting nature of the disease and that the patient would die from the disease.

Findings additionally demonstrated that, alongside carers, HCPs found a lack of prognostic certainty in relation to NMRD that resulted in difficulties determining disease progression. This aligned with previous research highlighting that prognostic uncertainty caused HCPs to experience difficulties in effectively managing patients with advanced COPD and recognising when their condition was declining (Spence *et al.* 2008, Pinnock *et al.* 2011). Our findings further highlighted that this is not isolated to COPD as HCPs perceptions also associated prognostication difficulties with bronchiectasis. Conversely findings highlighted that, unlike carers, HCPs perceived that it was easier to identify the prognosis of a patient with ILD due to clear prognostic indicators. Previous research in the UK (Bajwah *et al.* 2012) appears to align with our findings, highlighting that HCPs may not have provided patients with ILD and their carers with appropriate prognostic information.

Inequalities in the provision of palliative care across the island of Ireland can be influenced by geographic location (DHSSPSNI 2011, Joint Oireachtas Committee on Health and Children 2014, Murray *et al.* 2013) and was evidenced in the present study. Findings aligned with previous research as HCPs perceived that palliative care services were limited for patients living in rural areas (Robinson *et al.* 2009, Goodridge *et al.* 2010). The present study highlighted however that the influence of geographical location on palliative care for NMRD was not solely dependent on rurality. Findings concurred with previous research highlighting disparities between the availability of generalist and specialist palliative care services in the primary care setting across Europe (Lopez-Campos *et al.* 2014). Our study however illuminated perceptions that patients with NMRD in the ROI had limited access to palliative care services in the primary care setting, in comparison to NI. Patients with COPD can have several readmissions to hospital caused by a lack of follow up care in the community post discharge (Jeffs *et al.* 2014). Present findings additionally highlighted that the lack of services in the primary care setting in the ROI for patients with ILD and bronchiectasis, alongside COPD, may have influenced their place of death. This demonstrated how patients' geographical location and the palliative care services available in this location, potentially had an impact on whether or not they died in their preferred place of care.

Previous research has identified models of palliative care for patients with ILD and COPD, advocating the introduction of specialist palliative care early in a patient's disease trajectory (Higginson *et al.* 2014) or when a patients' symptom management becomes too complex for generalists to manage (Strang *et al.* 2013). In the present study participants perceived that specialist palliative care services were not involved with the majority of patients, concurring with previous findings related to patients with ILD (Bajwah *et al.* 2012, Lindell *et al.* 2014) and COPD (Beernaert *et al.* 2013). We additionally discovered that patients with bronchiectasis also experienced a lack of involvement from specialist palliative care providers. Carers' accounts highlighted that patients with NMRD and their carers wanted access to these services however service availability was often uncoordinated and varied. Healthcare professionals however perceived that referrals to specialist palliative care for patients with NMRD are increasing. Results conveyed that this may be equated to increased acceptability of the role of specialist palliative care for patients with non-malignant conditions.

Carers referred to feelings of role ambiguity caused when they felt excluded from elements of the patients care, but also highlighted how HCPs depended on the carer. Previous research in the UK highlighted that carers of patients with COPD felt unprepared for their role and often felt isolated, due to a lack of bio-psychosocial support from HCPs (Spence *et al.* 2008). We additionally ascertained that carers of patients with ILD and bronchiectasis, alongside COPD, also felt isolated when not included in the delivery of some elements of the patients care, especially in the secondary care setting. Healthcare professionals' perceptions aligned with the view that more effective carer assessments are required that would enable the appropriate identification of the needs and concerns of carers of patients with NMRD.

These findings have implications for clinical practice, policy and research. A key recommendation from regional palliative care guidelines was the timely provision of information to patients with a life-limiting illness and their carers regarding their illness (DHSSPSNI 2010). However findings demonstrated that the recommendations of these

palliative and end of life care strategies often may not be implemented by HCPs caring for patients with NMRD. Future respiratory and palliative care policies need to reinforce amongst HCPs the importance of providing information regarding prognosis and prognostic difficulties, to patients with NMRD and be effectively implemented in clinical practice.

The National Respiratory (COPD) Framework (Irish Thoracic Society *et al.* 2008) recognised the need for patients in the ROI with COPD to have access to multidisciplinary teams that included specialist palliative care input and this is available in the North and ROI (Murray *et al.* 2013, Belfast Health and Social Care Trust 2015, Northern Health and Social Care Trust 2015). However the present study and previous evidence (Murray *et al.* 2013), has highlighted that the availability and coordination of these services are fragmented and can be varied dependant on geographical location. Enhanced availability of these services would afford generalist palliative care providers in areas with fewer services to have rapid access to specialist support and advice. Whilst previous evidence referred only to patients with COPD and ILD (Irish Thoracic Society *et al.* 2008), the present study identified the need for these services to also filter down to patients with bronchiectasis.

To provide further evidence regarding the reasons for patients and carers lack of awareness regarding the life-limiting nature of NMRD, future research could explore the quality of palliative and end of life discussions with patients with NMRD and their carers. Previous research has explored these discussions with patients with COPD (Leung *et al.* 2012), however further investigation amongst patients with ILD and bronchiectasis, alongside COPD, that also includes the carer is warranted. A quantitative study that aims to investigate the quality of palliative and end of life care discussions between HCPs and patients with NMRD and their carers, through the previously validated Quality of Communication Tool (Curtis *et al.* 2008) could be conducted.

Limitations

Eighteen HCPs were recruited into the study however the majority who participated were nurses (n=13). Increased numbers of allied HCPs and medical staff may have provided more diverse perspectives. The majority of 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 ILD (n=4) or bronchiectasis (n=1). Recruiting greater numbers from the other two disease groups may have provided further perspectives. Findings also only represented the perspectives of carers and HCPs and not the patient's own perspective.

CONCLUSION

This study illuminated the challenges patients, carers and HCPs encountered due to the uncertain NMRD trajectory and how this had an impact on death preparedness and the receipt of palliative care. The availability and coordination of specialist and generalist palliative care services for patients with NMRD is fragmented and varied dependant on geographical location. Enhanced availability of these services would afford HCPs in areas with fewer services to have rapid access to specialist support and advice. To reduce inequalities in the provision of palliative care for NMRD, related to geographical location, service development measures must be put in place that are inclusive of patients with ILD and bronchiectasis. The management of patients with NMRD is complex and challenging with a clear need for a stronger and more integrative model of practice, incorporating palliative care in a responsive and dynamic way.

Author Contributions:

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE*):

- 1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- 2) drafting the article or revising it critically for important intellectual content.

*<http://www.icmje.org/recommendations/>

REFERENCES

- Bajwah S., Koffman J., Higginson I.J., Ross J.R., Wells A.U., Birring S.S. & 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), 84-90.
- 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.
- Belfast Health and Social Care Trust (2015) *Community Services*. Available at: <http://belfasttrust-cancerservices.hscni.net/CommunityServices.htm> (accessed 29 March 2015).
- 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.
- Connor, S. & Bermedo, M.S. (2014) *Global atlas of palliative care at the end of life*. World Health Organization and Worldwide Palliative Care Alliance, Geneva, Switzerland/London, UK.
- Curtis J.R, Engelberg R., Young J.P., Vig L.K., Reinke L.F., Wenrich M.D., Mc Grath B., Mc Cown E. & Back A.L. (2008) An approach to understanding the interaction of hope and desire for explicit prognostic information among individuals with severe chronic obstructive pulmonary disease or advanced cancer. *Journal of palliative medicine* **11**(4), 610-620.
- Department of Health, Social Services and Public Safety Northern Ireland (2011) *Transforming your care: A review of health and social care in Northern Ireland*. DHSSPSNI, Northern Ireland.

Department of Health, Social Services and Public Safety Northern Ireland (2010) *Living Matters Dying Matters. A palliative and end of life care strategy for adults in Northern Ireland*. DHSSPSNI, Northern Ireland.

Department of Health, Social Services and Public Safety Northern Ireland (2009) *Service Framework for Respiratory Health and Wellbeing. Respiratory Service Framework*. DHSSPSNI, Northern Ireland.

European Respiratory Association (2015) *Bronchiectasis*. Available at: <http://www.erswhitebook.org/chapters/bronchiectasis/> (accessed 29 December 2015).

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.

Goodridge D., Lawson J., Rennie D. & Marciniuk D. (2010) Rural/Urban differences in health care utilization and place of death for persons with respiratory illness in the last year of life. *Rural and Remote Health* **10**(1349), 1-15.

Gott M.C., Gardiner N.S., Payne S., Seamark D., Barnes S., Halpin D. & Ruse C. (2009) Barriers to advance care planning in chronic obstructive pulmonary disease. *Palliative Medicine* **23**(7), 642-648.

Hansell A., Hollowell J., Nichols T., Mc Niece R. & Strachan D. (1999) Use of the General Practice Research Database (GPRD) for respiratory epidemiology: a comparison with the 4th Morbidity Survey in General Practice. *Thorax* **54**(5), 413-419.

Hasson F., Spence A., Waldron M., M., Kernohan G., Mc Laughlin D., Watson B. & Cochrane B. (2008) I cannot get a breath: experiences of living with advanced chronic obstructive disease. *International journal of Palliative Nursing* **14**(11), 526- 531.

Hebert, R. S., Prigerson, H. G., Schulz, R. & Arnold, R. M. (2006) Preparing caregivers for the death of a loved one: a theoretical framework and suggestions for future research. *Journal of palliative medicine* **9**(5), 1164-1171.

Higginson I.J., Bausewein C., Reilly C.C., Gao W., Gysels M., Dzingina M., & Moxham J. (2014) An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. *The Lancet Respiratory Medicine* **2**(12), 979- 987.

Hynes G., Stokes A. & Mc Carron M. (2012) Informal care-giving in advanced chronic obstructive pulmonary disease: lay knowledge and experience. *Journal of clinical nursing* **21**(7-8), 1068-1077.

Irish Thoracic Society, Health Service Executive & Royal College of General Practitioners (2008) *National Respiratory (COPD) Disease Framework*. Irish Thoracic Society, ROI.

Jeffs L., Dhalla I., Cardoso R. & Bell C.M. (2014) The perspectives of patients, family members and healthcare professionals on readmissions: preventable or inevitable? *Journal of Interprofessional Care* **28**(6), 507-512.

Joint Oireachtas Committee on Health and Children (2014) *Report on End of Life and Palliative Care in Ireland*. Joint Oireachtas Committee on Health and Children, ROI.

Jupp V. (2006) *The SAGE Dictionary of Social Research Methods*. SAGE Publications Ltd., London.

King N. & Horrocks C. (2010) *Interviews in Qualitative Research*. Sage Publications Ltd, London.

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.

Lapan S.D., Quartaroli M.T. & Riemer F.J. (2011) *Qualitative Research: An introduction to methods and design*. John Wiley and Sons Inc., California.

- Leung J.M., Udris E.M., Uman J. and Au, D.H. (2012) The effect of end-of-life discussions on perceived quality of care and health status among patients with COPD. *Chest* **142**(1), 128-133.
- 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.
- Lopez-Campos J.L., Asensio-Cruz M.I., Castro-Acosta A., Calero C. & Pozo-Rodriguez F. (2014) Results from an Audit Feedback Strategy for Chronic Obstructive Pulmonary Disease In-Hospital Care: A Joint Analysis from the AUDIPOC and European COPD Audit Studies. *PloS one* **9**(10), e110394.
- Lowey S.E., Norton S.A., Quinn J.R. & Quill, T.E. (2013) Living with advanced heart failure or COPD: Experiences and goals of individuals nearing the end of life. *Research in nursing & health* **36**(4), 349-358.
- McLeod-Sordjan, R. (2014) Death preparedness: a concept analysis. *Journal of Advanced Nursing* **70**(5), 1008-1019.
- Mc Veigh C., Reid J., Hudson P., Larkin P., Porter S. & Marley A.M. (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* **70**(3), 687-697.
- Mc Veigh, 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**(1), 6.
- Murray E., Mc Loughlin K. & Foley S. (2013) *Access to Specialist Palliative Care Services and Place of Death in Ireland. What the Data Tells Us*. IHF, ROI.
- National Institute for Health and Care Excellence (2013) *Idiopathic pulmonary fibrosis: The diagnosis and management of suspected idiopathic pulmonary fibrosis*. NICE, UK.

National End of Life Care Intelligence Network (2011) *Deaths from Respiratory Diseases: Implications for End of Life Care in England*. National End of Life Care Intelligence Network, UK.

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.

Northern Health and Social Care Trust (2015) *Community Palliative Care*. Available at: <http://www.northerntrust.hscni.net/services/2531.htm> (accessed 29 March 2015).

Palliative Care 2020 (2014) *European Declaration on Palliative Care*. Available at: <http://www.palliativecare2020.eu/declaration/#P3> (accessed 30/12/15).

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.

Pincombe J., Brown M., Thorne D., Ballantyne A. & Mc Cutcheon, H. (2000) Care of dying patients in the acute hospital. *Progress in Palliative Care* **8**, 71–7.

Pinnock H., Kendall M., Murray S.A., Worth A., Porter M., Mac Nee W. & Sheikh A. (2011) Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. *British Medical Journal* **342**(d142): 1- 10.

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.

Robinson C.A., Pesut B., Bortorff J.L., Mowry A., Broughton S. & Fyles G. (2009) Rural palliative care: a comprehensive review. *Journal of Palliative Medicine* **12**(3): 253-258.

Spence A., Hasson F., Waldron M., Kernohan G., McLaughlin D., Cochrane B. & Watson B. (2008) Active carers: living with chronic obstructive pulmonary disease in the family. *International journal of palliative nursing* **14**(8), 368-372.

Strang S., Ekberg-Jansson A., Strang P. & Larsson L.O. (2013) Palliative care in COPD-
web survey in Sweden highlights the current situation for a vulnerable group of
patients. *Upsala Journal of Medical Sciences* **118**(3), 181-186.

World Health Organisation (2008) *Global Alliance against Chronic Respiratory Disease
Action Plan 2008–2013*. WHO, Italy.

Table 1: Participant Profiles

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)

Figure 1: Flowchart of Recruitment and Retention for Semi-Structured Interviews

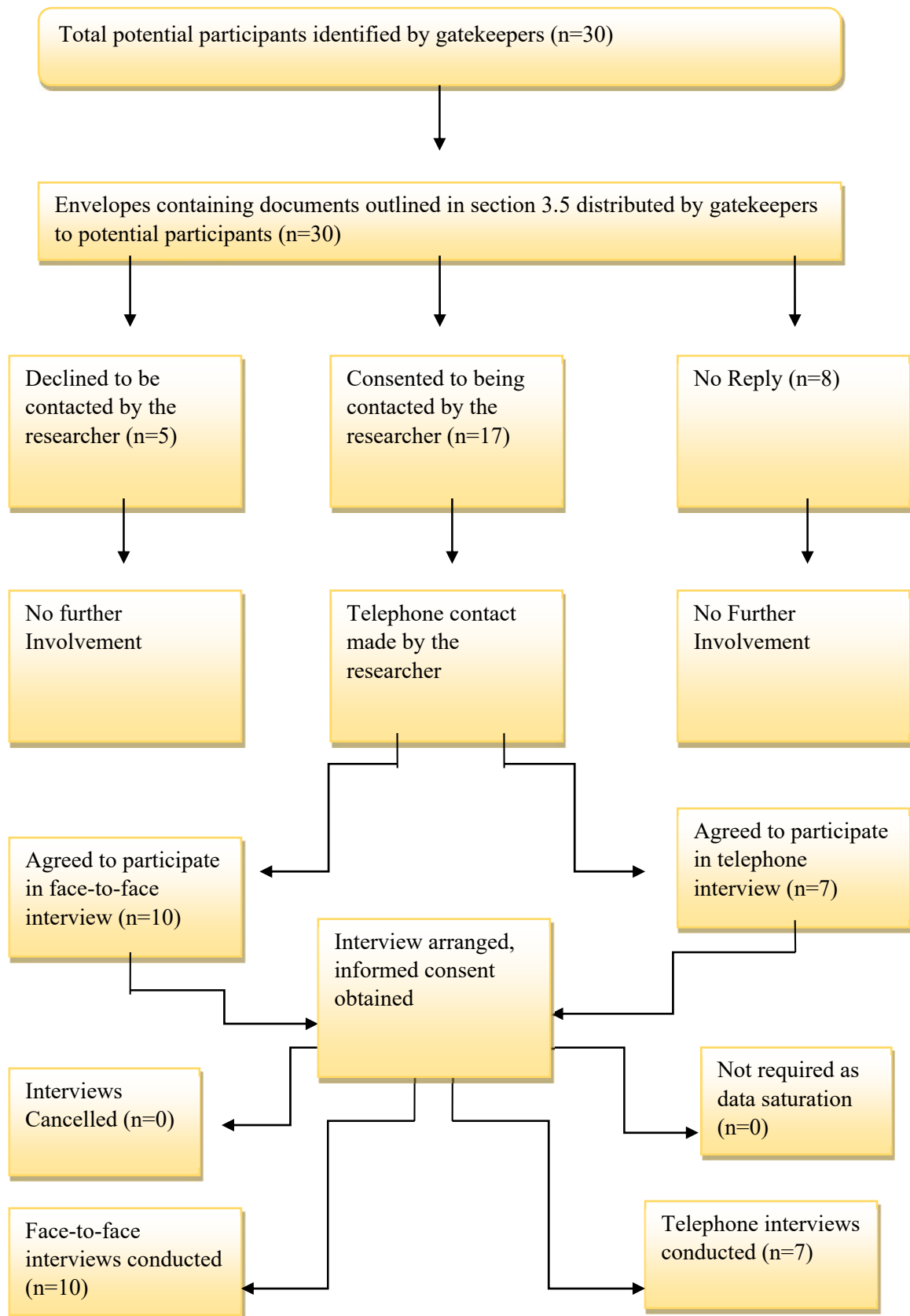
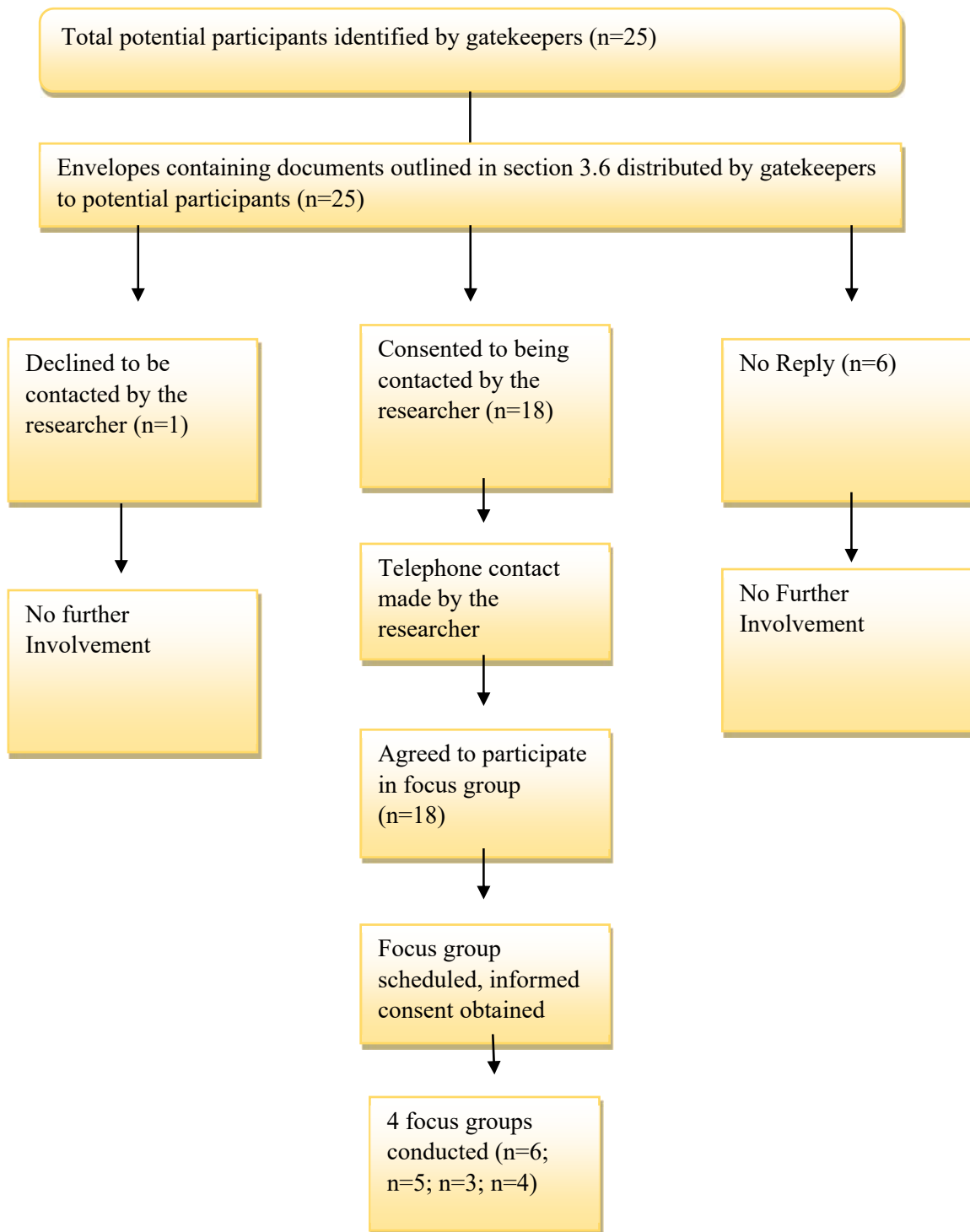


Figure 2: Flowchart of Recruitment and Retention for Focus Groups



Supplementary Table 1: Interview Guide

Opening Statement

Can you tell me about the care your relative received towards their end of life?

Topic Areas to Be Covered (Prompts in brackets)

1. One area I would like to talk about is what services and support did your relative experience from the health care profession in their last year of life? (What, who, efficiency, sufficiency, any further needed)
2. Another area I wish to discuss is what services and support did you experience from the healthcare profession while caring for your relative in their last year of life? (What, who, efficiency, sufficiency, any further needed)
3. I would like to discuss the symptoms your relative experienced in their last year of life and how these symptoms were managed. (Sufficiency of information, staff knowledge and expertise, quality of symptom management, emergency contacts for symptom management)
4. Can you tell me about when and where your relative died and if you felt this was their preferred place to die. (why they died here, anything further could have been done to facilitate preferred place to die)
5. Can you tell me about what support you received after the death of your relative, if any, and how did you feel about this support?
6. Thinking about your experience caring for your relative, do you think there was any service or support that could have been provided that would have been beneficial for you or your relative?

Supplementary Table 2: Focus Group Topic Guide

1. To start, could anyone tell me about the palliative health care provision that is currently available for people with non- malignant respiratory disease and their carers, both specialist and generalist?
2. What do you feel would make for a high standard of pall care post discharge for these patients and carers?
3. Can you tell me how well generalist palliative care and specialist palliative care services are organized and resourced both in the hospital and community setting?
4. Can you tell me how effective are the lines of communication between the HCPs involved? (Especially between generalist palliative care and specialist palliative care)
5. Can you tell me how well generalist palliative care and specialist palliative care services are accessed by this client group both in the hospital and community setting?
6. How do you perceive patients and their carers understand of the meaning of palliative care?
7. What do you perceive as good palliative care?
8. What are the barriers and facilitators of good palliative care?
9. Any suggestions for improvement?
10. How do you feel good generalist palliative care compares with specialist palliative care?
11. How do you perceive the generalist palliative care and specialist palliative care services available to patients with a diagnosis of either bronchiectasis or interstitial lung disease (ILD) and their carers, compares to the services available to those with a diagnosis of COPD?
12. How do you perceive the generalist palliative care and specialist palliative care services available to NMRD patients and their carers in rural areas compares to the services available to those in urban areas?
13. Can you tell me about any Models of Palliative Care that are used at present to guide the provision of palliative care?
14. How do you perceive the role of the Healthcare Support Worker in delivering palliative care to patients at home?
15. Can you tell me how you perceive how generalist palliative care and specialist palliative care providers communicate with NMRD patients and their carers?
16. Can you tell me your perceptions about how the information needs of carers and patients are met?
17. Can you tell me about the barriers and facilitators in relation to communicating with patients and carers?
18. Can you tell me how you feel about how effective discussions around end-of-life and prognosis with patients and carers are?
19. What are the barriers involved in having these conversations?
20. Any suggestions for improvement?
21. How effective do you feel HCPs are at taking into consideration the wishes of the patient and their family?

Supplementary Table 3: Overarching and Interpretative Themes

Bereaved Carers' Interview Findings

Overarching Themes	Interpretative Themes
1. Lack of preparedness for death	1 (a) Uncertainty related to unpredictability of disease 1 (b) <i>"We were never told they were nearing the end of their life."</i>
2. Lack of consistency in palliative care delivery	2 (a) <i>"I would have liked them to have been more involved."</i> 2 (b) Generalist palliative care in Northern Ireland
3. Role Ambiguity	3 (a) Carer felt excluded from elements of the patients care 3 (b) HCPs depend on the carer

Healthcare Professionals' Focus Group Findings

Overarching Themes	Interpretative Themes
1. Barriers to providing appropriate palliative care	1 (a) Lack of prognostic certainty 1 (b) Lack of understanding of the role of palliative care in relation to patient with NMRD 1 (c) Lack of referral for specialist palliative care for other NMRDs 1 (d) Lack of services due to geographical location
2. The future direction of palliative care for patients with NMRD	2 (a) Who will provide palliative care 2 (b) <i>"You have to take the carers on board as well"</i>

