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Palliative care needs and integration of palliative care support in chronic obstructive pulmonary disease (COPD): a qualitative study

running head: integration of palliative care in COPD services

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Competing interests

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Abbreviations

COPD: chronic obstructive pulmonary disease

FEV1: forced expiratory volume in 1s

SD: standard deviation

MDT: multidisciplinary team meetings

Take Home Point

The goal of this study was to explore palliative care needs and integration of palliative care support in COPD services. The findings demonstrated that patients and their carers have unmet needs for managing uncertainty and fear, daily living and finances. This study also suggested that palliative care is integrated into COPD services although models of working vary in the UK. Health professionals emphasised the value of timely palliative care input. A theoretical model was developed from the interview data to illustrate the concept and pathway of the integration of palliative care support in COPD. To improve timely palliative care input, this study suggests that future research should focus on the development of reliable screening and needs assessment tools to address the significant needs of this population.

ACCEPTED VERSION

ABSTRACT

Background

The provision of palliative care for severe chronic obstructive pulmonary disease (COPD) remains low resulting in unmet needs in patients and carers.

Research Question

This study aimed to 1) explore palliative care needs of patients living with severe COPD and their caregivers, 2) understand views of accessing and providing palliative care and factors influencing these experiences, and 3) explore to what extent palliative care and COPD services have been integrated.

Study Design and Methods

A multicentre qualitative study was undertaken in COPD services and specialist palliative care in the UK, involving patients with severe COPD, their carers and health professionals. Data were collected using semi-structured interviews and analysed using framework analysis. Themes were integrated using the constant comparison process, enabling systematic data synthesis.

Results

Four themes were generated from interviews with 20 patients, six carers and 25 health professionals: management of exacerbations, palliative care needs, access to palliative care and pathways, and integration of palliative care support. Uncertainty and fear were common in patients and carers, with identified needs for reassurance, rapid medical access, home care and finance advice. Timely palliative care was perceived as important by health professionals. Palliative care was integrated into COPD services although models of working varied across regions. Reliable screening tools and needs assessment, embedded psychological care and enhanced training in palliative care and communication skills were perceived important by health professionals for timely palliative care referrals and optimised management.

Interpretation

Palliative care is increasingly being implemented for non malignant diseases including COPD throughout the UK although models of working vary. A theoretical model is developed to illustrate the concept and pathway of the integration of palliative care support. A standardised screening and needs assessment tool is required to improve timely palliative care and address the significant needs of this population.

BACKGROUND

Chronic obstructive pulmonary disease (COPD) is a life-limiting disease ¹. In the UK, COPD is a leading contributor to mortality causing 30,000 deaths per annum with more than 90% over age 65 ². Symptoms are progressive contributing to high morbidity and mortality ³. The gradual decline in patients' independence and emotional wellbeing places a growing reliance on their families and caregivers ⁴.

Limited pharmacological interventions for COPD have modest effects on airflow limitation and no effect on survival ⁵. Non-pharmacological and person centred treatments are required for patients who suffer from panic, dyspnoea and anxiety ⁶⁻⁸. Both national and international clinical practice guidelines have recommended palliative care for people with end-stage COPD and their families focusing on symptom management and maintaining quality of life ^{1,9}. Different models of palliative care services are emerging for COPD patients, including integrated services, short-term palliative care and outpatient services ¹⁰. A set of palliative approaches has proved beneficial including pulmonary rehabilitation ¹¹, improving patients' breathlessness and psychosocial wellbeing ¹². However, research suggests that patients with COPD still have limited access to palliative care ¹³⁻¹⁵. Compared with lung cancer, patients with severe COPD received less palliative support ¹⁵⁻¹⁷ due to the difficulty in predicting prognosis and barriers to referral and adherence to services ^{18,19}. These issues can lead to poor palliative care input in terms of frequency and quality, and consequently, unmet needs and dissatisfaction in patients and carers ^{20,21}.

Responding to patients' unmet needs require proactive identification, assessment, and individualised management plans. Several tools have been recommended for chronic conditions and palliative care ^{22,23}. For example, the Sheffield Profile for Assessment and Referral to Care (SPARC) ²⁴ and Holistic Common Assessment (HCA) tool ²³. However, these tools are not disease sensitive and designed to identify general needs regardless of diagnosis or disease stage. It may also be ineffective to apply such tools in a mechanical and service driven manner, without understanding the context of individuals' needs. The aim of this study was to 1) explore palliative care needs of patients living with severe COPD and their caregivers, 2) understand views of accessing and providing palliative care and factors influencing these experiences, and 3) explore to what extent palliative care and COPD services have been integrated.

METHODS

Ethics

Ethical approval was granted by the Health Research Authority in the UK (19/YH/0358; 19/NW/0623). Data were collected with the written informed consent of participants.

Study design

A multicentre qualitative study was undertaken involving two primary and two secondary COPD services and two specialist palliative care settings in Northern England and Northern Scotland.

Participants and Data collection

Purposive sampling^{25,26}, a nonprobability sampling method for identification and selection of information-rich cases, was used to identify individuals who were knowledgeable about and/or experienced with COPD services and specialist palliative care. This enabled a maximum variation in their experience and an understanding of patients' referral pathways to palliative care. Participants were patients who were receiving palliative care services and those who were considered eligible for the service predominantly due to their COPD severity, caregivers of patients who participated in this study and health professionals connected to COPD and/palliative care services. Eligibility criteria are presented in Table 1. Data saturation guided the sample size²⁷.

[insert Table 1]

Qualitative data were collected using semi-structured individual interviews and focus groups for pragmatic considerations to reduce refusals or withdrawals, as participants could choose the method that was convenient for them²⁸. Topic guides were developed specifically for each group and reviewed by a respiratory consultant. Topics included disease symptoms, service provision, experiences and management of exacerbations, and understanding/experience of palliative care. With patients and caregivers, the acceptance of palliative care and influencing factors were also explored. With health professionals, referral pathways, service provision and integrated palliative care support were discussed in relation to their routine practice for patients with COPD. Interviews were carried out by local researchers. Interviews were digitally recorded and transcribed verbatim for analysis.

Data analysis

Framework analysis^{29,30} was applied to analyse the data and synthesise themes. Initial line-by-line coding was carried out in each data set. An analytical framework evolved as the coding process progressed and themes emerged. A framework matrix was also generated summarising the data by category and theme from each transcript. The connections and relationships of these codes were explored across three datasets, contributing to the development of themes. Themes were compared and reorganised using the constant comparison process through the review of data across the matrix. On completion, themes from each data set were compared and integrated enabling the interpretation of the study data as a whole. NVivo 12 software was used to analyse the data³¹.

Two authors contributed to coding, developing frameworks and themes to ensure consistency and trustworthiness in the interpretation of the data, and regularly discussed these with the wider research team for peer debriefing.

RESULTS

Out of 54 individuals invited, 51 participants (94.4%) were interviewed (20 patients, six carers and 25 health professionals). Three patients (5.6%) initially agreed to the participation but declined due to their unpredicted exacerbations. A total of 39 individual interviews (16 patients, two carers and 16 health professionals) and six mini focus groups (four with patient-carer pairs and two with health professionals working at the same setting) were undertaken. Patients ranged in age from 65 to 88 years (mean 76.15), and were White British and retired, with the majority being Christian (95.0%), having a secondary school education (80.0%) and living alone (75.0%). Five carers were patients' spouses and one daughter, with an average of 5.33 years of caring. One carer worked in full-time employment while others were retired. Health professionals had a mixture of specialities and roles across primary care, hospitals and palliative care. More than two thirds (68.0%) had received training in palliative care although only a third worked directly in specialist palliative care settings. Characteristics of participants are presented in Tables 2 and 3.

[insert table 2]

[insert table 3]

The interview data generated four themes: management of exacerbations, palliative care needs, access to palliative care and pathways, and Integration of palliative care with standard care. All needs identified were mapped onto the themes presented in Table 4. More interview quotations supporting each theme are presented in Supplementary 1.

[insert table 4]

Management of exacerbations

Exacerbations were described as traumatic by patients and carers. Extreme shortness of breath, low oxygen levels and wheezing more than usual were reported. Health professionals highlighted other triggers including infection, anxiety, and comorbidities. All participants agreed that measures to limit exacerbations were important. These included self-management and monitoring, immediate crisis responses and supportive and education care post exacerbation and were facilitated by person centred approaches and frequent home visits. There was an increase in providing smoking cessation and pulmonary rehabilitation, mainly in primary care, however, challenges to uptake and completion were articulated by health professionals.

Actions were taken by patients, recommended by health professionals or from personal experiences to manage exacerbations, such as applying breathing exercises, taking rescue medications and contacting health professionals and emergency services. Although managing exacerbations at home was preferred, most patients and carers faced difficulties in making timely decisions about taking medications and/or requesting home visits. Making decisions without sufficient support especially during out of GPs' working hours often frustrated patients and carers, resulting in delayed responses, unavoidable ambulance use and hospital readmissions.

It was her stats, her oxygen levels were all over the place. Every time she went in it was 999 and one occasion it was the helicopter. It was a rush job. [H.CO2, carer]

Honest conversations on prognosis were considered necessary by health professionals to help manage expectations. This could occur in hospital followed through by the primary team. For example, a poor prognosis letter issued by the hospital in Northern Scotland was used to alert GPs to the severe status of patients. Patients could feel exhausted and more anxious about dying after an acute exacerbation. Such experiences could shift patients' priorities. This was evident among patients who had received specialist palliative care input. Despite changes in patients' preferences, updating and sharing information in practice was inefficient.

Needs for palliative care

The term "palliative care" was considered a major barrier to palliative care conversations. Most of the patients and some health professionals held the traditional belief that palliative care only applied for cancer. Patients reported a range of unmet needs including managing fear, distress, frequent monitoring and reassurance, home based services, and support on daily living and finance. Carers were concerned about their capacity to care affected by their own health conditions, level of knowledge and skills, and relationships and communications with health professionals. Innovative services were described by health professionals varied across countries, such as a virtual ward and hospice "bootcamp". However, a lack of embedded specialist staff addressing psychological needs was reported in primary and secondary care. Health professionals acknowledged limited awareness of information and resources for financial support and home adaptations and home care.

I think the psychological side is a real struggle. I often don't know what to do. [L.HP09, hospital consultant]

Health professionals were unclear as to when to discuss palliative care and had concerns about balancing hope with pragmatism due to the unpredicted prognosis and inadequate guidance. This led to hesitation, lack of confidence and the risk of fragmented care. Conversely, experienced health

professionals were creative in their approaches to exploring patients' future needs. Health professionals with long standing relationships and providing frequent contact were considered best situated for a timely discussion on palliative care. For specialist palliative health professionals, having good understandings of incurable illnesses targeted therapies and clinical pathways in primary and secondary settings were perceived as necessary to inform the holistic management plan.

Health professionals shared multiple ways to assess disease severity and health needs, such as the COPD assessment tool (CAT) score, Medical Research Council (MRC) scale and the frequency of exacerbations, facilitated by observations, judgements and relationships with patients and families. However, there was no systematic approach to assess and address their palliative care needs. Besides, health professionals expressed preferences for early identification, effective communications, holistic needs assessment, and individualised management plans to be implemented in routine practice.

Often the best palliative care is not provided because there isn't that step back and that holistic assessment in a timely fashion. [H.HP08, hospice consultant]

Access and pathways

Palliative care referrals were mainly based on patients' symptoms and their responses to treatments, often through multidisciplinary team meetings (MDTs) involving primary care, respiratory and palliative care services. Patients expressed feelings of uncertainty and fear about palliative care, which health professionals responded to by providing relevant information and offering taster sessions in hospices. Improvements in raising awareness and referral volume within hospital and community respiratory services were reported. Most of the patients under specialist palliative care services (hospice) seemed satisfied with their experience and health outcomes where they were offered a range of activities and self-management skills supported by a range of expertise including physiotherapists, complementary therapists, and occupational therapists. For some patients, this experience altered their views on death and dying, and enabled them to plan for the future. Others gained their confidence to manage their symptoms at home.

I've got my insurance sorted so the family don't pay for the funeral, but I would definitely, definitely want to be in a hospice, if it was possible. [L.P04, patient]

Barriers to uptake included restricted mobility to manage the long distance, previous family experiences and the group format for learning and sharing.

Differentiating between specialist and generalist palliative care was problematic for health professionals, mainly due to lack of regular needs assessment on patients and knowledge on who was responsible for what services. Although patients and carers were satisfied with hospice services, the

absence of continuous assessment remained a barrier for health professionals to evaluate the referral appropriateness despite the increased volume of referrals to hospices.

From a specialist service, [the questions are]what are we actually offering and who is best to manage those acute exacerbations? [L.HP05, hospice consultant]

Assessment of patients' management ability and/or carers' capacity was also considered important by health professionals to enable the development of individual management plans, needs-based referrals and efficient use of resources.

Integration of palliative care

Integration of palliative care and standard COPD care was implemented in all localities and the degree of integration was perceived to have increased, but with varying degrees of success. The implementation of integrated services enabled two way communication. It facilitated palliative care referrals, but also enabled stable patients after short team palliative care input to continue standard care. In Northern England, the integration occurred through monthly MDT in a hospital with community healthcare and specialist palliative care, whereas in Northern Scotland COPD services served as a bridge between primary and secondary care. However, the capacity for addressing patients and carers' psychological and financial needs were reported limited in these integrated services. Health professionals with palliative care mindsets and well trained in palliative care delivery were perceived as facilitators to improve the quality of integrated palliative care support. Factors influencing the integration of palliative care are summarised in Table 5.

[insert table 5]

The shared understanding of the term integration was limited among health professionals and responses were symptomatic of the complexity of this concept. Many health professionals in hospital perceived palliative care as a speciality to improve symptom control and quality of life rather than a process to support dying. To this extent, they recognised that all interventions provided were palliative in nature. Where integrated services had developed health professionals positively commented on improved knowledge exchange, team collaborations, peer support, shared decision making and reduction of unplanned health care utilisation. Whereas the change of work patterns could also result in less integration and creation of barriers to using the strengths of MDT effectively in some locations.

The combined integrated working with the Palliative MDT has helped enormously... we're more aware of each other's roles and how that works in together. [L.HP11, respiratory nurse specialist]

Other areas use the structure as an excuse not to do that. It's like it's a barrier of reasons why not to ... it's a kind of 'can't do' culture [H.HP01, respiratory advanced nurse practitioner]

Information sharing, staffing and workload were consistently considered as barriers to effective integration across settings. A shared IT system which highlighted the status of severe COPD was considered necessary to facilitate effective communications. Lack of time and being short of staff also limited people's involvement in MDT and professional development.

I think one of the worst hurdles for us is staffing, the gaps in posts and recruitment. [H.SM01, district nurse lead]

DISCUSSION

This study explored the palliative care needs of patients with severe COPD, their carers and health professionals across primary and secondary care, and across disciplines and sectors in regions of two countries. The integration of palliative care and COPD services is increasingly implemented across sites yet there are unmet needs in patients and carers in managing uncertainty and fear, decision making, daily living and finance. Timely but holistic palliative approaches are needed in practice.

A theoretical model was developed from the interview data in this study, based on the framework proposed by Maddocks, Lovell, Booth, Man, Higginson³². It consists of three phases (identification, needs assessment and management optimisation) illustrating the integration of palliative care support (Figure 1). Although it is presented as a linear process, it needs to be interpreted in practice together with the disease and palliative care trajectory and factors identified in Table 5. COPD patients can be offered a range of standard services using a pragmatic approach, but patients' fluctuating health and motivation largely impact on the uptake and completion³³. Initiatives reported from this study address such barriers and target monitoring, home-based services and fast access to medical care. However, it is worth noting that the reach of these initiatives varies by service structure and availability in different geographical regions. There are also measures to assess the severity and predict prognosis, but the reliability and clinical evidence of these tools remain in doubt. Instead, MDT is often used as a vehicle for early palliative care referrals. However early advance care planning and effective communication are found to be challenging, especially when balancing hope and pragmatism. The lack of holistic needs assessment and the limited understandings on specialist and generalist palliative care provision also hinder the development of the needs-based management plan for patients and carers. A further step is still needed to optimise management plans integrating expertise and resources of specialist and generalist palliative.

[insert Figure 1]

Many guidelines recommend early palliative care for patients with non-malignant respiratory disease^{1,34-36}, however there are neither standard definition nor recommended structures for the integration of palliative care in respiratory services. In the UK, different integrated palliative care models have been piloted in practice¹², focusing on adopting an holistic approach combining pharmacological and non-pharmacological interventions delivered by multiple specialities and disciplines. For example, patients referred to the London Breathless Support Service and Cambridge Breathlessness Intervention Service have reported high satisfaction³⁷ and a positive impact on their emotional health³⁸. This is reflected in this study with patients expressing increased confidence after receiving palliative care services.

COPD is more prevalent in females than males in many developed countries because of gender differences in susceptibility and underlying mechanisms³⁹. This difference is also reflected in this study sample. Not only do females suffer more severe COPD with early onset disease⁴⁰, but also a higher risk of hospitalisation and mortality from respiratory failure and comorbidities⁴¹. Evidence has also suggested that being female had a significant association with palliative care support¹⁵. Despite gender differences, there are no consistent differences in COPD treatment provided or differences in their responses to the treatment⁴². Future studies may be useful to explore gender-associated difference in palliative care outcomes in COPD.

Similar to other studies^{43,44}, patients reported experiencing distress and fear. A high level of frustration and anxiety was also reported by carers in this study, not only associated with their own health conditions but also making care decisions without adequate support. There is a consistent lack of specialist psychological care as part of the respiratory team resulting in unmet needs and fragmented care, which is in line with the significant need for psychosocial and existential support highlighted in a meta-synthesis on the experience of advanced COPD²¹. Previous research has revealed that non-pharmacological interventions such as psychological strategies and cognitive behavioural techniques may yield a small (less than the minimal important difference⁴⁵) impact on patients anxiety and depression⁴⁶⁻⁴⁸. Patients in this study who were offered psychological and educational interventions in hospices expressed an encouraging shift in confidence in managing their needs. Future research with rigorous study design is warranted to determine the effective elements and establish direct efficacy on patient reported outcomes, as well as the best model to integrate psychological care within existing services, with attention and support to addressing home care and financial needs.

This study provides evidence that a palliative approach can be integrated into COPD services specifically, although models of integrated working vary. A concept is also emerging that treatment and services provided for incurable progressive diseases such as COPD are regarded as palliative in nature. However, pathways and care delivery model for generalist palliative care are less clear. Previous literature has also suggested a lack of structure for advance care planning and palliative care provision in the context of COPD management ⁴⁹. Further research is needed to evaluate these initiatives and models to identify scope to strengthen the integration of palliative care support and improve early palliative care access. This study has also identified a list of factors suggesting that successful integration is related to both service implementation and acceptance by service users based on a shared understanding of palliative care. This highlights the importance of raising public awareness and patients' understanding to improve the acceptability and value of early palliative care. Further work is required to develop reliable identification tools and needs assessment to promote needs-based palliative services, with training, support and guidance for health professionals in communication skills and building trusting relationships with patients and carers.

Strengths and limitations

This study provided a comprehensive view of palliative care needs for severe COPD. The combination of interview data elaborated and enhanced the rigour in data analysis. The constant comparison process that compared and integrated similar, dissimilar and complementary data was applied to address the potential risk of having disparate views from individual interviews and focus groups. Although qualitative research, in general, lacks statistical-probability generalisation, this study reached naturalistic generalisability ⁵⁰ by analysing similarities and differences in perceptions of multi-stakeholders as well as providing participants' characteristics, interview quotations and layered theoretical model, helping the wider population make connections to their own experience and needs.

All study participants recruited were White British which may not reflect the experiences of those from minority ethnic communities, future work is needed to capture their views. Participants were sampled from two services which may not reflect the integration of palliative care in other COPD services across the UK. Also, patients' presence and severity of comorbidities were not systematically collected that may impact on their palliative care needs and the degree of integrated support. However only patients with severe COPD were recruited whose needs were reported consistently in this study. Future work can be undertaken to investigate what and how comorbidities may impact on patients' needs and health professionals' support. Although the sample size for carers was small, all carers who met the criteria were successfully recruited and their needs are consistently reported. This may also reflect the reality that many older patients with COPD live alone facing challenges. There is

a need for future studies to identify the diversity of needs and predict needs across disease stages and to develop effective interventions targeting their needs.

INTERPRETATION

Patients with severe COPD and their carers have unmet needs for managing uncertainty and fear, daily living and finances, although palliative care is being increasingly integrated and implemented for non malignant diseases including COPD throughout the UK. A standardised screening and needs assessment tool is required to achieve early palliative care and address the identified needs of this population.

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References

1. GOLD. Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease. 2018; <https://goldcopd.org/wp-content/uploads/2018/02/WMS-GOLD-2018-Feb-Final-to-print-v2.pdf>. Accessed 1st Aug, 2018.
2. British Lung Foundation. Chronic obstructive pulmonary disease (COPD) statistics. 2016; <https://statistics.blf.org.uk/copdg>. Accessed 5th Aug, 2019.
3. Franssen FME, Rochester CL. Comorbidities in patients with COPD and pulmonary rehabilitation: do they matter? *European Respiratory Review*. 2014;23(131):131.
4. Halpin DMG. Palliative care for people with COPD: effective but underused. *European Respiratory Journal*. 2018;51(2):1702645.
5. Calverley PM, Anderson JA, Celli B, et al. Salmeterol and fluticasone propionate and survival in chronic obstructive pulmonary disease. *New England Journal of Medicine*. 2007;356(8):775-789.
6. Halldórsdóttir BS, Svavarsdóttir EK. Purposeful Therapeutic Conversations: Are they effective for families of individuals with COPD: A quasi-experimental study. *Vård i Norden*. 2012;32(1):48-51.
7. Momen N, Hadfield P, Kuhn I, Smith E, Barclay S. Discussing an uncertain future: end-of-life care conversations in chronic obstructive pulmonary disease. A systematic literature review and narrative synthesis. *Thorax*. 2012;67(9):777-780.
8. Wilson DM, Ross C, Goodridge D, Davis P, Landreville A, Roebuck K. The care needs of community-dwelling seniors suffering from advanced chronic obstructive pulmonary disease. *Canadian Journal on Aging/La Revue canadienne du vieillissement*. 2008;27(4):347-357.
9. NICE. Chronic obstructive pulmonary disease in over 16s: diagnosis and management (NG115). 2018. Accessed 2nd Aug, 2019.
10. Cherny NI, Fallon M, Kaasa S, Portenoy RK, Currow D. *Oxford textbook of palliative medicine*. Oxford University Press, USA; 2015.
11. McCarthy B, Casey D, Devane D, Murphy K, Murphy E, Lacasse Y. Pulmonary rehabilitation for chronic obstructive pulmonary disease. *Cochrane database of systematic reviews*. 2015(2).
12. Brighton LJ, Miller S, Farquhar M, et al. Holistic services for people with advanced disease and chronic breathlessness: a systematic review and meta-analysis. *Thorax*. 2019;74(3):270-281.
13. Goodridge D, Lawson J, Duggleby W, Marciniuk D, Rennie D, Stang M. Health care utilization of patients with chronic obstructive pulmonary disease and lung cancer in the last 12 months of life. *Respiratory medicine*. 2008;102(6):885-891.
14. Rush B, Hertz P, Bond A, McDermid RC, Celi LA. Use of palliative care in patients with end-stage COPD and receiving home oxygen: national trends and barriers to care in the United States. *Chest*. 2017;151(1):41-46.
15. Bloom CI, Slaich B, Morales DR, Smeeth L, Stone P, Quint JK. Low uptake of palliative care for COPD patients within primary care in the UK. *European Respiratory Journal*. 2018;51(2).
16. Bausewein C, Booth S, Gysels M, Kühnbach R, Haberland B, Higginson IJ. Understanding breathlessness: cross-sectional comparison of symptom burden and palliative care needs in chronic obstructive pulmonary disease and cancer. *Journal of palliative medicine*. 2010;13(9):1109-1118.

17. Butler SJ, Ellerton L, Gershon AS, Goldstein RS, Brooks D. Comparison of end-of-life care in people with chronic obstructive pulmonary disease or lung cancer: A systematic review. *Palliative Medicine*. 2020:0269216320929556.
18. Almagro P, Yun S, Sangil A, et al. Palliative care and prognosis in COPD: a systematic review with a validation cohort. *International journal of chronic obstructive pulmonary disease*. 2017;12:1721.
19. Coventry PA, Grande GE, Richards DA, Todd CJ. Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review. *Age and Ageing*. 2005;34(3):218-227.
20. Gardiner C, Gott M, Payne S, et al. Exploring the care needs of patients with advanced COPD: an overview of the literature. *Respiratory medicine*. 2010;104(2):159-165.
21. Disler RT, Green A, Lockett T, et al. Experience of advanced chronic obstructive pulmonary disease: metasynthesis of qualitative research. *Journal of pain and symptom management*. 2014;48(6):1182-1199.
22. NICE. NICE guideline: supportive and palliative care draft scope for consultation 31 December 2015–January 2016. 2015; <https://www.nice.org.uk/guidance/ng142/documents/draft-scope-2>. Accessed 27th April, 2020.
23. NHS National End of Life Care Programme. *Holistic Common Assessment of Supportive and Palliative Care Needs for Adults Requiring End of Life Care*. Leeds: NHS and National Cancer Action 2010.
24. Ahmed N, Hughes P, Winslow M, Bath P, Collins K, Noble B. Feasibility study of the sheffield profile for assessment and referral for care. *BMJ Supportive & Palliative Care*. 2012;2(Suppl 1):A43.
25. Patton MQ. *Qualitative research & evaluation methods: Integrating theory and practice*. Sage publications; 2014.
26. Boddy CR. Sample size for qualitative research. *Qualitative Market Research: An International Journal*. 2016.
27. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field methods*. 2006;18(1):59-82.
28. Lambert SD, Loiselle CG. Combining individual interviews and focus groups to enhance data richness. *Journal of advanced nursing*. 2008;62(2):228-237.
29. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC medical research methodology*. 2013;13(1):117.
30. Ritchie J, Lewis J, Nicholls CM, Ormston R. *Qualitative research practice: A guide for social science students and researchers*. sage; 2013.
31. QSR International Pty Ltd. *Nvivo (Version 12)*. <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home2018>.
32. Maddocks M, Lovell N, Booth S, Man WDC, Higginson IJ. Palliative care and management of troublesome symptoms for people with chronic obstructive pulmonary disease. *The Lancet*. 2017;390(10098):988-1002.
33. Steiner MC, Lowe D, Beckford K, et al. Socioeconomic deprivation and the outcome of pulmonary rehabilitation in England and Wales. *Thorax*. 2017;72(6):530-537.

34. Lanken PN, Terry PB, DeLisser HM, et al. 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*. 2008;177(8):912-927.
35. Spruit MA, Singh SJ, Garvey C, et al. An official American Thoracic Society/European Respiratory Society statement: key concepts and advances in pulmonary rehabilitation. *American journal of respiratory and critical care medicine*. 2013;188(8):e13-e64.
36. Yang IA, Brown JL, George J, et al. COPD-X Australian and New Zealand guidelines for the diagnosis and management of chronic obstructive pulmonary disease: 2017 update. *Medical Journal of Australia*. 2017;207(10):436-442.
37. Reilly CC, Bausewein C, Pannell C, Moxham J, Jolley CJ, Higginson IJ. Patients' experiences of a new integrated breathlessness support service for patients with refractory breathlessness: results of a postal survey. *Palliative medicine*. 2016;30(3):313-322.
38. Farquhar MC, Prevost AT, McCrone P, et al. The clinical and cost effectiveness of a Breathlessness Intervention Service for patients with advanced non-malignant disease and their informal carers: mixed findings of a mixed method randomised controlled trial. *Trials*. 2016;17(1):185.
39. Barnes PJ. Sex differences in chronic obstructive pulmonary disease mechanisms. American Thoracic Society; 2016.
40. Sørheim I-C, Johannessen A, Gulsvik A, Bakke PS, Silverman EK, DeMeo DL. Gender differences in COPD: are women more susceptible to smoking effects than men? *Thorax*. 2010;65(6):480-485.
41. Prescott E, Bjerg AM, Andersen PK, Lange P, Vestbo J. Gender difference in smoking effects on lung function and risk of hospitalization for COPD: results from a Danish longitudinal population study. *European Respiratory Journal*. 1997;10(4):822-827.
42. Robles PG, Brooks D, Goldstein R, Salbach N, Mathur S. Gender-associated differences in pulmonary rehabilitation outcomes in people with chronic obstructive pulmonary disease: a systematic review. *Journal of cardiopulmonary rehabilitation and prevention*. 2014;34(2):87-97.
43. Halpin D, Hyland M, Blake S, et al. Understanding fear and anxiety in patients at the time of an exacerbation of chronic obstructive pulmonary disease: a qualitative study. *JRSM open*. 2015;6(12):2054270415614543.
44. Janssen DJ, Spruit MA, Leue C, et al. Symptoms of anxiety and depression in COPD patients entering pulmonary rehabilitation. *Chronic respiratory disease*. 2010;7(3):147-157.
45. Puhan MA, Frey M, Büchi S, Schünemann HJ. The minimal important difference of the hospital anxiety and depression scale in patients with chronic obstructive pulmonary disease. *Health Qual Life Outcomes*. 2008;6:46-46.
46. Ma R-C, Yin Y-Y, Wang Y-Q, Liu X, Xie J. Effectiveness of cognitive behavioural therapy for chronic obstructive pulmonary disease patients: A systematic review and meta-analysis. *Complementary Therapies in Clinical Practice*. 2020;38:101071.
47. Baraniak A, Sheffield D. The efficacy of psychologically based interventions to improve anxiety, depression and quality of life in COPD: A systematic review and meta-analysis. *Patient Education and Counseling*. 2011;83(1):29-36.

48. Smith SM, Sonogo S, Ketcheson L, Larson JL. A review of the effectiveness of psychological interventions used for anxiety and depression in chronic obstructive pulmonary disease. *BMJ Open Respir Res.* 2014;1(1):e000042.
49. Gott M, Gardiner C, Small N, et al. Barriers to advance care planning in chronic obstructive pulmonary disease. *Palliative medicine.* 2009;23(7):642.
50. Smith B. Generalizability in qualitative research: Misunderstandings, opportunities and recommendations for the sport and exercise sciences. *Qualitative research in sport, exercise and health.* 2018;10(1):137-149.

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Tables

Table 1 Eligibility for study participants

	Inclusion	Exclusion
Patients	<ul style="list-style-type: none">• aged 65 or over• severe COPD (one or more of the following)<ul style="list-style-type: none">- FEV1 (forced expiratory volume in 1s) \leq 30%- 2+ exacerbations in the last 12 months- long term oxygen therapy- non-invasive ventilation- have developed cor pulmonale- clinician's expectation of death in 12 months• cognitively intact*• able to communicate in English	<ul style="list-style-type: none">• living with or receiving treatment for cancer
Carers	<ul style="list-style-type: none">• aged 18 or over• identified by patients and health professionals• cognitively intact• able to communicate in English	none
Health professionals	<ul style="list-style-type: none">• delivering active treatment• providing palliative care for COPD• managing the service	none

*cognitively intact is screened by health professionals for having no diagnosis or treatment for cognitive impairment in the medical records.

Table 2: Characteristics of patients and carers (n=26)

Socio-demographic characteristics		N	%
Patients		20	
Age (mean (SD), range, year)		76.15 (6.57)	65-88
Gender			
	Male	6	30.0
	Female	14	70.0
Ethnicity			0.0
	White British	20	100.0
	Non-British	0	0.0
Education			
	University degree	2	10.0
	Further (Alevel or equivalent)	2	10.0
	Secondary (GCSE or equivalent)	16	80.0
	Primary degree	0	0.0
Religion			
	Christian	19	95.0
	Jewish	0	0.0
	Hindu	0	0.0
	Muslim	0	0.0
	No religion	1	5.0
Marital status			
	Married/living with a partner	5	25.0
	Separated/Divorced	6	30.0
	Widowed	9	45.0
	Single	0	0.0
Employment			
	Retired	20	100.0
	Part-time job	0	0.0
	Full-time job	0	0.0
	Self-employed	0	0.0
Carers		6	
Gender			
	Male	3	50.0
	Female	3	50.0
Years of caring (mean (SD), range)		5.33 (2.25)	3-9
Relationships with patients			
	Spouse	5	83.3
	Child	1	16.7
Frequency of caring			
	Daily	6	100.0
	Weekly	0	0.0
Employment status			
	Retired	5	83.3
	Part-time job	0	0.0
	Full-time job	1	16.7
	Self-employed	0	0.0

SD: standard deviation

Table 3: Health professionals' characteristics (n=25)

Characteristics	N	%
Years of working (mean (SD), range)	16.70 (7.39)	3-29
Area of service		
Palliative care	9	36.0
Hospital respiratory medicine	6	24.0
Community respiratory services	7	28.0
Primary care	2	8.0
others	1	4.0
Speciality		
Consultant	6	24.0
General practitioner	2	8.0
Nurse	10	40.0
Physiotherapist	2	8.0
Occupational therapist	2	8.0
Complementary therapist	1	4.0
Service manager	2	8.0
Employment		
Full-time	16	64.0
Part-time	9	36.0
Training in palliative care		
Yes	17	68.0
No	8	32.0

SD: standard deviation

Table 4: Domains of needs identified

Themes	Patients	Carers	Health professionals	Organisations
Management of exacerbations	Breathlessness; home based services; 24/7 access; reassurance; recognition of triggers; prevention strategies; self-management; post exacerbation support	Supported decision making; home based services; 24/7 access; reassurance; recognition of triggers; prevention strategies; Home care support	Treatment optimisation; early identification; recognition of triggers; prevention strategies; patients and carers education; monitoring; holistic management plan; reducing hospital readmission; patient/carer-professional relationships	Widening the reach of community services; information sharing
PC needs	Breathlessness; decline in function and independence; acceptance of “palliative care”; feeling uncertain and fear; anxiety and distress; home based services; reassurance; limited knowledge on palliative care; financial support;	Capacity to care; concerns of their health conditions; home care support; financial support	Reliable identification tools; holistic needs assessment; lead health professionals for PC conversations; tailored management plan; embedded psychological care; training and support on insensitive communication; patient/carer-professional relationships; patients and carers education;	Information recording and sharing on PC needs; MDT; integration of palliative care; different working models/formats of PC delivery
Access and pathways	Rapid access; lack of knowledge on service provision; fear of death and dying; long distance;	Lack of knowledge on service provision; fear of death and dying; communication with health professionals	Early referrals; needs based referrals; developing mindset and raising awareness; embedded psychological care; training and support on insensitive communication;	Integration of PC; different working models/formats of PC delivery; differentiating specialist and generalist PC; service evaluation
Integration of PC with COPD care	-	-	Collaborative working; knowledge exchange; limited understanding of the term; training and support in PC delivery; short of funds and staff;	Integrating with primary care; information sharing; exploring ways to enhance integration; holistic services; service evaluation

PC: palliative care; MDT: multidisciplinary team meetings

Table 5: Perceived factors influencing the degree of integrated palliative care support

Influencing factors	Integration of palliative care
Nature of disease	Fluctuating health; comorbidities; functioning decline; incurable but progressive nature; unpredictable trajectory
Users' (patients and carers) related	Uncertainty and fear; misconception of PC; engagement of PC conversations; rapid access of services
Health professionals' related	Understanding of PC; early identification of severe cases; holistic and person centred needs assessment; needs based referrals; MDT and collaborative working; recognition and appreciation of roles and skills across disciplines; capacity building in PC delivery and sensitive communication and interpersonal skills
Organisational related	Integrated psychological support; effective information sharing systems; models of integrated working; communication systems within and across teams; funds and resources

PC: palliative care

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Figure

Figure 1 Theoretical model illustrating integrated clinical pathways

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