

**Supplementary file 4: Characteristics of included studies**

<b>Author, Year, Country</b>	<b>Qualitative methodology (e.g. grounded theory, ethnography, phenomenology)</b>	<b>Data collection methods (interview, focus groups etc.)</b>	<b>Recruitment source (setting) and strategy (e.g. tertiary clinic)</b>	<b>Sampling approach (convenience, purposive etc.)</b>	<b>Number of participants</b>	<b>ILD type/s - definition</b>	<b>Area/s of oxygen therapy reported on (e.g. ambulatory for exertional hypoxemia)</b>	<b>Aims of study</b>	<b>Demographics</b>
Belkin et al, 2014 [32] USA	Iterative process involving established qualitative content methods and reflexive team analysis	3 semi-structured focus groups of informal caregivers of patients with IPF	Interstitial Lung Disease Clinic at National Jewish Health between June 2012 and March 2013	Convenience	14 informal caregivers	IPF based on accepted criteria [ATS/ERS/JRS /ALAT 2011]	Informal carers perspectives on oxygen therapy	To learn about the effects of the disease on those closest to patients with IPF	Informal caregivers (n=14) Age mean 67±7 years, Gender (13 female, 1 male)
Burnett et al, 2019 [28] Australia	Grounded theory	Semi-structured interviews	Australian IPF Registry	Purposive	100 respondents	IPF - diagnosed by MDM	Patient experiences of modern IPF care that includes oxygen therapy	To assess the patient experience of modern IPF care.	100 respondents 61 males Group 1=5 Group 2=46 Group 3= 7 Group 4=39 Age range: 57-90 FVC 46 to 106% predicted (median 77%) DLCO 21 to 95% predicted (median 54%)

<p>Duck et al, 2015 [29] UK</p>	<p>Grounded theory</p>	<p>Semi-structured interviews</p>	<p>Regional, single specialist respiratory and lung transplant centre, where respondents had access to specialist ILD clinicians and a support group</p>	<p>Convenience</p>	<p>Patients with IPF=17 Informal carers =6</p>	<p>MDT IPF diagnosis</p>	<p>Non -specific - Part of understanding perceptions, needs and experiences of patients with IPF</p>	<p><b>Patients</b> Median age 67 years Smoking status: ex- or current smokers=10, never =7 Mean %predicted FVC (n = 17) 68% (range 44–104). Mean % predicted DLCO for 13 patients was 43% (range 23–67), 4 unable to do</p> <p>Family history of IPF n=3 <b>Oxygen therapy:</b> - None n=5 -LTOT and ambulatory n=10 -Ambulatory only n=2 Lung transplant waiting list n=3 Clinical trial participant n=3 Family member contributed to interview n=6 --5 spouses (3 females, 2 males), 1 daughter</p>
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<p>Graney et al, 2017 [31] Informal caregivers (IC) USA</p>	<p>Grounded theory</p>	<p>Structured telephone interviews</p>	<p>Participants enrolled in longitudinal observational study</p>	<p>Purposive</p>	<p>20 informal carers of patients with PF</p>	<p>n/a</p>	<p>Impact of oxygen on ICs of patients with PF, specifically (1) to gain an enhanced understanding of the experience of ICs as they are forced to incorporate O2 into their lives and (2) to hear ICs' perceptions about the effects of O2 on their PLOs (Patient loved-ones)</p>	<p>Understanding the multiple effects of supplemental oxygen therapy on ICs of patients with PF</p>	<p>Female/Male: 17/3 Age (range) 62.2 ± 9.7 (44–76) years - Relationship to Patient: 16 Spouses, 4 Children State of residence 2 CA, 4 CO, 2 WA, and 1 each from FL, GA, ID, IL, MD, MN, NE, NM, NY, OH, PA, UT <b>Duration of O2 use</b> (years) 3.9 ± 3.0 <b>O2 set-up; In-house:</b> 19 home concentrator, 1 liquid oxygen <b>Portable:</b> - 9 compressed gas only -3 liquid oxygen only -4 POC only - 3 compressed gas and POC available- 1 liquid oxygen and POC available</p>
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<p>Graney et al, 2017 [24] Patients with pulmonary fibrosis USA</p>	<p>Conventional content analysis</p>	<p>Structured telephone interviews</p>	<p>Participants enrolled in longitudinal observational study</p>	<p>Purposive</p>	<p>5 with PF</p>	<p>Diagnoses were confirmed by review of medical records and high-resolution chest computed tomography scans.</p>	<p>Effect of any oxygen on symptoms, physical activity and quality of life in patients with PF</p>	<p>To better understand the perceptions and experiences of patients with pulmonary fibrosis as they confronted the possibility and realities of using supplemental oxygen.</p>	<p>Female/Male 3/2 Age (range) in years 64.6 ± 9.4 (53-76) <b>Smoking history:</b> <i>Never 3, Past 2</i> <b>PF diagnosis</b> <i>IPF 4, CHP 1</i> Comorbid conditions <i>None 2</i> <i>PH + OSA 1</i> <i>HTN + OSA 1</i> <i>CAD +HTN+ DM2</i> <i>1</i> <b>Years of PF,</b> median (range) 2 (2e15) FVC% 52.2±14.8 (40-77)</p>
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Igai et al, 2019 [30] Japan	Meta-ethnography	Systematic review of 8 databases 1976 to 2016	n/a	n/a	4 articles - total 101 participants with IPF	Study 1): physician confirmed IPF 2) MDT IPF diagnosis 3) International guidelines diagnosis, >40 years, family caregivers >18yrs 4) Stable patients or physician confirmed diagnosis, >40yrs, Borg scale sore >=1 on exertion	Non-specific Self-care and coping experiences	To conduct a meta-synthesis of patients' narratives regarding their self-care and coping experiences with IPF, from waiting for the initial diagnosis to facing the realities of their diminishing health, the results of which might lead to the discovery of new findings in order to inform nursing interventions that are closely related to, and are aligned with, patients' experiences.	Age (study 1-4): 67 (median) 67 (median) 71.1 (median) 71.2± 8.9 (average) Sex: 22 Male (49%), 23 female (51%) 7 Male (41%), 10 female (59%) 15 Male (60%), 10 female (40%) 13 Male (93%), 1 female (7%) <b>Home oxygen therapy</b> Study 1: Continuous: 18 (40%), Non-continuous: 7 (16%), None: 20 (44%) Study 2: Continuous: 10, Ambulatory: 2, None: 5 Study 3: Continuous: 7 Study 4: Continuous: 8, Non-continuous: 4 <b>Smoking history</b> Study 1: Ex-smoker: 34 (76%), Never 11
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									(24%) Study 2: Ex- or current: 10, never: 7 Study 3: Ex-smokers: 20, Never: 5 Study 4: Ever smoked: 13, Never 1
Khor et al, 2017 [35] Physicians Australia	Grounded theory	Semi-structured interviews	Respiratory physicians currently working in Australia	Purposive	26 respiratory physicians who were currently in practice	Any ILD	Domiciliary oxygen therapy (DOT)	To explore perspectives of adults with interstitial lung disease about domiciliary oxygen therapy, comparing insights from patients using and not using oxygen therapy	26 respiratory physicians Location in Australia: Australian Capital Territory (ACT)-5, New South Wales (NSW) - 4, Queensland (QLD) - 2, South Australia (SA)-1, Victoria (VIC) - 18 Average duration in respiratory

									medicine = 13 years Sub-speciality in ILD n=10
Khor et al, 2017 [25]  Patients with ILD Australia	Grounded theory	Semi-structured interviews	ILD clinic at Austin Health in Victoria	Purposive	13 patients with ILD	Any ILD	Domiciliary oxygen therapy (DOT)	To explore perspectives of adults with interstitial lung disease about domiciliary oxygen therapy, comparing insights from patients using and not using oxygen therapy	<b>Patients receiving DOT</b> Gender: 7 males, 5 females Age (median, IQR): 68.5 (64.25-75.75) Diagnosis: NSIP (n=1), CTD-ILD (n=3), IPF (n=2), Chronic HP (n=2), Asbestosis (n=1), IPAF (n=1), Sarcoidosis (n=1) Diagnosis duration: 3.9 (1.43-4.45) FVC % pred: 57.5 (40-67) DLCO %pred: 33.5 (21.25-39.25) MMRC dyspnea scale: 3 (2.25-4) Type of DOT: Ambulatory (n=4); Ambulatory, self-funded LTOT (n=1); ambulatory, LTOT, self-funded portable oxygen concentrator (n=1);

									ambulatory, LTOT, portable oxygen concentrator (n=1) Oxygen therapy duration: 10 (8- 32.25) <b>Patients          NOT receiving          DOT</b> Gender: 9 males, 3 females Age: 67.5 (64.5- 73.75)Diagnosis: CPFE (combined pulmonary fibrosis and emphysema) n=2), CTD-ILD (n=2), IPAF (interstitial pneumonia with autoimmune features) (n=2); IPF (n=4), NSIP (n=1), Chronic HP (n=1) Diagnosis duration: 2. (1.18-4.08) FVC %pred: 70 (54.4–79.5) DLCO %pred: 43 (38.25–49.5) MMRC dyspnea scale: 3 (2–3)
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Lindell et al, 2019 [27] USA	Grounded theory	"Other" responses to two open ended questions from interviews with patients from "Patient Supplemental Oxygen Survey" What is the biggest problem that you would say you have with your oxygen? Is there some issue, other than those mentioned above, that you are having related to your oxygen?	Lung disease related websites  Lung disease professional organizations in US  ATS Public Advisory Roundtable	Convenience  Adults in the United States prescribed oxygen as a consequence of lung disease.	Survey respondents =1926	Any lung disease	Any problem related to oxygen use	To supplement the quantitative data provided in the ATS Nursing Assembly Oxygen Survey Working Group Patient Supplemental Oxygen with qualitative data from 2 select survey items to obtain more detailed information from the respondents' perspective	N=1926 Age: 64±11 years of age, female - 72%, 51% from suburban areas, and represented every state 44% living in a (CBP) area, 45% were unsure, and 11% lived in non-CPB areas. COPD (39%) and interstitial lung disease (ILD) (27%) most common diagnoses. Majority were retired (47%) or disabled (41%), with only 23% working outside the home. <b>Duration of oxygen use</b> <1 yr 17 % 1–5 yr 51% >5 yr 32% <b>mMRC dyspnea score (mean ±SD)</b> using oxygen: 1.5 (1.2) not using oxygen 2.6 (1.2)
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Ramadurai et al, 2018 [33] USA	Conventional content analysis	2 X 1 hour focus groups	Interstitial Lung Disease Clinic at National Jewish Health in 2016	Convenience Patients and caregivers were recruited through database query or in person	13 patients 4 caregivers	IPF- made according to accepted guidelines [ATS/ERS/JRS /ALAT 2011]	Non-specific	To improve the understanding of the information desired and believed to be needed by patients and caregivers and how each could use the information to improve the patient's disease journey and in what format(s) the information should be developed	<b>Patients n=13</b> Male sex 7 (54%), Caucasian race 13 (100) , Mean age, years 68.1±7.2 Supplemental oxygen - None 1 / Exertion only 5 / Continuous 7 Disease duration, years 5.7±4.4  <b>Caregivers n=4</b> Male sex 2 (50), Caucasian race 4 (100) Mean age, years 63.3±7.7
Sampson et al, 2015 [34] UK- Wales	Mixed- methods Interpretative Phenomenological Analysis (IPA)	Semi-structured interviews	Interstitial lung disease clinics Oct 2012-Aug 2014	Purposive	27 patients with IPF 21 carers (defined as person of patient's choice who contributed most to care of patient or provided emotional support during early stages)	IPF - American Thoracic Society criteria	Non-specific Associated with perceptions of disease progression, understanding symptoms and medical interventions	1. Describe changes in individuals' and carers' perceived care needs at different stages of IPF in order to improve future service interventions 2. Identify time points or triggers at which supportive and palliative care services might	<b>Patients</b> Age range 56-87 years; 9 females, 14 males; 5 on oxygen (3 extensive progressive, 2 extensive stable); 2 had lung transplant (extensive group) <b>Carers:</b> majority female

								effectively be introduced 3. Define what information individuals with IPF and their carers require over time 4. Evaluate the experiences and roles of carers for people with IPF	
Schoenheit et al , 2011 [26] Germany, France, Italy, Spain and UK	Grounded theory	In-depth interviews using projective (respondents asked to select images that express their feelings) and constructive techniques (recall what was said in particular situation) 1 hour duration Conducted in respondents homes		Convenience	45	Physician - confirmed diagnosis of IPF	Role of supplemental oxygen	1) To generate in-depth insights regarding the patient journey, including symptoms, triggers to seeking medical care, referral patterns, initial diagnoses, follow-up, and current disease management. 2) To explore the emotions encountered at each stage of this health care 'journey' and examine perceived	Median age, years 67, 65 years 23 (51%); Gender: Female 23 (51%) Country of residence: France 9 (20%), Germany 9 (20%), Italy 9 (20%), Spain 9 (20%), United Kingdom 9 (20%) Year of diagnosis: 2006–2010-- 27 (60%) Smoking history: Ever 34 (76%), Never 11 (24%), Current 0 (0%) <b>Supplemental oxygen use:</b> None 20 (44%),

								relationships with health care practitioners and caregivers, with the overall aim of identifying unmet needs and opportunities for improving the perceived quality of care	Continuous 18 (40%), Noncontinuous 7 (16%) <b>Environmental/occupational exposures:</b> asbestos 9 (20%), air pollution 17 (38%), mould 5 (11%), toxic gas, pesticide, and chemical 18 (40%) dust and fibers 2 (4%) <b>Family history of IPF:</b> Confirmed 1 (2%), Suspected 5 (11%)
Visca et al 2018 [35] UK	Grounded theory	Semi-structured interviews	Three interstitial lung disease centres (Royal Brompton Hospital, Aintree University Hospital, and North Bristol NHS Trust) in the UK.	Convenience	21 /56	Fibrotic interstitial lung disease	Ambulatory oxygen for non-hypoxic at rest	whether portable ambulatory oxygen was associated with improved HRQOL compared with no intervention in patients with fibrotic interstitial lung disease.	<b>N=21</b> 62% male 76% married or living with partner 81% retired 43% IPF, 57% other ILD  DLCO%pred 38.7