



# Barriers to and facilitators of the use of oxygen therapy in people living with an interstitial lung disease: a systematic review of qualitative evidence

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**Effective implementation of oxygen therapy in ILD requires more robust scientific evidence, technological innovations, equitable funding models and access to information and support to empower users.** <https://bit.ly/43B8l1R>

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## Abstract

**Background:** Oxygen therapy is prescribed to treat hypoxaemia in people with interstitial lung disease (ILD); however, uptake and adherence remain an ongoing challenge. This systematic review aimed to identify the barriers to and facilitators of use of oxygen therapy in people with ILD, caregivers and health professionals.

**Methods:** A systematic search for qualitative literature was undertaken using five electronic databases (MEDLINE, CINAHL, Embase, PsycINFO, PubMed). Qualitative analysis identified themes that were mapped to the Theoretical Domains Framework and the Consolidated Framework for Implementation Research and classified as barriers, facilitators or both.

**Results:** A total of 13 studies were eligible for inclusion. Commonly represented domains were associated with the design of the oxygen delivery system, the associated cost, financing, stigmatisation, the physical environment and the individual needs that acted as barriers to and facilitators of the optimisation of oxygen therapy.

**Conclusion:** Effective implementation of oxygen therapy in ILD requires more robust evidence to strengthen international guidelines, sustainable and equitable funding models, and improved oxygen delivery systems that meet the needs of users. Increased information and support for users will be critical to optimise the uptake and outcomes of this important therapy.

## Introduction

Interstitial lung diseases (ILDs) are a group of heterogeneous inflammatory and/or fibrotic conditions affecting the lung parenchyma that give rise to significant morbidity and mortality [1]. People with ILD experience a heavy and debilitating symptom burden that includes dyspnoea (shortness of breath), cough and fatigue [2].

Oxygen therapy is commonly prescribed for people with ILD with the aim of improving survival, reducing symptoms and increasing physical capacity through improved gas exchange [3]. Current recommendations for oxygen therapy are based on low-level scientific evidence and expert opinion [4]. This makes prescription of oxygen challenging for clinicians and often creates unrealistic expectations in people with ILD regarding the expected benefits [3, 5]. Levels of adherence are generally low (reported at 11–28% in those with mild-to-moderate disease) [6] and remain an ongoing challenge [7].



Qualitative studies provide an insight into the lived experience of oxygen therapy for people with ILD and have identified a number of individual and contextual factors that may act as barriers to and facilitators of implementation efforts, or both. However, anecdotal and scientific evidence suggest that the implementation of oxygen therapy to date has been less than successful, with ongoing barriers to utilisation and inequitable access to therapy. This has necessitated the re-examination of the implementation process with a focus on the rationale for treatment prescription, identifying those who would benefit most and addressing equipment issues.

Numerous frameworks have been developed to guide implementation of interventions and identify barriers and facilitators based on behavioural change at various levels [8, 9]. The Theoretical Domains Framework (TDF) and the Consolidated Framework for Implementation Research (CFIR) are two such frameworks that provide a systematic and theoretical basis for understanding and changing behaviour at the individual level (TDF) and at a more collective level (CFIR) [8, 10, 11]. The TDF has 14 theoretical domains, whilst the CFIR is composed of five major domains that provide an overarching typology to guide the verification about what works where and why across various contexts (supplementary file 2) [11]. Using both the TDF and CFIR frameworks allowed for the identification of facilitators of implementation as well as factors and contexts that create barriers to the optimisation of oxygen therapy [12]. In turn, this will help guide the development of pragmatic and effective changes to the implementation of this therapy that could potentially translate into more beneficial outcomes for people with ILDs.

Thus, the objective of this systematic review was to synthesise information from qualitative studies to address the question “What are the barriers to and facilitators of the use of oxygen therapy for people with an ILD, caregivers and healthcare professionals?”

## Methods

This systematic review was reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines and the protocol was registered on PROSPERO (CRD42021284702) ([https://www.crd.york.ac.uk/prospero/display\\_record.php?ID=CRD42021284702](https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021284702)).

### Inclusion criteria

Inclusion criteria included 1) qualitative design or mixed-method studies where the qualitative component was a discrete part of the study; 2) published in English; 3) patients aged  $\geq 18$  years with a diagnosis of ILD according to investigators' definition; 4) ILD including but not limited to pulmonary fibrosis (PF), idiopathic pulmonary fibrosis (IPF), nonspecific interstitial pneumonitis, sarcoidosis and silicosis; 5) caregiver aged  $\geq 18$  years involved in the care of people with an ILD; and 6) health professionals (*e.g.* respiratory physicians, nurses) involved in the management of people with ILD.

The phenomena of interest were the experiences and/or perceptions of oxygen therapy for ILD as described by people with an ILD, caregivers of people with an ILD or health professionals.

### Search strategy

The search strategy combined terms for “interstitial lung disease”, “oxygen therapy” and “qualitative study design”. Five electronic databases (MEDLINE, CINAHL, Embase, PsycINFO, PubMed) were searched from inception to November 2021. The search strategy used for MEDLINE (supplementary file 3) was adapted for each of the remaining four databases.

### Identification of studies

Citations retrieved from searches were uploaded into Covidence ([www.covidence.org](http://www.covidence.org)) where duplicates were removed before titles and abstracts were screened independently by two reviewers (MH, CM) with conflicts resolved by discussion and adjudicated by a third reviewer (GT). Full texts of potentially eligible studies were retrieved and independently assessed against the inclusion/exclusion criteria by two reviewers (MH, CM) with conflicts resolved through discussion.

### Quality assessments

The Critical Appraisal Skills Programme (CASP) tool was used to appraise the quality of included studies [13, 14] through the assessment of domains incorporating aims, design, methods, data analysis, interpretation, findings and value of the research. Quality was independently evaluated by two reviewers (GT, MH) with a final quality rating achieved by consensus. Each criterion was scored as “1” if the criterion was completely met; “0.5” if the criterion was partially met; and “0” if the criterion was not applicable, not met or not mentioned. Scores of 9–10 are defined as high quality, scores 7.5–9 as moderate quality and  $< 7.5$  as low quality.

### Data extraction

Two reviewers (GT, MH) independently undertook data extraction. A study-specific standardised form was used to collect data relating to qualitative methodology employed, data collection methods, sampling approach, ILD types, areas of oxygen therapy, main themes and outcomes reported from each study along with supporting quotes. Concordance was achieved through discussion.

Thematic analysis techniques were used to synthesise data (themes and representative quotes) from each study. Data from studies involving patients and caregivers were synthesised separately from those involving healthcare professionals. Data extraction and analysis were conducted in two stages. In the first instance, individual units of data (“items”) from included papers were mapped against the 14 domains of the TDF (supplementary file 1) [15]. Where clarification of the definition of a domain(s) was required to map an extracted data item, questionnaire content developed by HUG *et al.* [16] was used to guide the decision-making process. All raw data were mapped to the TDF, including participant quotations from qualitative studies. Themes were also mapped to the relevant CFIR domains and specific constructs (supplementary file 2). The “Implementation” domain will not be discussed in any detail because it incorporates data outside the scope of this systematic review. Mapping was undertaken by GT and verified through consensus with a second author (AEH). Themes were identified as barriers, facilitators or both.

The second stage of the analysis comprised frequency analyses [17]. The least and most frequently reported domains were identified based on the cumulative frequency of each domain identified across all included studies.

### Results

The literature search identified 366 potentially relevant studies of which 67 were duplicates. The remaining 299 studies were screened based on title and abstract with 284 excluded, leaving a total of 15 studies where the full text was retrieved and reviewed for inclusion. Two studies were then excluded, leaving a total of 13 included studies (2359 participants) (figure 1).

#### Characteristics of included studies

Seven studies (54%) reported the perspective of people living with PF/ILD only [18–24], two studies (15%) reported the perspectives of caregivers only [25, 26], three studies (23%) combined the views of people with PF and caregivers [27–29] and one study (8%) was based on physicians’ perspectives [30]. Characteristics of included studies are provided in supplementary file 4.

The methodological quality of the included studies based on the CASP criteria is reported in table 1. Nine out of 13 studies were of high quality and three were moderate quality. Because one study was a meta-synthesis of qualitative research, we employed the CERQual (Confidence in the Evidence from Reviews of Qualitative research) tool to assess the confidence of the evidence [31, 32]. The level of confidence was assessed as being “moderate”, indicating that it is likely that the review finding is a reasonable representation of the phenomenon of interest.

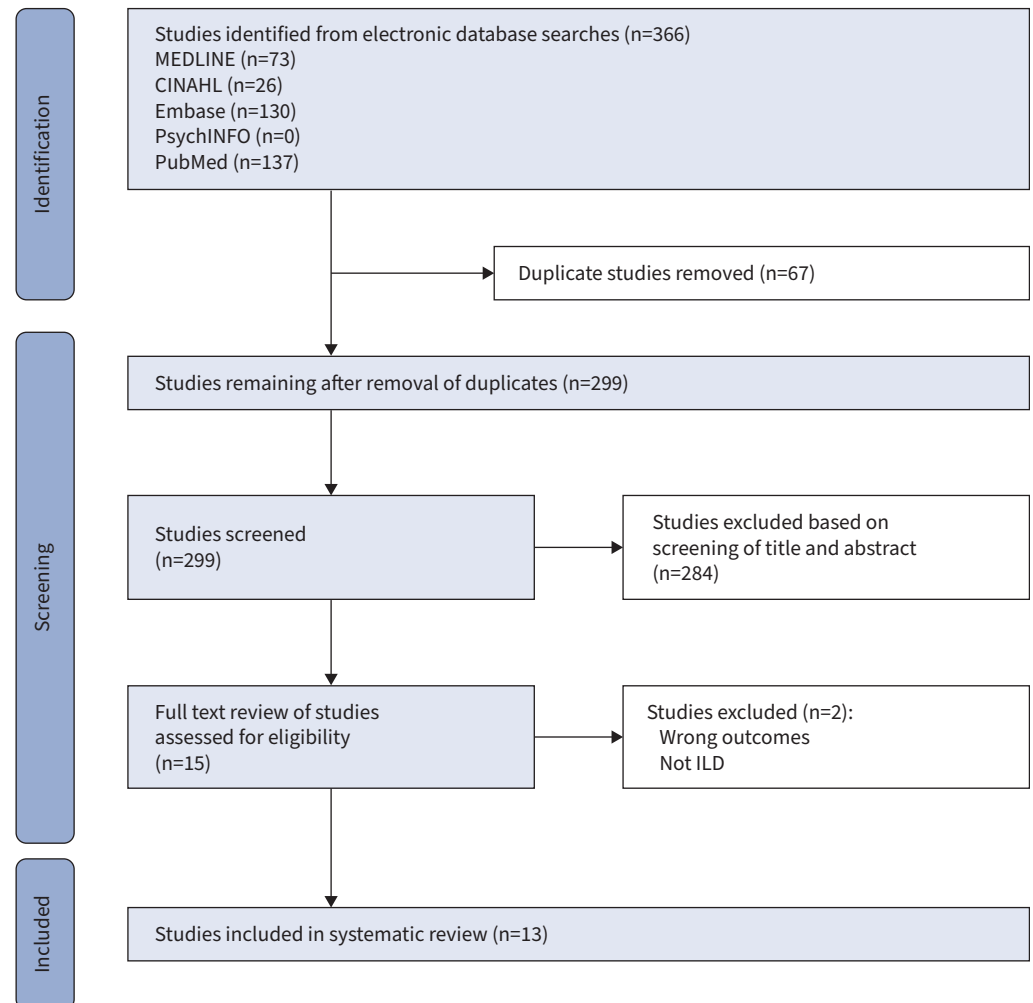
#### Summary of the barriers to and facilitators of oxygen use mapped to the TDF domains

A total of 220 items were mapped to the TDF. Table 2 summarises the TDF domains represented by each of the 13 studies. “Beliefs about consequences” (acceptance of the truth, reality or validity about outcomes of using oxygen therapy) was the most represented domain (12 out of 13 included studies). “Social or professional role/identity” (identity, how one is perceived by society), “Environmental context and resources” (circumstances of a person’s environment that promotes (or impedes) the use of oxygen) and “Emotion” (a complex reaction, drawing on experience that allows an individual to attempt to deal with significant event/issue) were represented in 10 out of 13 studies respectively. “Knowledge” (procedural and disease-related) was represented in nine out of 13 included studies. “Behavioural regulation” (self-monitoring, action planning) and “Reinforcement” (approaches to ensuring oxygen is used) were the least represented domains, with “Memory attention and decision processes” being the only domain not represented by any study.

#### Barriers and facilitators mapped to the TDF

##### Beliefs about consequences

“Beliefs about consequences” was the most common TDF domain mapped across the 13 studies. Representative quotes can be found in table 3. For people with PF and their caregivers, oxygen therapy was generally viewed as a salient event that became a total intrusion to life. For many, it provided some symptom relief but also resulted in the loss of spontaneity and independence and was a constant reminder



**FIGURE 1** Preferred Reporting Items for Systematic Reviews and Meta-analyses flow of qualitative studies through the systematic review. ILD: interstitial lung disease.

of “losing the battle with IPF” [26]. Many acknowledged that oxygen was not a cure but expected that it would allow them to breathe easier.

For those not yet on oxygen therapy, the anticipated benefits included improvements in symptoms (cough, fatigue, dyspnoea), physical function and endurance. There was also an expectation that oxygen would allow them to “return to who they were”. An overwhelming majority of physicians reported prescribing domiciliary oxygen therapy for symptom relief but also for improving quality of life and correction of hypoxaemia but not necessarily extending life [19].

For those on oxygen therapy, many described symptom relief, improved capacity to be more active, increased self-confidence, independence and a sense of security [29]. Caregivers noted that their loved ones looked more comfortable when on oxygen and had “colour in his face” [25]. However, not all people with ILD experienced the expected symptom relief, with many finding the use of oxygen restricted their movement and activities. In addition, possible safety and supply issues provided a source of anxiety. Caregivers reported concern including electricity outages, the possibility that the oxygen cylinders would explode or cause a fire in the home, or if they had sufficient supply to maintain adequate blood oxygen levels if they left home for extended periods of time [28, 30].

Both people with ILD and caregivers expressed the view that the need for oxygen denoted a significant progression in the disease (“the end of the line”) and so avoided it for as long as possible. This notion was supported by physicians who conveyed that the use of oxygen therapy signified an important milestone of

**TABLE 1** Methodological quality assessment of the 13 included studies based on Critical Appraisal Skills Programme criteria

First author [ref.] (year)	Population	Aims	Qualitative methods appropriate	Connection to theoretical framework	Recruitment strategy	Data collection	Reflexivity	Ethical issues	Data analysis	Clear statement of findings	Value of research	Total score <sup>#</sup>
BELKIN [26] (2014)	Caregivers	1	1	1	1	1	0.5	1	1	1	1	9.5
BURNETT [22] (2019)	People with IPF	1	1	1	0.5	1	1	1	1	1	1	9.5
DUCK [23] (2015)	People with IPF and caregivers	1	1	1	1	0.5	0.5	1	1	1	1	9
GRANEY [18] (2017)	People with PF	1	1	1	1	0.5	0.5	1	0.5	1	1	8.5
GRANEY [25] (2017)	Caregivers	1	1	1	0.5	1	0.5	1	1	1	1	9
KHOR [19] (2017)	People with ILD	1	1	1	0.5	1	1	1	1	1	1	9.5
KHOR [30] (2017)	Respiratory physicians	1	1	1	0.5	1	0.5	1	1	1	1	9
LINDELL [21] (2019)	Any lung disease	1	1	1	1	1	1	1	1	1	1	10
RAMADURAI [27] (2018)	People with IPF and caregivers	1	1	1	1	0.5	1	1	0.5	1	1	9
SAMPSON [28] (2015)	People with IPF and caregivers	1	1	1	1	0.5	0.5	1	0.5	1	1	8.5
SCHOENHEIT [20] (2011)	People with IPF	1	1	1	1	0.5	1	1	0.5	1	1	9
VISCA (2018) [29]	People with fibrotic ILD and caregivers	1	1	1	1	0.5	0.5	1	0.5	1	1	8.5

1: criterion completely met; 0.5: criterion partially met; 0: criterion not applicable, not met or not mentioned. IPF: idiopathic pulmonary fibrosis; PF: pulmonary fibrosis; ILD: interstitial lung disease. #: scores of 9–10 are defined as high quality, scores 7.5–9 as moderate quality and <7.5 as low quality.

**TABLE 2** Theoretical Domains Framework domains by study

Study [ref.] (year)	Knowledge	Skills	Social or professional role/identity	Beliefs about capabilities	Optimism	Beliefs about consequences	Reinforcement	Intentions	Goals	Memory attention and decision processes	Environmental context and resources	Social influences	Emotion	Behavioural regulation	Total domains per study (n)
BELKIN [26] (2014)															7
BURNETT [22] (2019)															5
DUCK [23] (2015)															4
GRANEY [25] (2017)															10
GRANEY [18] (2017)															8
IGAI [31] (2019)															7
KHOR [30] (2017)															6
KHOR [19] (2017)															9
LINDELL [21] (2019)															4
RAMADURAI [27] (2018)															3
SAMPSON [28] (2015)															3
SCHOENHEIT [20] (2011)															3
VISCA [29] (2018)															7
<b>Total studies (n)</b>	<b>9</b>	<b>2</b>	<b>10</b>	<b>8</b>	<b>4</b>	<b>12</b>	<b>1</b>	<b>2</b>	<b>2</b>	<b>0</b>	<b>10</b>	<b>5</b>	<b>10</b>	<b>1</b>	

Grey shaded cells represent the Theoretical Domains Framework represented within each study.

TABLE 3 Representative quotes for barriers to and facilitators of oxygen therapy mapped to the Theoretical Domains Framework

TDF domain	Representative quotes
<b>Beliefs about consequences</b>	<p>“You’re not free, can’t laugh or cry fully because if you do you won’t be able to breathe even with oxygen – that is terrible and upsetting. Also, being tied to oxygen makes you feel like you’re stuck inside the cage.” (Participant with IPF, oxygen therapy use unknown, UK) [23]</p> <p>“I thought once I get oxygen I’ll be back to being who I was, but that didn’t happen but it makes life easier.” (Participant with ILD on oxygen therapy) [24]</p> <p>“O<sub>2</sub> does denote a progression...in my disease that I wouldn’t be happy about and...feels like maybe it would be a setback” (Female participant with chronic hypersensitivity pneumonitis on oxygen therapy) [28]</p> <p>“Once I start doing that [using oxygen], I reckon that’s the end of the line” (Participant with ILD not on oxygen therapy) [22]</p>
<b>Environmental context and resources</b>	<p>“I mean, you, you have to adapt to, to planning to take the charger and the machine and the cannula and, you know, the cleaning supplies that go with, you know, that, all that stuff” (Male participant with IPF on oxygen therapy) [28]</p> <p>“I’ve got the oxygen. I used to be on it when I first got it, I used to hire it. I was on it in hospital, two units I think it was and then came home and I hired one. I was on that 24 h a day and then I thought this is too expensive. The specialist said I’ll be on it forever so I thought oh well I’ll just buy one, so \$4700 later.” (Participant with IPF on oxygen therapy) [25]</p> <p>“Everything was an expedition if we were going out” Before leaving, they had to “figure out what your [O<sub>2</sub>] needs are going to be while you’re gone” (Caregiver of person with IPF on oxygen therapy) [25]</p>
<b>Emotion/optimism</b>	<p>“It’s maintaining her and, uh, for that I’m grateful. And I saw a lot of confidence when I gave her the portable oxygen machine initially. She was super-excited about it; you could tell that she felt good. She felt confident.” (Caregiver of person with PF on oxygen therapy) [22]</p> <p>“Well, [I think about] the harm [of running out of oxygen]. Basically, going to collapse. And, need to get an ambulance, get some oxygen, that’s going to take some time.” (Participant with ILD on oxygen therapy) [25]</p> <p>“We’ve been to Tesco’s and I’ve run out (oxygen)....I was really gagging for breath. That’s when the panic attack starts setting in and you know they’re terrible. I mean I have to carry Valium all the time now.” (Participant with ILD on oxygen therapy) [23]</p>
<b>Social or professional role and identity</b>	<p>“Just the stigma of it. I don’t know...I know a lot of people assume that they put themselves in that position, by smoking or COPD and I don’t want people to think that of me, because that’s not why I have it.” (Female participant with IPF not yet on oxygen therapy) [28]</p> <p>“...you ride a fine line between how firm do you get, you know, and how soft do you stay, to get accomplished what you feel is important.” PLOs would sometimes heed their IC’s advice and other times “totally ignore it” (Caregiver of person with PF on oxygen therapy) [28]</p> <p>“I just felt embarrassed for having these tubes running up my nose and from a tank on my back. If it was a pill, nobody notices it, but with a cylinder on your back and a plastic tube up your nose it is much more visible.” (Male participant with fibrotic ILD on oxygen therapy, 69 years old) [29]</p>
<b>Beliefs about capabilities</b>	<p>“Well, it certainly has expanded my ability to do the things I want to do. [I am] more comfortable pushing what might be the limits of my breathing ability and knowing that there is some relief available other than just trying to huff your way through it.” (Male participant with IPF, 67 years old, on oxygen therapy for 9–12 months) [28]</p> <p>“Freedom. Being able to do things I haven’t been able to do for such a long time. It made me feel less tired. It made me feel less breathless. My cough wasn’t so bad. I could do things without having to stop. It taught me how much this disease has stopped me from doing things. It’s not because I don’t want to do them—I’d love to do them—it’s the fact that I physically, because of the breathlessness, can’t do it” (Female participant with fibrotic ILD, 52 years old) [29]</p>

TDF: Theoretical Domains Framework; IPF: idiopathic pulmonary fibrosis; PF: pulmonary fibrosis; ILD: interstitial lung disease; COPD: chronic obstructive pulmonary disease; PLO: patient loved one; IC: informal caregiver.

disease progression to advanced stages of ILD. Physicians also reported that discussions with patients on domiciliary oxygen therapy often caused anxiety due to a range of concerns such as social stigma, fear of dying and fear of dependence or addiction [19, 30].

#### Emotion/optimism

Oxygen therapy evoked strong, mostly negative emotional reactions from people with ILD and caregivers. Representative quotes can be found in table 3. Oxygen was viewed as psychologically and physically limiting and part of the “rollercoaster of IPF” [26]. There was constant fear and concern regarding safety of use around heating, electricity supply and running out when needed [19, 23]. Being so dependent on

oxygen led to constant concern and anxiety that it would run out, with participants reporting on the need to do careful calculations to know how long they could be out of the house [21, 29].

For those not currently on oxygen, there was a sense of fear and anticipated regret because it would be a reminder of the losing battle with IPF [26]. Conversely, some caregivers expressed a decreased level of worry and concern for their loved one when the use of oxygen resulted in health benefits [25].

People with PF and caregivers generally viewed oxygen with pessimism. Caregivers described oxygen as a life-changing event that was a constant reminder of the insidiousness of the disease and seen as being “a failure” [19].

#### *Environmental context and resources*

Commonly reported environmental-associated barriers to oxygen therapy related to equipment, its management and required resources. Representative quotes can be found in table 3. Participants reported a significant physical barrier with ambulatory oxygen, namely cylinders being described as too heavy and bulky to carry or wheel. Portable oxygen concentrators, whilst easier to use, had reduced oxygen delivery capacity, batteries with a short life and were often perceived to be too expensive. As a result, many reported feeling frustrated and anxious, with some finding that outings were “more trouble than it’s worth” [21]. In addition, some reported on the significant logistical planning required when taking an excursion outside the home and the constant anxiety that the possibility of running out of oxygen created for both users and caregivers [20, 29].

Inside their homes, people with ILD using long-term oxygen therapy were viewed as being “on a leash” with the length of the tubing restricting movement and cannulas often getting caught on furniture, creating potential hazards [25]. Excursions outside the home required significant logistical planning that often resulted in loss of spontaneity and became a limiting factor in being able to perform daily activities and going places [23]. Physicians also recognised that many patients considered oxygen to be burdensome given the weight and size of cylinders that often had to be managed along with other mobility supports [19]. Access and supply issues were also a major challenge for some with PF, with services being highly variable both across and within countries and jurisdictions [19–21]. Issues included delays from companies supplying oxygen, restrictions and delays in changing suppliers, issues with oxygen suppliers (poor support and service, billing issues, lack of operational standards for suppliers) and limited liquid oxygen supply sites [21]. Physicians described how variable funding arrangements both within and between different jurisdictions created inequitable access to oxygen [30]. Cost was also a concern for many people with PF with an increase in electricity bills associated with ongoing need. Lighter, more convenient delivery devices with remote control capability to adjust oxygen flow rates were suggestions for addressing some of the challenges faced by those on oxygen [21, 25].

#### *Social or professional role and identity*

Fear of being stigmatised was a major perceived barrier associated with oxygen therapy for people with ILD. Representative quotes can be found in table 3. In addition to the commencement of oxygen therapy being a life-changing event, many voiced concerns about the unwanted attention it attracted and how they viewed themselves as being “judged” by society. Whilst many tolerated the benefits of oxygen therapy at home, some described it as a “double-edged sword” [24]. Caregivers described oxygen as an “in your face” reminder of being sick [25]. For some it became a role-changing event because looking after a loved one on oxygen became a “24/7” job that consumed all their time as they assumed the responsibility of ensuring that oxygen was used as prescribed and maintaining the equipment [25].

Physicians also reported how there was concern from patients when discussing oxygen about standing out from the crowd that caused some anxiety [30]. Having an “oxygen buddy” was identified as a valuable resource to improve the patient experience [18].

#### *Knowledge and skills*

Lack of knowledge (both procedural and disease-related) was commonly reported by some with ILD and their caregivers. Many felt they had received insufficient information and practical support prior to commencing on oxygen and during the early days and, therefore, did not use it very much [22]. Many requested practical guidance on the entire process of using oxygen that ranged from managing expectations to how to use a pulse oximeter [25]. Others felt they were not well informed about many other facets associated with the use of oxygen, such as how to manage it whilst travelling or during trips outside the home and the supply and costs.



Caregivers also wanted practical information about how to manage medications and the “ins and outs” of oxygen therapy, including a rationale for why it was prescribed and the potential benefits [27]. Caregivers with prior knowledge reported being able to better manage the oxygen requirements for their loved ones. Whilst most physicians reported not providing written information regarding oxygen to their patients, patients and caregivers reported obtaining information from oxygen clinics, pulmonary rehabilitation programmes and oxygen supply companies that empowered them with the knowledge and confidence when starting on oxygen [19]. The internet was also a source of information on how to live with oxygen but was often reported as being unreliable owing to the degree of misinformation and highly variable quality of internet sites [28]. Having a consistent person with procedural knowledge about oxygen was identified as being important in facilitating the ongoing challenges experienced by those using oxygen.

#### *Beliefs about capabilities*

For many with PF, breathlessness was a significant symptom affecting even basic daily activities such as shaving or walking. Many participants found oxygen helped to manage their breathlessness and in doing so made them feel more in control of their lives. The benefits of oxygen provided many with greater self-efficacy to be more active, allowed greater independence and improved their confidence to do more of what they wanted to do [23]. However, others who did not experience the benefits of oxygen saw it as an indicator of their deteriorating condition and struggled with not being able to resume their normal level of exertion [24]. Representative quotes can be found in table 3.

#### *Social influences*

The use of oxygen particularly out in the community made people with PF feel self-conscious and embarrassed with many attempting to avoid the stigma associated with being on oxygen of being old or as a consequence of being a smoker [25, 26, 29]. Caregivers felt the oxygen called attention to them in public, allowing others to view them as being ill and different to others [26].

#### *Intentions/goals*

Overall, the primary intent and goal of oxygen therapy was for symptom relief. However, there was a widespread variation in usage of oxygen therapy as reported by people with PF that ranged from only during exertion to continuous usage [19]. Similarly, an overwhelming majority of physicians reported symptom relief as their major goal when prescribing oxygen and not necessarily expecting it to extend patients' lifespan [30].

#### *Behavioural regulation and reinforcement*

In terms of behavioural regulation, carers described leaving home with oxygen as “an expedition”, requiring extensive logistical planning and preparation to ensure adequate oxygen supply with carers themselves often taking on the responsibility. Most caregivers assumed the role of ensuring their loved ones were using oxygen as prescribed, which could create angst in relationships, with caregivers describing “riding a fine line” between remaining firm and letting things go [25].

#### **Qualitative evidence mapped to CFIR domains and constructs**

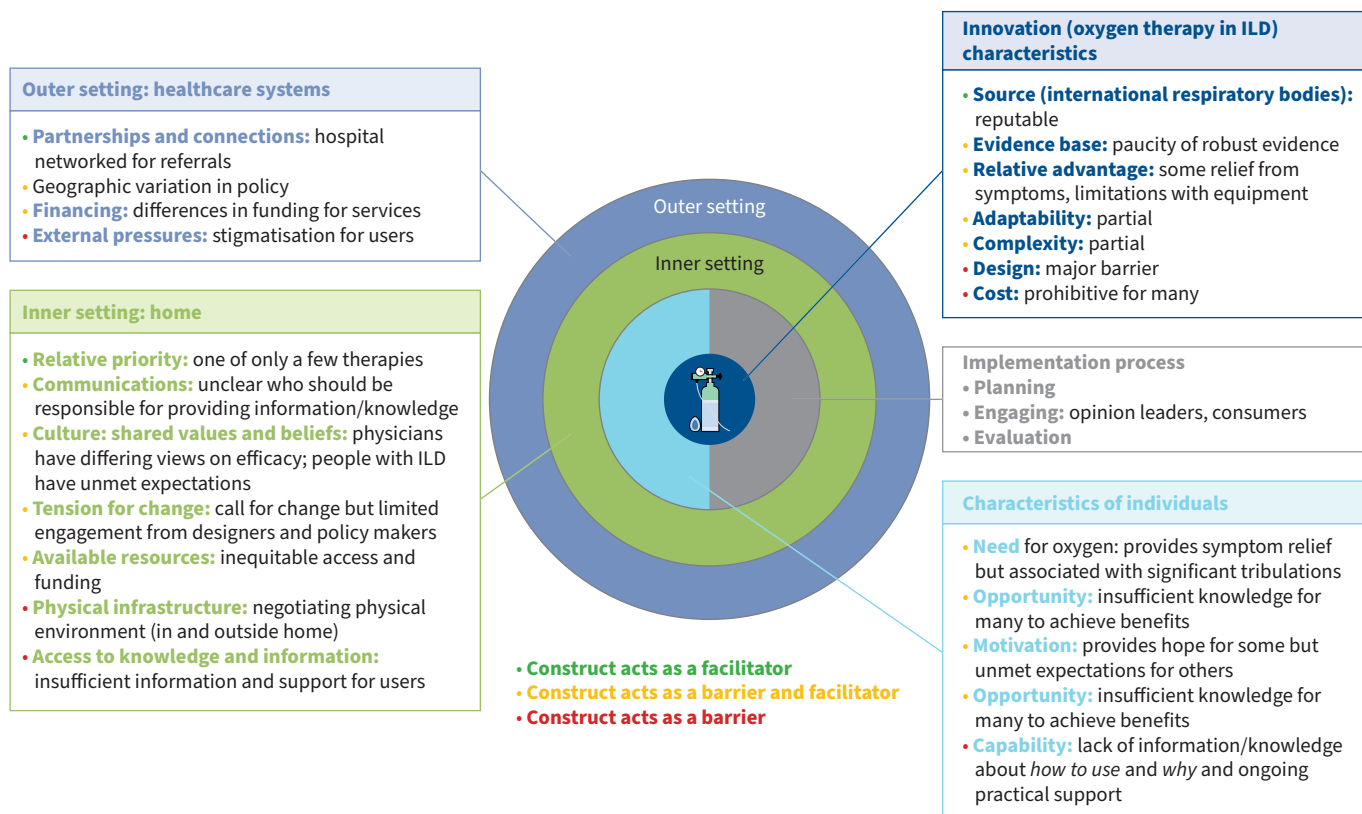
Figure 2 shows the mapping of qualitative themes to the relevant CFIR domains and constructs. Supplementary file 5 provides further details on each construct relevant to oxygen therapy.

#### *Innovation domain*

The “Innovation” domain relates to the intervention itself (*i.e.* oxygen therapy) in terms of development, evidence base, design and cost. The themes mapped under this domain re-affirmed the need for a more robust evidence base to guide recommendations for the prescription of oxygen and identification of patients that would benefit most. The mapped constructs also highlighted the significant issues associated with inadequate design, adaptability and the cost of oxygen equipment that created barriers to uptake [18, 21]. For example, the heavy cylinders that were difficult to manage and restricted mobility combined with the often prohibitive costs of ongoing supplies were reported by many participants [18, 21, 22, 27]. The limited adaptability in terms of more portable devices provided only a partial advantage over cylinders as they were associated with other limitations, including a smaller oxygen supply and battery life issues [19]. In terms of complexity, many participants expressed a lack of procedural and disease-specific information, particularly prior to commencing on oxygen, and ongoing support as causes of frustration [18, 19, 22, 24, 27, 28].

#### *Outer setting domain*

In this context, the “Outer setting” refers to the healthcare systems through which oxygen therapy is prescribed and supported. Relevant constructs included external policies/laws and partnerships, financing and external pressures. Whilst professional respiratory bodies provide recommendations for the use of



**FIGURE 2** Barriers to and facilitators of the use of oxygen therapy based on the Consolidated Framework for Implementation Research (CFIR). ILD: interstitial lung disease.

oxygen therapy as a treatment option for ILD, there was some heterogeneity in defining eligibility primarily due to the scarcity of scientific evidence [5]. Hospitals are often networked for oxygen referrals either through internal or external service departments; however, the extent of available services varied owing to financial and/or personnel constraints [25].

Differences in financial support and reimbursements for oxygen services created inequitable access to oxygen for people with ILD. This was compounded by a lack of local suppliers and the large out-of-pocket expenses reported by users associated with the ongoing costs of oxygen equipment, supply and electricity costs. Respiratory physicians also reported that differences in financial assistance across jurisdictions created an inequity to access [19].

Societal pressure, namely stigmatisation, was identified as a major barrier to implementation and delivery of oxygen therapy by both users and prescribers. Many people with ILD expressed reluctance to be seen both at home and in the community with an oxygen cylinder because they felt “judged” by others and it made their disease visible to all [18–28, 30].

**Inner setting domain**

The “Inner setting” domain encompasses constructs associated with the setting where oxygen therapy is implemented, which in this context would include at home or during daily activities. Structural characteristics associated with the use of oxygen equipment were commonly reported as barriers to utilisation. The use of oxygen at home created many challenges as participants negotiated tubes and cylinders around furniture, whilst out of the home, pulling cylinders over rough surfaces, in and out of cars and up and down stairs were disincentives to use [18–22, 25, 26]. The need for disease-related knowledge and procedural information regarding oxygen was reported by many people with ILD and caregivers, and addressing this need could enable greater utilisation [18, 27, 28]. Whilst many caregivers assumed the role of ensuring appropriate oxygen use, they did so without support from external sources or financial assistance. Participants identified that having a central contact person knowledgeable in oxygen therapy

would alleviate many of the challenges and issues [21]. However, it remains unclear as to who (healthcare provider, oxygen supplier, other) should be responsible for providing accurate, consistent information. In addition, there are few incentives to support the use of oxygen from external bodies and little to no incentive for technology companies to develop better systems.

### *Individuals domain*

The “Individuals” domain captured areas relating to the need for oxygen therapy in people with ILD, the knowledge and skill to utilise its use and the opportunity and motivation to uptake oxygen therapy. The need for oxygen therapy was generally viewed with negativity and trepidation because it forces people with ILD to confront the reality of their progressive disease [25, 26]. The lack of information and practical support was a significant frustration that left many feeling inadequately skilled to use oxygen [22]. The oxygen experience often required compromises for people with ILD [24]. For some it provided relief from the debilitating breathlessness and other symptoms allowing them to perform daily activities [22, 23] whilst at the same time restricting their mobility and independence and subjecting them to stigmatisation [19, 30]. Others reported no benefits or that their needs were not met owing to the inadequacy of the oxygen supply system [19, 22].

### **Discussion**

This systematic review identified 13 studies that examined the perceptions and experiences of oxygen therapy in people with ILD using qualitative methods. Findings highlighted the complex and costly nature of this therapy, with barriers to and facilitators of implementation acting at both the individual level and across multiple collective levels, including organisations and environments. The review synthesised the perspectives of people from several jurisdictions (Australia, UK, USA, Europe) with differing healthcare systems; however, the barriers and facilitators identified were commonly reported across all jurisdictions.

“Beliefs about consequences”, “Social role/identity”, “Environmental context and resources” and “Emotion” were the most commonly represented TDF domains acting as both barriers and facilitators. Mapping themes to the CFIR identified dimensions related to the “Innovation” (*e.g.* design and cost), “Outer setting” (financing, external pressures), “Inner setting” (roles and responsibilities, access to knowledge/information) and the “Individual” domain (*e.g.* need, capability, opportunity and motivation) that act as barriers to and facilitators of the optimisation of oxygen therapy.

Given the limited treatment options for ILD, there is an urgent need to address the paucity of evidence on which guidelines and recommendations are based. More robust and direct evidence will allow for the development of more consistent guidelines and may result in a more standardised approach to clinical management. Having a stronger scientific base for prescribing oxygen therapy will also guide the establishment of more equitable access to oxygen through clearly defined eligibility criteria across jurisdictions. This may also assist in developing policies around government reimbursements, funding opportunities and more accountability from oxygen supply companies. Thus, more research into the benefits of oxygen therapy needs to become a priority for all stakeholders including respiratory leaders, policymakers and technology companies.

There is a clear call from people with ILD, caregivers and healthcare professionals to address the longstanding practical issues associated with current oxygen delivery systems. All stakeholders wanted a more fit-for-purpose oxygen delivery system that is lighter, more portable and therefore easier to manage, whilst still being able to meet oxygen requirements. Major shortcomings and inadequacies of oxygen therapy equipment to meet patient needs has been a longstanding barrier to oxygen therapy and is acknowledged by key respiratory bodies [5, 7, 33]. Findings from this review suggest that there has been little improvement in this area. Many people with ILD are older, frail and have other comorbidities so the physical and practical burden of large and heavy cylinders was reported as a common disincentive for oxygen use. Alongside the design and portability issue was the inadequacy of the oxygen system to provide a high, consistent flow rate of oxygen required by some with substantial hypoxaemia. A lighter, more efficient portable system with a remote control were commonly desired features reported by participants. Whilst the need for an overhaul of oxygen delivery systems is undisputed, such a task would require substantial technological innovation in design, as well as incentives for policy makers and equipment companies to deploy new technologies.

This review has also highlighted the need for greater support for people with ILD and caregivers when oxygen is prescribed. Types of support included access to knowledge and information prior to commencing on oxygen; ongoing support (procedural and psychological), particularly when issues arise; and financial support to assist with the costs of oxygen. People with ILD have often expressed unmet

needs, in particular the need for better information about their disease and treatments [29, 34]. In terms of oxygen therapy, this review showed that sources of information were varied and included internet sites, healthcare professionals and oxygen suppliers. Participants commonly expressed frustration at the lack of procedural information received before starting on oxygen that often omitted aspects such as managing cylinders and tubing and associated costs. Some participants felt that knowledge and ongoing support whether through a peer (“oxygen buddy”) or health professional provided greater confidence to manage and persevere with oxygen. The latter was supported by a study in which patients who received education from healthcare personnel were less likely to report oxygen problems compared with those educated by the delivery person or those who received no education [33]. Peer support programmes are available in some jurisdictions for people with PF and have shown that the sharing of experiences and provision of mutual support to be beneficial and alleviated some of the uncertainty and emotional distress [35]. Caregivers commonly reported the need to better understand their loved one’s disease and the role of oxygen, with many reporting a lack of understanding as to “why” oxygen was prescribed and “when” it should be used. Other support options identified by participants included having a central contact person knowledgeable in oxygen therapy to be available for patients to contact, similar to the ILD respiratory nurses who play a pivotal role in looking after people with ILD through tertiary clinics.

The high cost of oxygen therapy and inequitable access to supply and funding were significant barriers. Costs associated with the initial set up and then the ongoing supply and running costs forced many to forsake optimal use. In addition, coverage of costs or reimbursements by insurance companies across some jurisdictions was often non-existent or problematic. Issues with supply companies such as inadequate service, billing inconsistencies and lack of operational standards for suppliers generated anxiety about being left with an insufficient supply. To address this, people with ILD highlighted the need for a patient advocacy protection system to be implemented to ensure oxygen suppliers were meeting the required standards and complying with contractual stipulations. Physicians also acknowledged the differing access and funding arrangements both within and between jurisdictions that created an inequitable access to the therapy [30]. This lack of an adequate funding model for oxygen was also identified as a key priority in the “American Thoracic Society’s Workshop on Optimising Home Oxygen Therapy Report” that recommended the revision of reimbursement practices as a means of improving oxygen accessibility [7].

#### **Strengths and limitations**

A strength of this review was the use of both the TDF and CFIR frameworks to identify barriers to and facilitators of oxygen therapy at both the individual and collective levels and the inclusion of qualitative studies that incorporated the views of people with ILD, caregivers and respiratory physicians. Of note, experiences of supplemental oxygen appeared more positive for participants in a clinical trial compared to other included studies, which may reflect greater support provided to patients in that context [29]. Our findings are a synthesis of currently available studies; however, the perspectives reported may not represent the views and experiences of all people with ILD, caregivers and physicians. Although the number of relevant studies identified using a systematic and comprehensive search was modest, the quality was assessed as predominantly high and studies were conducted within numerous jurisdictions.

#### **Points for clinical practice**

- Providing patients with procedural and disease knowledge prior to commencement on oxygen therapy may facilitate greater adherence.
- Patients and caregivers of those on oxygen therapy require ongoing (practical and psychological) support to navigate the challenges associated with the oxygen delivery system and the significant impact of the therapy on everyday life.
- Patients, caregivers and health professionals consistently identify the need for innovation in oxygen delivery devices to better meet the needs of this patient group.

#### **Conclusion**

This systematic review has highlighted the complex interplay between physical, psychological, social and organisational factors influencing the use of oxygen therapy, and suggests that improving efficacy and adherence may require targeting changes at the individual, organisational, community and societal levels. Of note was the absence of data from low- and middle-income countries, highlighting the longstanding inequities in access to medical oxygen in these countries that remain largely unaddressed [36].

Greater research efforts are needed to address the gaps in evidence regarding the benefits of oxygen therapy in ILD to provide more direct and robust evidence to guide international recommendations on when to

prescribe, to whom and for what benefit. There is an urgent need for innovation in oxygen delivery systems and sustainable equitable funding mechanisms to better meet the needs of users. Increased information and support for users will be critical to optimise the uptake and outcomes of this important therapy.

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