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Palliative and Supportive Care Research Development

What are the attitudes and perceptions of patients with pulmonary fibrosis and their carers towards use of oxygen therapy?

Date 29/11/18

Review Methods

Search Strategy:
A systematic search was conducted across a wide-ranging set of databases: Ovid Medline, including In-Process & Other Non-Indexed Citations, Ovid Embase, Ebsco CINAHL Clarivate Analytics, Web of Science and Cochrane Library.
The preliminary search strategy was developed on Ovid Medline using both text words and Medical subject headings from January 2008 to October 2018 restricted to English language humans. The search strategy was modified to capture indexing systems of the other databases. (Search strategies available upon request).

In addition, electronic tables of content for the last two years were scanned in the following journals:

- BMC Pulmonary Medicine,
- BMJ open respiratory research
- European Respiratory Journal,
- The Lancet Respiratory Medicine
- Chest
- Respiratory Medicine
- Thorax

Reference lists of systematic reviews were checked for any relevant studies. The searches generated 153 citations after removing duplicates and irrelevant records. Figure 1 represents the flow of information through the different phases of the review.

Inclusion: Studies reporting perceptions or experiences of patients with pulmonary fibrosis and their carers. Only studies published in English language from 2008 to October 2018

Exclusion: Studies set in a non-Organization for Economic Cooperation and Development (OECD) countries; non-english language studies

Study selection/Quality Assesment/ Data Extraction:
Study selection was based upon a two-step selection process, that is, study selection on the title and abstract followed by full text of the articles assessed by one reviewer for eligibility according to inclusion criteria and checked by a second reviewer. Data extraction and quality assessment of the eligible studies was carried out by one reviewer and checked by another using appropriate quality assessment check-lists. Any discrepancies between the two reviewers were resolved by consensus or by discourse to a third reviewer.

Context

Idiopathic Pulmonary Fibrosis (IPF) is a common interstitial lung disease of unknown aetiology, usually occurring between 50-70 years of age. It is a progressive and ultimately fatal disease with a mean survival of less than 3 years from diagnosis. The majority of patients die from respiratory failure and have a high symptom burden. There are no curative treatments and so best supportive care and symptom palliation are mainstays of treatment for all patients.
As the disease advances, breathlessness becomes a major determinant of quality of life, and oxygen (O_2) desaturation contributes to exertional intolerance. However, there is limited data on the benefits of O_2 use in this patient group and anecdotal evidence suggests some patients are reluctant to instigate it. This can be a barrier to providing high quality supportive care. Given the incidence of IPF of 20-30/100,000 per year, better understanding of patient and carer perceptions of O_2 use in this context will have important implications for multidisciplinary practice in Wales in support of a sizable patient population. The purpose of this rapid review is therefore to understand key facilitators and barriers to the use of O_2 therapy from the perspective of patients with IPF and their carers.

Key Findings

The 7 studies included in this review identified widespread variation in the use of O_2 therapy among patients with IPF, but also the emergence of consistent themes with implications for practice.

Patients and carers uniformly perceived the introduction of O_2 therapy as a negative milestone in the illness trajectory with connotations of disease progression and loss of usual lifestyle. There was significant stigma associated with the use of O_2 therapy, particularly amongst patients, and for those not yet using O_2 the attitude was one of avoidance where possible.

There appeared to be a general lack of preparedness for the realities of O_2 use both in terms of practicalities of equipment use and psychological impact. There appeared to be significant gaps in education and instruction for patients and carers on O_2 use. For the vast majority their only education was received from the O_2 delivery person with few receiving instruction from a clinician.

Practical problems associated with equipment use were commonplace and added to the burden for carers who often assumed responsibility for the day to day practicalities, and adopted a heightened vigilance in the context of perceived deterioration. For those established on O_2, there was recognition of benefits in terms of symptoms (often other than breathlessness) and mobility, although very often O_2 use was associated with reduced ability to mobilise outside the home and a perception of reduced social functioning. In a randomised cross over trial of O_2 use, patients reported improvements in mobility and functioning both in patient reported outcome scores and in qualitative interviews, even though the majority were sedentary and there was no improvement in objectively measured step counts.

The findings have important implications for multidisciplinary team care prior to and following the introduction of supplemental O_2, particularly in relation to patient and carer preparedness and education, practicalities of equipment use and how to support this, and the particular needs of carers.

A. Reliability of evidence

Methods of data capture and analysis were generally well described. The studies were conducted across a wide range of diagnostic groups, utilised a variety of data capture methods and analysis techniques and generally used convenience sampling, all of which introduce risks of bias. For example use of convenience sampling and recruitment from single institutions risk bias in terms of background population and practice (e.g. Belkin 2013, Duck 2015, Khor 2017 and Visca 2018) as does the use of online survey techniques (Jacobs 2016).

Three studies were specifically in IPF patients and/or their carers (Belkin 2013, Duck 2015, Overgaard 2016), 3 studies were in a broader group of ILD patients (Graney 2017, Khor 2017, Visca 2018) and 1 study was in patients with a wide range of lung diseases (Jacobs 2016). Whilst four of the studies (Visca, Graney, Jacobs, Khor) specifically examined patient/IC perspectives on O_2 therapy, the remaining 3 studies (Belkin, Duck, Overgaard) looked more generally at patient/IC experience of living with IPF where some but not all, participants used supplemental O_2.

We cannot rule out the risk of publication bias, particularly where experience of O_2 use was captured within a study of broader patient and carer experience but which was not identifiable within our search strategy.

B. Consistency of evidence

Although there was significant heterogeneity in terms of diagnostic categories, methods of data capture and analysis, there was striking consistency in the themes that emerged across studies. As detailed above there was recurrent description of the negative connotations of O_2 use, lack or preparedness, loss of social functioning and the practical challenges of equipment use. In terms of positive impact there were consistent reports of improvements in symptoms and mobility. Consistently reported challenges for informal caregivers were the psychological concerns of disease progression and the assumption of added responsibilities for the day to day practicalities of equipment function and use.

C. Relevance of evidence

All but 2 of the studies were undertaken in non-UK settings including US, Scandinavia and Australia. The significant differences in healthcare organization and delivery could affect the external validity of some of the findings. However, it is notable that many of the emergent themes were replicated within the UK studies. It is likely therefore that the findings are relevant to UK population and practice.

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Evidence Implications:

Clinical:

ILD multidisciplinary teams should recognise the introduction of oxygen therapy as a highly significant milestone for IPF patients and their carers, and as a trigger for more intensive support around its introduction. Particular consideration should be given to preparing patients and caregivers in advance for the psychological impacts and practical challenges of use. Key domains to address include perceived stigma, perceived prognostic implications, loss of role and social functioning, and managing the practicalities of ambulatory oxygen use and equipment malfunction. Introduction of oxygen should be a trigger for considering the role of palliative care services in addressing some of these domains.

Policy:

The evidence presented suggests significant gaps in education for patients and carers on oxygen use, challenges in terms of cumbersome and heavy ambulatory equipment, and inconsistencies in support at times of equipment malfunction.

This evidence has important policy implications for the national introduction of consistent and comprehensive patient/caregiver needs assessment at the time of oxygen introduction by ILD MDTs.

It also implies the need for a more uniform approach to education provision and training for both patients and carers on oxygen use, with greater engagement by clinicians.

Given the palliative and supportive nature of the intervention to improve symptoms and quality of life, the cost-benefits of the use of lighter ambulatory equipment options should be considered for this patient group. There also needs to be a clear pathway described for patients and carers to access rapid support in the context of equipment malfunction.

Flow Diagram:

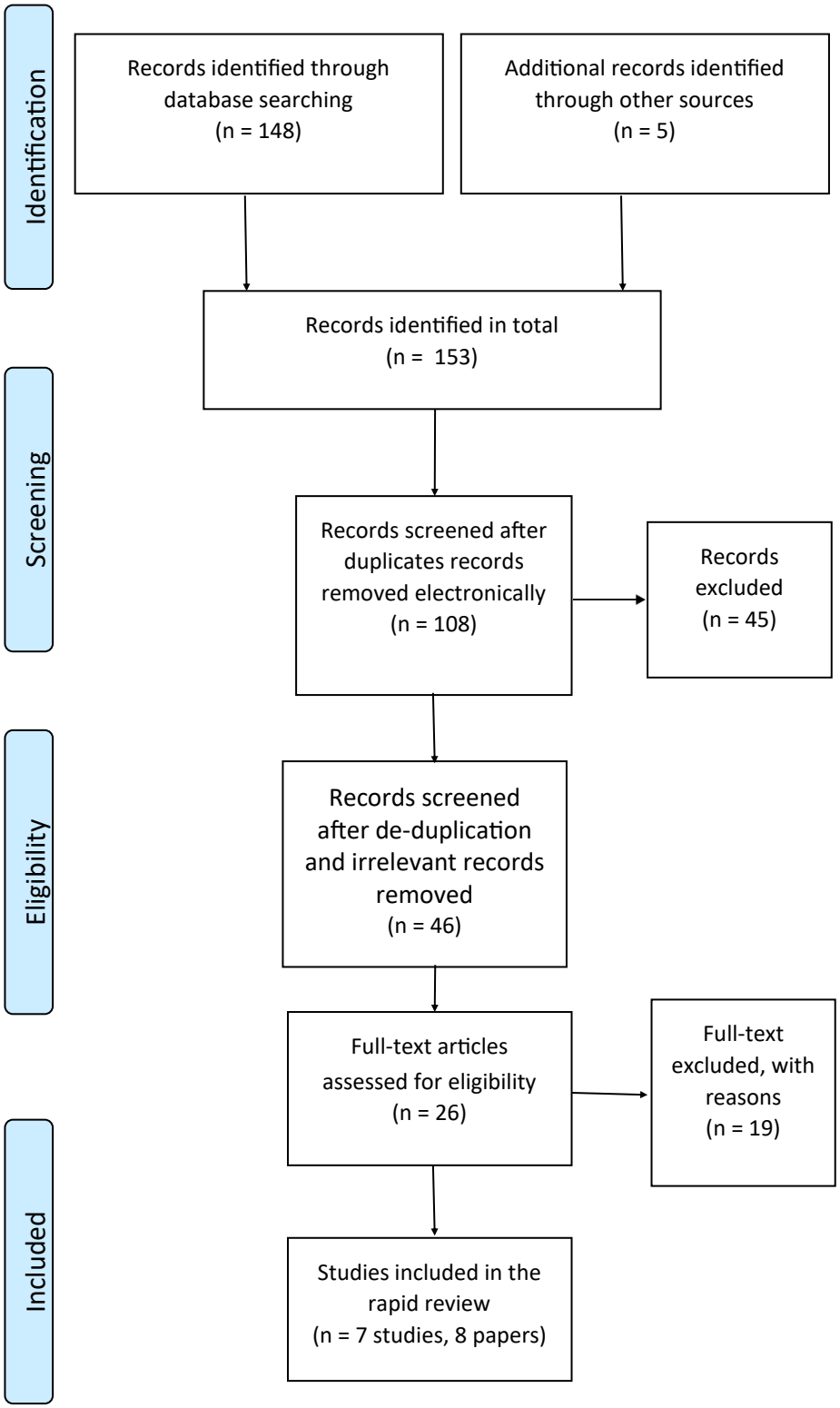

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Table 1: Characteristics of Included Studies

Belkin et al 2013	**Study Setting & Design** – Qualitative focus group study of Informal Carers (ICs) of IPF patients attending a single Interstitial Lung Disease Clinic in USA.
Objectives	The aim of this study was to capture informal caregivers' perspectives on how they are affected by having a loved one with IPF. Data were also collected on their perceptions of how IPF impacted their partners over the course of the disease.
Participants	Convenience sample of 14 ICs of patients with IPF participated. Age range 55-76; 13/14 were female. 10/14 IPF patients required oxygen 24/7. ICs were recruited via telephone or approached at the time of their partners clinic visit.
Intervention/ Comparator/ Methods	Semi-structured focus groups were conducted with 3 groups of 6, 5 and 3 ICs. Reflexive team approach using content analysis was used to analyse the transcripts.
Proposed Outcomes	To better understand the challenges of being an IC to a patient with IPF To understand how ICs perceive the impact of IPF on their patient-partners.
Summary of Results	Introduction of oxygen therapy was seen as a significant and burdensome shift in the disease trajectory. The ICs of patients who had not yet been prescribed oxygen viewed it forebodingly and, like their partners, as an unwelcome milestone of disease progression and a significant impediment to a carefree lifestyle (for themselves and their partners). They sought to avoid if possible as it represented disease progression, failure and stigma. The ICs of patients who were using oxygen agreed that it was 'enormously limiting' psychologically and physically and created significant burden for the caregiver in dealing with the practicalities of use. Supplemental oxygen had the effect of shrinking both patients' and ICs' worlds, thus validating the concerns of ICs whose loved ones had not yet been prescribed oxygen.
Appraisal Summary	This study used a convenience sample of caregivers at a single specialist clinic in a US setting with limited information on disease extent, although ten of the 14 patients were using oxygen therapy. The use of focus group interview approach may have created bias in the reporting of perceptions by more dominant group members, and the vast majority of the caregivers (13 of 14) were female so may not be representative of ICs of IPF in general population.

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Table 1: Characteristics of Included Studies

Duck et al 2015	**Study Setting & Design** – Qualitative interview study; regional respiratory and lung transplant centre in North West England
Objectives	To understand the perceptions, experiences and needs of patients with IPF
Participants	17 patients (median age 67 yrs, 12 receiving oxygen) with an MDT confirmed diagnosis of IPF with moderate to advanced severity; and 6 of their informal carers. 12/17 patients were using long term and/or ambulatory oxygen.
Intervention/ Comparator/ Methods	Semi-structured recorded and transcribed interviews of approximately 1 hour duration. Prior experience indicated that patients might want their main informal carer to be present during the interviews; this eventuality was therefore accommodated in study design and data collection. Data was collected in 2007 but there was a delay in analysis which wasn't completed until 2012.
Proposed Outcomes	To understand 'what it is like to live with IPF', 'how patients cope with it', and what their support needs are.
Summary of results	Main themes were 1) Struggling to get a diagnosis; 2) Loss of the life I previously had; 3) Living with IPF. 'Living with oxygen' was one of the sub-themes of 'Living with IPF'. 12/17 participants were using long-term oxygen therapy and/or ambulatory oxygen. Most participants said that oxygen helped their breathlessness and some felt it helped their cough. Despite being symbolic of deteriorating disease, most participants described how oxygen improved their confidence and enabled them to do the things they wanted. Learning to use oxygen helped participants to feel more in control of their lives. By contrast, however, being so dependent on oxygen meant that there was the constant worry that it would run out, and participants needed to calculate how long they could be out of the house.
Appraisal Summary	The sample size is small and from a single centre. Oxygen therapy was a sub-theme, only 12/17 patients were using oxygen, perceptions of 'most' of these 12 patients were described, but full data on all the patients is not presented.

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Table 1: Characteristics of Included Studies

2 x Graney et al papers Both 2017	**Study Setting & Design** – Qualitative studies using telephone interviews, embedded in a larger observational study of oxygen use across the US.
Objectives	1)To better understand the perceptions and experiences of patients with pulmonary fibrosis as they confronted the possibility and realities of using supplemental oxygen; 2)To understand the multiple effects of supplemental oxygen therapy on informal carers (ICs)
Participants	1) 5 patients with PF (3 females and 2 males, age range 64-94). It is not clear where these patients were from as recruitment was from across the US using a variety of methods. 2) 20 ICs of patients with PF who were using oxygen for at least 8 months recruited from either the Interstitial Lung Disease Clinic at National Jewish Health (NJH) or using an online strategy through the Participation Program for Pulmonary Fibrosis website
Intervention/ Comparator/ Methods	Serial, structured telephone interviews: 1) Longitudinal arm: the 5 patients were enrolled in a longitudinal arm with structured telephone interviews at four time points: 1) enrolment; 2) 7-10 days prior to initiation of oxygen; 3) one month after initiation of oxygen; and 4) 9-12 months after initiation of oxygen. 2) Single semi-structured telephone interviews were conducted with ICs
Proposed Outcomes	1) Thematic data before and after oxygen therapy to better understand patients experiences of using supplemental oxygen 2) Thematic data to understand the multiple effects of supplemental oxygen therapy on ICs of patients with PF.
Summary of Results	Prior to starting supplemental oxygen, participants uniformly expected it would improve their physical function and quality of life. They also expected practical and psychological limitations, which after starting oxygen, they found to be more pronounced than anticipated. Despite the challenges, participants attributed benefits in symptoms, confidence and mobility to oxygen and came to a reluctant acceptance of it. Their expectations for guidance and support were inadequately met. ICs initially reacted to oxygen with trepidation and sadness as they came to recognize the changes it would cause in the lives of their patient-loved one (PLO). ICs recognized both beneficial (e.g. more active) and negative (tethered) effects of oxygen on their PLOs. ICs also realized that oxygen created significant changes in their own lives, including introducing new responsibilities for them (e.g. filling/carrying tanks), altering their home environments and significantly impacting their relationships with their PLOs (e.g. spontaneity no longer an option, going out was an "expedition"). Although oxygen was a tangible and constant reminder of disease progression, over time ICs were able to adapt and accept their new lives with oxygen.
Appraisal summary	The longitudinal aspect allows examination firstly of patients perceptions and then actual experience of oxygen therapy over time. However, patient sample size is small considering the recruitment strategy from across the US, furthermore, structured telephone interviews may limit responses.

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Jacobs et al 2016	**Study Setting & Design** – Qualitative online questionnaire survey of a convenience sample of adults from across the USA
Objectives	To seek perspectives of oxygen users on the frequency and types of problems experienced by supplemental oxygen use.
Participants	Adults prescribed oxygen as a consequence of lung disease. 1,926 survey respondents from suburban areas across the USA, age 64 ± 11 yrs. 72% female; Duration of oxygen use: <1yr 17%; 1-5yr 51%; >5yr 32%; COPD (39%) and ILD (27%) were the most common diagnoses.
Intervention/ Comparator/ Methods	The American Thoracic Society (ATS) Public Advisory Roundtable website posted the survey link from 1 Sep 2016 to 24 Oct 2016. Pulmonary organizations placed the link on their websites also. Clinicians provided flyers about the survey in their clinics, pulmonary rehabilitation (PR) programs, and support groups. Items were generated by an ATS working group including multi-professional clinicians, patients and advocacy representatives. The survey was pilot tested on oxygen users. The web-based Checklist for Reporting Results of Internet E-Surveys (CHERRIES) and E-Survey guidelines directed the methodology for this analysis with a descriptive report generated.
Proposed Outcomes	To understand the perspective of oxygen users on the frequency and type of problems encountered.
Summary of results	The survey was not specific to those with IPF, although 51% of IPF users reported problems. Overall predominant areas of concern related to education, equipment and mobility, and there were no significant differences across diagnostic groups in the nature of the problems encountered, although the frequency of issues did differ. **Education**: Approximately two thirds of overall participants received their only education on supplemental oxygen use from the delivery person. Only 8% received instruction from a clinician and 10% received no instruction of any type. **Equipment**: 80% respondents used a portable system outside the home. The most commonly encountered problems were equipment malfunction (15%), lack of a physically manageable portable system (13%), and lack of a portable system capable of giving sufficiently high flow rates(13%), The type of portable system was not related to participants' reports of problems with their oxygen systems. **Mobility**: Mobility was a concern; 38% reported only being able to leave their home for up to 2 hours because of portable system capacity whereas 66% of respondents wanted their portable system to last 5–6 hours. Respondents reported their ability to travel (30%), socialize (22%), and keep their saturations at more than 90% (20%) was limited by their portable system.
Appraisal summary	This paper describes results for an unselected group of oxygen users with a wide range of diagnoses. Twenty seven percent had a diagnosis of interstitial lung disease. Nonetheless the type of problem encountered appeared similar across diagnostic groups. As an internet based survey, it targeted an English speaking, IT literate population of oxygen users with associated results bias. There was also a preponderance of female respondents and the overall response rate is unknown. The fact that most respondents stated they used pulse oximeters and an unusually high number attended a Pulmonary Rehabilitation programme may further skew the results, suggesting a highly motivated population more likely to be active outside the home.

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Khor et al 2017	**Study Setting & Design** – Qualitative study using semi-structured interviews at a single institution in Australia.
Objectives	To explore perspectives of adults with interstitial lung disease about domiciliary oxygen therapy, comparing insights from patients using and not using oxygen therapy.
Participants	24 subjects recruited from a single ILD Clinic. 12 were using domiciliary oxygen therapy (7M, 5F, median age 68); 12 were eligible for, but declined to use, of oxygen therapy (9M, 3F, median age 67). Subjects had a wide range of ILD diagnoses, 2 patients in the oxygen experienced group and 4 patients in the oxygen naiive group had IPF.
Intervention/ Comparator/ Methods	Individual, semi-structured interviews , either in person or via telephone, were conducted in oxygen experienced and oxygen-naïve ILD patients. The intention was to use a grounded theory approach to analysis although it is unclear if this was used in a relatively small group. The description more closely aligned with thematic analysis.
Proposed Outcomes	To explore the perspectives on using oxygen therapy in patients with ILD, comparing insights from those who were oxygen-experienced and those who were oxygen-naive.
Summary of results	Five major themes were identified for those using oxygen: 1.Widespread variation in the usage of oxygen (e.g. continuous, during exertion only, post exertion recovery) 2.Positive impacts of using oxygen (eg relief of some symptoms, improved functional capacity but not specifically dyspnoea) 3. Negative impacts of oxygen (unmet symptom relief particularly in relation to breathlessness, anxiety, lifestyle interference, physical restriction) 4.Psychosocial adjustment to oxygen (self-consciousness in community with associated stigma, acceptance after contemplation) 5.Practical challenges (usability of equipment, access to oxygen therapy, education & support) Five major themes for those NOT using oxygen: 1.Psychosocial impacts (fear of dependence, signifier of end stage disease, embarrassment) 2.Expectation of the effects of using oxygen (relief of dsypnoea, uncertainty of the effects, lifestyle interference and physical restriction) 3.Anticipation of using oxygen (perceived no current need, acceptance for using in future) 4.Practical considerations (lifestyle interference and physical restriction, unsatisfactory design of equipment) 5.Education (more information wanted, relying on past experience in others or acute/rehabilitation settings)
Appraisal Summary	This study is limited by the convenience nature of the sample from a single clinical setting and the large range of conditions with a small number with IPF specifically. However, it highlighted the disparity between expectations and experiences of using oxygen therapy regarding symptom management for patients with ILD (not specifically IPF) and allowed for comparison with a cohort not using oxygen.

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Table 1: Characteristics of Included Studies

Overgaard et al 2016	**Study Setting & Design** – Qualitative interview study; specialist clinics at 2 university hospitals in Denmark
Objectives	To increase knowledge of life with IPF in patients and family caregivers
Participants	25 IPF patients (50-91 years, mean 71), and 24 caregivers. Seven patients were long-term oxygen users but it is unclear if other patients had used oxygen.
Intervention/ Comparator/ Methods	Joint in-depth dyadic interviews with patient and family caregiver were conducted by two experienced qualitative researchers. Framework analysis was chosen as the analytical method.
Proposed Outcomes	To describe the experiences and needs of patients living with idiopathic pulmonary fibrosis, and their carers.
Summary of results	Six main themes emerged: 1) information and disclosure; 2) reactional dyssynchrony; 3) perpetual vigilance; 4) emotional ambivalence; 5) gradual and tacit role shift; 6) adapted coping strategies. The use of oxygen emerged in two themes: 'perpetual vigilance' and 'emotional ambivalence'. Oxygen therapy was perceived overall as a negative milestone in the illness trajectory, being seen as both a marker of deterioration and an added limitation. Patients and caregivers avoided discussion of the subject to spare each other anguish. Once oxygen was started, patients were limited to a smaller radius of action and the sound of the oxygen concentrator became a constant reminder of the situation. Some recognised its usefulness for symptomatic benefit but carers felt responsible for the practical aspects of its use, and were increasingly vigilant after its introduction.
Appraisal Summary	The study used a purposive sampling strategy, approaching consecutive patients in clinic, rather than seeking to interview patients across the range of illness severity. Only seven of the 25 patients interviewed were on long term oxygen therapy, thus limiting the generalisability of the data. Eighty percent of the patients interviewed lived with a spouse, limiting the generalisability of the results to those living alone.

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Table 1: Characteristics of Included Studies

Visca et al 2018	**Study Setting & Design** – Open-label, mixed-method, crossover randomised controlled clinical trial; three ILD Centres in the UK., with a qualitative component conducted at Royal Brompton Hospital only.
Objectives	To assess the effects of ambulatory oxygen on HRQOL in patients with interstitial lung disease with isolated exertional hypoxia.
Participants	Eligible patients were aged 18 years or older, had fibrotic interstitial lung disease, were not hypoxic at rest but had a fall in transcutaneous arterial oxygen saturation to 88% or less on a screening visit 6-min walk test, and had self-reported stable respiratory symptoms in the previous 2 weeks. 84 patients were included in the RCT, The most frequent diagnosis was IPF (58%). 21 patients and 3 carers were included in the qualitative arm reported here; it is not clear how many of these had IPF.
Intervention/ Comparator/ Methods	Participants were randomly assigned (1:1) to either oxygen treatment or no oxygen treatment for 2 weeks, followed by crossover for another 2 weeks. To record participants' experiences of using ambulatory oxygen at home, audio-recorded semi-structured interviews following a topic guide were undertaken by a qualitatively trained research nurse within 2 weeks of trial completion at the Royal Brompton Hospital only. Analyses were undertaken using a Framework analytical approach.
Proposed Outcomes	**Primary outcome:** The difference after each 2-week treatment period between the oxygen and no-oxygen groups in HRQOL, measured with the King's Brief Interstitial Lung Disease Questionnaire (K-BILD), with a difference of 8 deemed the minimal clinically meaningful difference and used for power calculation. **Key secondary outcomes:** -Patient-reported global assessment of change (ie, same, better, or worse) in the previous 2 weeks in breathlessness on exertion and ability to walk, and scores on the University of California, San Diego Shortness of Breath Questionnaire (UCSDSOBQ), -Scores on the St George's Respiratory Questionnaire (SGRQ) and the Hospital Anxiety and Depression Scale (HADS) - qualitative interviews to explore their experience of oxygen use.
Summary of Study results	Ambulatory oxygen was associated with improvements in total K-BILD scores compared with no treatment but did not reach the minimally clinically meaningful difference of 8, adjusted mean difference 3·7 [95% CI 1·8–5·6]. Ambulatory oxygen use was also associated with significant improvements in scores on the breathlessness and activity and chest symptoms subdomains of K-BILD, in UCSDSOBQ scores, and in global assessments of change in breathlessness and walking ability (key secondary outcomes), but it is notable that most patients were largely sedentary and there was no difference in objective step counts between the two groups. Analysis of qualitative interviews showed that almost all interviewed patients, although initially apprehensive about oxygen use, thought that oxygen was beneficial with improvements in symptoms and mobility, and 16/21 interviewed continued oxygen use after the trial ended. Participants however also reported physical challenges with the use of portable cylinders and reluctance of employers to accommodate oxygen use in the workplace. About half of those interviewed expressed concerns about stigma and the visibility of oxygen equipment
Appraisal Summary	The qualitative data was only a small component of the larger RCT study and all of the interviewees were recruited from a single centre. Only 3 carers were included in the interviews. However, consistent themes emerged in terms of perceived benefits and challenges of oxygen use and the embedded qualitative component was appropriately reported in the main trial publication, with the implications of the qualitative outcomes addressed within the context of the remainder of the trial results.

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Included Studies:

Studies were included where it was reported that the perceptions of patients with IPF and their carers towards use of oxygen therapy either lived or anticipated.

[1] Belkin A, Belkin A, Albright K, Swigris J. A qualitative study of informal caregivers' perspectives on the effects of idiopathic pulmonary fibrosis. [Erratum appears in BMJ Open Respir Res. 2014;1(1):e000007corr1; PMID: 25582666]. BMJ open respiratory research. 2014;1:e000007.

[2] Duck A, Spencer LG, Bailey S, Leonard C, Ormes J, Caress AL. Perceptions, experiences and needs of patients with idiopathic pulmonary fibrosis. Journal of Advanced Nursing. 2015;71:1055-65.

[3] Graney BA. Informal caregivers experience of supplemental oxygen in pulmonary fibrosis. Health and Quality of Life Outcomes. 2017;15:no.

[4] Graney BA, Wamboldt FS, Baird S, Churney, Graney BA. Looking ahead and behind at supplemental oxygen: A qualitative study of patients with pulmonary fibrosis. Heart & Lung. 2017;46:387-93.

[5] Jacobs SS. Patient perceptions of the adequacy of supplemental oxygen therapy: Results of the American thoracic society nursing assembly oxygen working group survey. Annals of the American Thoracic Society. 2018;15:24-32.

[6] Khor YH, Goh NSL, McDonald CF, Holland AE, Khor YH, Khor YH. Oxygen Therapy for Interstitial Lung Disease. A Mismatch between Patient Expectations and Experiences. Annals of the American Thoracic Society. 2017;14:888-95.

[7] Overgaard D, Kaldan G, Marsaa K, Nielsen TL, Shaker SB, Egerod I. The lived experience with idiopathic pulmonary fibrosis: a qualitative study. The European respiratory journal. 2016;47:1472-80.

[8] Visca D, Mori L, Tsipouri V, Fleming S, Firouzi A, Bonini M, et al. Effect of ambulatory oxygen on quality of life for patients with fibrotic lung disease (AmbOx): a prospective, open-label mixed-method, crossover randomised controlled trial. Lancet Respiratory Medicine. 2018;6:759-70.

Excluded Studies:

A number of studies have been excluded due to various reasons including the following: no information regarding patient or care giver perspectives or attitudes towards the use of oxygen therapy and overviews concerning palliative decision making for patients with advanced lung disease.

For a full list of studies excluded at full text reading stage please contact PaCERSWCRC@cardiff.ac.uk

This report should be cited as follows: Palliative Care Evidence Review Service. A rapid review**:** What are the attitudes and perceptions of patients with pulmonary fibrosis and their carers towards use of oxygen therapy? Cardiff: Palliative Care Evidence Review Service (PaCERS); 2019 January.

Additional materials available upon request:

- Critical appraisal / data extraction forms
- Search strategies
- List of excluded studies

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Glossary:
IPF—Idiopathic Pulmonary Fibrosis
MDT—Multidisciplinary Team
PF—Pulmonary Fibrosis
ICs—Informal Caregiver/s
O2—Oxygen
NJH—National Jewish Health
US—United States
PLO –Patient-loved one
PR—Pulmonary resuscitation
PR—Pulmonary Rehabilitation
ILD—Interstitial Lung Disease
COPD—Chronic Obstructive Pulmonary Disease
LAM—lymphangioleiomyomatosis
PAH—Pulmonary Arterial Hypertension
AATD—Alpha-1 Antitrypsin Disease
POCs—Portable O2 Concentrators
mMRC—Modified Medical Research Council
K-BILD—King's Brief Interstitial Lung Disease Questionnaire
HRQOL—Health Related Quality of Life
RCT—Randomised Controlled Trial
UCSDSOBQ—University of California, San Diego Shortness of Breath Questionnaire
SGRQ—St George's Respiratory Questionnaire
HADS—Hospital Anxiety and Depression Scale

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