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# Perspectives on palliative oxygen for breathlessness: systematic review and meta-synthesis

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**Patients', caregivers' and clinicians' differing perceptions of the benefits and burdens of palliative oxygen should be considered when defining the goals of therapy and determining clinically relevant interventions offered for chronic breathlessness** http://bit.ly/2ZE285P

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## Abstract

Oxygen therapy is frequently prescribed for the palliation of breathlessness, despite lack of evidence for its effectiveness in people who are not hypoxaemic. This study aimed to compare and contrast patients', caregivers' and clinicians' experiences of palliative oxygen use for the relief of chronic breathlessness in people with advanced life-limiting illnesses, and how this shapes prescribing.

A systematic review and meta-synthesis of qualitative data was conducted. MEDLINE, CINAHL and PsycINFO were searched for peer-reviewed studies in English (2000–April 2019) reporting perspectives on palliative oxygen use for reducing breathlessness in people with advanced illnesses in any healthcare setting. After data extraction, thematic synthesis used line-by-line coding of raw data (quotes) to generate descriptive and analytical themes.

Of 457 articles identified, 22 met the inclusion criteria by reporting perspectives of patients (n=337), caregivers (n=91) or clinicians (n=616). Themes common to these perspectives were: 1) benefits and burdens of palliative oxygen use, 2) knowledge and perceptions of palliative oxygen use beyond the guidelines, and 3) longitudinal trajectories of palliative oxygen use.

There are differing perceptions regarding the benefits and burdens of using palliative oxygen. Clinicians should be aware that oxygen use may generate differing goals of therapy for patients and caregivers. These perceptions should be taken into consideration when prescribing oxygen for the symptomatic relief of chronic breathlessness in patients who do not quality for long-term oxygen therapy.

## Introduction

Chronic breathlessness is a cardinal symptom across many life-limiting illnesses, including cancer, respiratory, cardiac and neuromuscular diseases [1], and one of the most feared aspects of dying [2]. At a population level, approximately 9% of people live with some degree of chronic breathlessness and 2.6% of people are housebound due to extremely debilitating breathlessness [3]. In later disease stages, breathlessness prevalence increases greatly [1] and tends to intensify as death approaches [4]. Chronic breathlessness caries a significant symptom burden affecting people's physical and psychosocial wellbeing, resulting in decreasing functionality and increasing social isolation and dependence on others [5]. Caregivers' quality of life is also detrimentally affected chronically [6].

Oxygen therapy is frequently prescribed for the palliation of breathlessness in people who do not fulfil current criteria for long-term oxygen therapy (LTOT), despite lack of evidence for its effectiveness in providing symptomatic relief [7, 8]. Current guidelines limit the funded prescribing of LTOT to hypoxaemic patients (arterial oxygen tension <55 mmHg) [9]. Palliative oxygen continues to be initiated for the management of breathlessness in nonhypoxaemic patients with advanced life-limiting illnesses despite growing evidence for its inappropriateness [10, 11], often with little or no reference to the underlying pathophysiology [11]. A recent multinational survey to which 440 respiratory and palliative medicine specialists responded found that palliative oxygen prescribing is decreasing, but that the majority of palliative and just over half of respiratory physicians continue to prescribe it for the symptomatic relief of chronic breathlessness in the palliative care setting, outside current guidelines [12].

Oxygen therapy carries appreciable burdens. People using LTOT may face physical, psychological and emotional challenges, including having to adapt to new life circumstances, living in a restricting world, and submission to and dependency on a chronic therapy [13]. Self-immolation (for people who smoke) can also be a problem [14], as can the psychological burden of having to rely on a machine [15]. Data on quality of life and patient preferences using oxygen are conflicting, often finding that people prefer to discontinue their oxygen due to poor tolerability [16].

The multidimensional nature of chronic breathlessness and individual responsiveness to treatment require an understanding of the broader context in which oxygen is prescribed and used. Ideally, this should include the person receiving the oxygen therapy together with their caregiver and the clinicians providing care for them. Individual patient and clinician perceptions of oxygen therapy have been synthesised [13, 17, 18], but are lacking for caregivers. Importantly, there is a gap in the literature that compares and contrasts perspectives that capture the complexity around oxygen prescribing, assessment and impact on patients' and caregivers' everyday lives. Combining patients', caregivers' and clinicians' perspectives, and comparing them with the evidence base, is important to help determine the most relevant patient and caregiver clinical outcomes, and the drivers for prescribing and adherence to oxygen therapy in clinical practice [19]. This, in turn, will help inform future research interventions for this population, ensuring they are aligned with people's needs, values and preferences.

This review brings a triangulated perspective (patients, caregivers and clinicians) on the use of oxygen for the symptomatic relief of chronic breathlessness in people with an advanced life-limiting illness who do not quality for funded LTOT, hereafter called "palliative oxygen". The review defines chronic breathlessness as breathlessness that persists despite optimal treatment of the underlying condition(s) and life-limiting illness as any incurable malignant or nonmalignant illness from which a person is likely to die [20, 21].

Our aim was to compare and contrast patients', caregivers' and clinicians' experiences of palliative oxygen use for the relief of chronic breathlessness in people with advanced life-limiting illnesses, and how this shapes prescribing.

## Methods

This study was a systematic review and meta-synthesis [22, 23] of patients' with advanced life-limiting illnesses, their caregivers' or clinicians' narratives reporting their perceptions and experiences of using palliative oxygen. The conduct and reporting followed the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) guidelines [24]. The systematic review protocol was registered at PROSPERO with identifier number CRD42019140813.

### *Eligibility criteria*

Studies were included if they were peer reviewed, published in English from 2000 onwards, and reported the perspectives of patients, caregivers or clinicians on the use of palliative oxygen for the symptomatic relief of chronic and acute-on-chronic breathlessness in people with an advanced life-limiting illness. Studies had to report empirical qualitative data, defined as raw data, *i.e.* direct quotes (*e.g.* verbatim patient statements). Articles were required to contain at least one sample of raw data in line with minimum reporting standards [25]. Data collection methods were unrestricted (*e.g.* interviews, focus groups, open-ended survey questions, *etc.*) [26–30], as were approaches to data analysis (*e.g.* phenomenology, grounded theory, *etc.*). Quantitative and mixed-methods studies were included if they reported raw qualitative data separately in their findings. Studies reporting quantitative results only were excluded, as were (systematic) reviews, commentaries, editorials, case reports, dissertations and abstracts. Primary studies in (systematic) reviews were screened for eligibility.

The study population comprised adults ($\geqslant$18 years old) with advanced life-limiting illnesses who had been prescribed oxygen for the symptomatic reduction of their breathlessness. The use of oxygen could be for chronic and acute-on-chronic breathlessness, and in the inpatient, outpatient or community (home and aged care) settings. Studies reporting the use of oxygen in populations other than people with advanced diseases were excluded.

### *Information sources*

Databases searched included MEDLINE, CINAHL and PsycINFO, augmented by desktop searching of CareSearch for PubMed and CareSearch Grey Literature (if articles resulted in a peer-reviewed publication). Lateral searching of Google Scholar and the reference lists of included studies and relevant reviews was conducted manually. Database and desktop searches were conducted on 5 and 7 April 2019.

### *Search*

The search strategy was informed by two systematic reviews on the use of oxygen [7, 16], and included Medical Subject Headings (MeSH) terms and text words for these domains of interest: 1) dyspnoea/dyspnea/breathlessness/shortness of breath, 2) oxygen/oxygen inhalation therapy/oxygen therapy/long-term oxygen therapy/supplemental oxygen/home oxygen/domiciliary oxygen and 3) palliative care (using the Palliative Care Search Filter for MEDLINE and text word for all other databases) [31]. CareSearch for PubMed used the search for “dyspnoea” combined with “oxygen” as key words. CareSearch Grey Literature was searched using “oxygen” and “breathlessness” as key words. The MEDLINE search strategy is provided in supplementary table S1.

### *Study selection*

Results were imported into EndNote X9 (Clarivate, Philadelphia, PA, USA) and duplicates removed. Title/abstract screening with full-text review was independently performed by two researchers (S.K. and D.F.) using Covidence systematic review software (Veritas Health Innovation, Melbourne, Australia).

### *Data collection and data items*

Data extraction was two-fold. Raw quotes relating to people’s experiences and perspectives on the use of palliative oxygen for the symptomatic relief of breathlessness were imported into NVivo 12 (QSR International, Doncaster, Australia) for coding and analysis (M.G.). Additional data items were extracted (S.K. and D.F.) using electronic proformas (Word/Excel 2016; Microsoft, Redmond, WA, USA). These included author, year, country, aims, sample characteristics (patients/caregivers/clinicians, sample size setting and sociodemographics), study characteristics (design, data collection method and theoretical framework), themes/findings and conclusions. For studies with patient participants, data were extracted on the person’s health condition (*e.g.* type/stage/duration of disease, was oxygen prescribed to people who do not qualify for funded provision under current international guidelines [32] and length of oxygen therapy). For studies with caregiver participants, data were extracted on the nature of the relationship to the person receiving oxygen, the patient’s health condition and the length of caregiving. For studies with clinician participants, data were extracted on any professional characteristics reported (*e.g.* discipline and years of experience).

### *Quality appraisal*

The Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields [33] was used to appraise studies of varying design. Study quality was assessed independently by two reviewers (M.G. and D.F.); disagreements were resolved by a third reviewer (S.K.). For qualitative studies, the sum of all scores (“yes”=2; “partial”=1; “no”=0) was divided by the highest possible score of 20. For survey studies with free-text comments, the sum of all scores (“yes”=2; “partial”=1; “no”=0) was divided by the highest possible score of 28, minus any nonapplicable fields where the survey was purely descriptive.

The quality appraisal did not eliminate studies but provided an overall view of the quality of data collection and reporting. The threshold for high quality was set at $\geqslant 0.75$ [33].

### *Synthesis of results*

A three-stage thematic synthesis [22] was facilitated by: 1) free line-by-line coding of extracted raw data, 2) organisation of the “free codes” into “descriptive” themes, commencing the synthesis process, and 3) development of “analytical themes” informed by the “descriptive themes” to answer the research question.

Initial line-by-line coding was performed for the raw data of each included article (M.G.), and then discussed until consensus was reached on its accuracy and consistency (S.K. and D.F.). The development of descriptive and analytical themes was carried out by S.K. and D.F. in the first instance, and then discussed with the remaining authors (M.G., J.P. and D.C.) until consensus was reached. Descriptive and analytical themes were derived iteratively. All qualitative data (raw quotes) contributed to theme development.

Combining the three perspectives used the framework analysis [34] consisting of: 1) familiarisation (reading the quotes and results from included articles), 2) identifying a thematic framework (developing a coding system for descriptive themes consistent across different participants' groups), 3) indexing (open coding of the findings section of each article and comparison of findings between articles), 4) charting (developing analytical codes and regrouping data into overarching themes), and 5) mapping and interpretation (identifying similarities and differences between codes from different groups, *i.e.* patients, caregivers and clinicians, using a framework matrix).

## Results

### *Study selection*

Of 457 articles identified, 22 met the inclusion criteria and were included in the meta-synthesis (figure 1) [35–56]. The characteristics of the study populations and included studies are summarised in tables 1 and 2, respectively.

### *Study population*

Most studies were undertaken in high-income countries [35–49, 51–56], other than one study from China [50]. Of the 1044 participants, most were clinicians (n=616), with under a third being patients (n=337) and less than 10% being caregivers (n=91). The majority of studies only included patients (n=12) [35, 36, 39, 41, 42, 44, 46, 47, 49–51, 54, 55]. A smaller number included patients only with caregiver quotes (n=1) [35], caregivers only (n=2) [38, 43] or clinicians only (n=4) [37, 48, 52, 56]. Two studies included mixed patients/caregivers/clinicians [45, 53] and one study included mixed patents/clinicians [49].

The primary underlying conditions generating breathlessness were chronic obstructive pulmonary disease (COPD) (n=200 (59%)), followed by cancer (n=63 (19%)). Of the caregivers, 42% were spouse/partner (n=38) or relative (n=38); relatives included adult children, siblings or in-laws. Across studies, 77% of clinicians (n=477) were doctors, followed by nurses (n=122 (20%)).

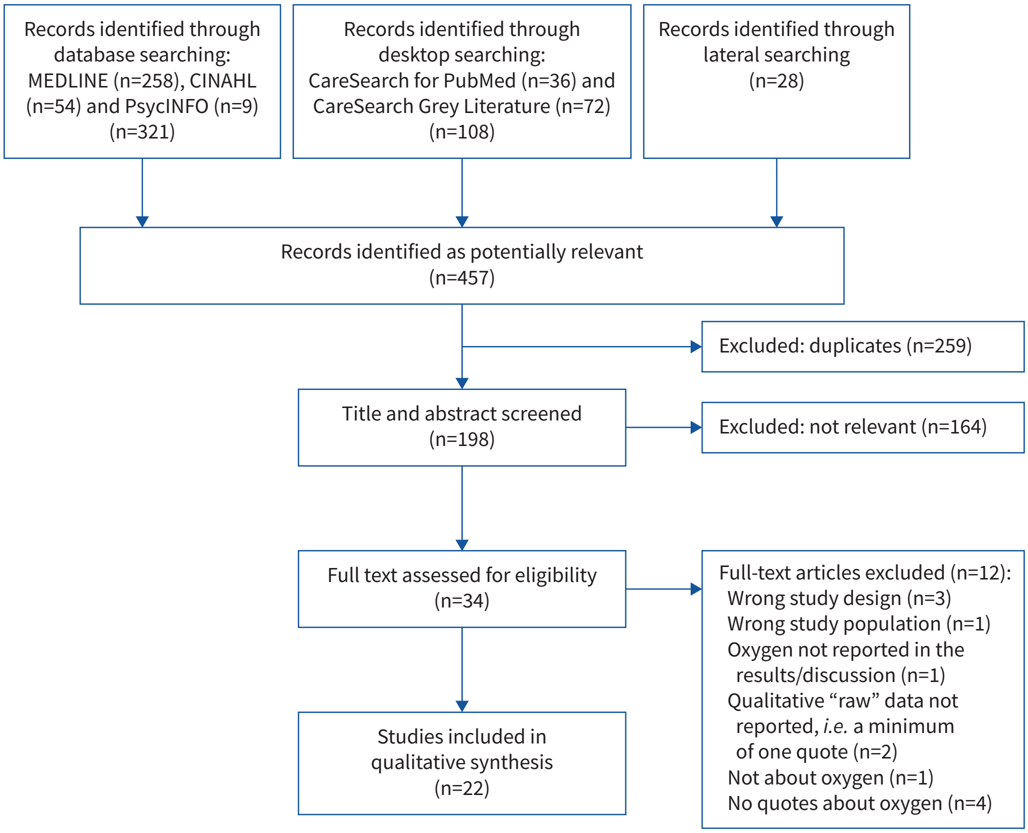

**FIGURE 1** PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) flowchart of included and excluded studies.

**TABLE 1** Summary characteristics of the 22 included studies [35–56]

| | Patients | Caregivers | Clinicians |
|---|---|---|---|
| **Subjects** | 337 | 91 | 616 |
| **Country** | | | |
| UK | 129 (38) | 35 (38) | 44 (7) |
| USA | 92 (27) | 36 (40) | 81 (13) |
| Germany | 51 (15) | | |
| Australia | 19 (6) | 20 (22) | 51 (8) |
| New Zealand | 15 (4) | | |
| Sweden | 12 (4) | | |
| China | 11 (3) | | |
| Canada | 8 (2) | | |
| Multiple | | | 440 (71) |
| **Primary aetiology of breathlessness** | | | |
| COPD | 200 (59) | | |
| Cancer | 63 (19) | | |
| Chronic heart failure | 15 (4) | | |
| Motor neuron disease | 9 (3) | | |
| Interstitial lung disease | 7 (1) | | |
| Other causes[#] | 5 (1) | | |
| Multiple causes[¶] | 10 (3) | | |
| Not reported | 28 (8) | | |
| **Service** | | | |
| Respiratory medicine | 82 (24) | | 199 (32) |
| General practice | 51 (15) | | 10 (2) |
| Palliative care | 19 (6) | | 339 (6) |
| Pulmonary rehabilitation | 10 (3) | | |
| Oncology | | | 26 (4) |
| Internal medicine | | | 8 (1) |
| Multiple | 59 (18) | | 34 (6) |
| Not reported | 116 (34) | | |
| **Patient setting** | | | |
| Community | 196 (58) | | |
| Outpatient | 65 (19) | | |
| Hospital (not specified) | 27 (8) | | |
| Inpatient | 11 (3) | | |
| Mixed | 28 (8) | | |
| Not reported | 10 (3) | | |
| **Relationship to the person receiving oxygen** | | | |
| Spouse/partner | | 38 (42) | |
| Friends | | 5 (6) | |
| Relative (adult children, sibling, in-law) | | 38 (42) | |
| Not specified | | 10 | |
| **Clinician profile** | | | |
| Doctors | | | 477 (77) |
| Nurses | | | 122 (20) |
| Paramedics | | | 6 (1) |
| Pharmacists | | | 5 (1) |
| Others | | | 6 (1) |
| **Data collection method** | | | |
| Semistructured interview | 280 (83) | 85 (93) | 91 (15) |
| Quantitative methods plus interview | 27 (8) | | |
| Focus group | 16 (5) | 6 (7) | 60 (10) |
| Unstructured interview | 10 (3) | | |
| Interviews, phone calls and field notes | 4 (1) | | |
| Survey (quantitative with some open-end questions) | | | 25 (4) |
| Survey (case vignette with free-text comments) | | | 440 (71) |

Data are presented as n or n (%). COPD: chronic obstructive pulmonary disease. [#]: other causes: bronchiectasis, lobectomy for lung cancer, "out of breath" (heavy smoker), "mark on his lung" and congestive heart failure; [¶]: multiple causes: COPD/cancer, COPD/bronchiectasis, COPD/pulmonary hypertension, COPD/asthma, pulmonary vasculitis/COPD, emphysema/asthma, hypoventilation/obesity syndrome, sleep apnoea/type II respiratory failure, COPD hypoventilation/obesity syndrome and COPD/lobectomy.

**TABLE 2** Summary of the 22 included studies

| First author [ref.] | Country | Focus | Participants | Setting | Theoretical approach and primary method of data collection | Patterns of oxygen use/ oxygen prescription | Findings (oxygen-related only) |
|---|---|---|---|---|---|---|---|
| Arnold [35] | UK | COPD patients' use of domiciliary oxygen | Patients with documented COPD (n=27) | Community | Grounded theory; semistructured interviews | Oxygen cylinder (3.4 kg) delivered with shoulder bag to allow patients to carry it; did not qualify for LTOT and had stand-alone ambulatory oxygen cylinders (n=2); already using LTOT before being prescribed ambulatory oxygen (n=11); receiving both LTOT and ambulatory oxygen together (n=14) | Lack of directions on how to use oxygen. Uncertainty about the benefits. Fear the system would run out while they were using it. Embarrassment at being seen with the system in public. Unable to carry the system (cylinder weight). Essential role of carers highlighted, as participants with no immediate carers did not use ambulatory oxygen outside the house. |
| Breaden [36] | Australia | Perspectives and experiences of people with breathlessness towards oxygen use at home | Patients with breathlessness: COPD (n=9), respiratory failure (n=2), COPD and bronchiectasis (n=1), bronchiectasis (n=1), PH and COPD (n=1), metastatic breast cancer with lung, liver and bone involvement (n=1), lung disease (n=1), asbestosis (n=1), pulmonary fibrosis (n=1), declined to state (n=1) | Hospital | Constructivism and naturalistic inquiry; semistructured interviews | Receiving home oxygen (n=13) 86%; not receiving home oxygen (n=6) 32%; of the 13 participants on oxygen, seven qualified for home oxygen and six received oxygen outside of the current funding guidelines or at their own expense | Managing distress and living with chronic breathlessness syndrome, with or without oxygen, requires a range of self-management strategies. Expectations of oxygen use: "Not as good as I thought it would be". The stigma of using oxygen: the visible and invisible. |
| Breaden [37] | Australia | Factors influencing Australian specialist palliative care nurses' initiation of home oxygen for their patients | Specialist palliative care nurses (n=51) | Community | Symbolic interactionism; focus groups | In the previous 12 months, nurses had prescribed oxygen approximately nine times (mean, range 0–100) and estimated that only three patients (median, range 0–15) had been prescribed home oxygen outside of the current guidelines | Logistic/health service issues (not reported in this paper) involving the local context of prescribing. Clinical care issues involving assessing the patient's need for home oxygen and ongoing monitoring concerns, including oxygen as a second-line treatment after other interventions providing no sufficient symptomatic benefit; concerns with safety issues. A person living alone did not emerge as a specific issue among the nurses interviewed. |

Continued

**TABLE 2** Continued

| First author [ref.] | Country | Focus | Participants | Setting | Theoretical approach and primary method of data collection | Patterns of oxygen use/ oxygen prescription | Findings (oxygen-related only) |
|---|---|---|---|---|---|---|---|
| Collier [38] | Australia | Caring for someone receiving LTOT | Caregivers (n=20): spouses (n=14), friends (n=1), children (n=5) | Hospital | Constructivist grounded theory; semistructured interviews | People receiving LTOT for chronic breathlessness and a life-limiting illness irrespective of whether they were hypoxaemic | Oxygen as a “breath of life”. Oxygen has physical and emotional benefits. Caregivers ask for oxygen. Oxygen use escalates over time. Oxygen’s burden (equipment required, difficulties leaving the house, financial costs, noise of the oxygen concentrator). Benefits of LTOT are often overestimated, whereas its potential harms are underestimated. |
| Cornford [39] | UK | Oxygen use in people who were receiving domiciliary oxygen | Patients with unspecified chronic conditions (n=24) | Community | Theoretical approach not reported; semistructured interviews | Patients receiving oxygen on repeat prescriptions | Oxygen helped maintain mastery and self-control over illness by relieving symptoms, thus enabling daily activities and roles to continue, and by the reassurance that it was available, even if not used. Self-control over the illness was maintained by individual experimentation with the best ways to use oxygen, which increased personal involvement in treatment. Concerns that oxygen should not master the individual through inducing dependency on its use. |

Continued

**TABLE 2** Continued

| First author [ref.] | Country | Focus | Participants | Setting | Theoretical approach and primary method of data collection | Patterns of oxygen use/ oxygen prescription | Findings (oxygen-related only) |
|---|---|---|---|---|---|---|---|
| Earnest [40] | USA | Lay beliefs about oxygen therapy of patients receiving domiciliary treatment | Patients with moderate to severe COPD (n=27; n=7 in the pilot and n=20 in the main study) | Community | Grounded theory; quantitative questionnaires and semistructured interviews | All participants were hypoxaemic | Three patterns of adherence to oxygen therapy: as-needed, part-time and full-time use. For many individuals, pattern of adherence changed with time, reflecting their struggle to optimally manage their health, symptoms, physical function and social milieu. Adherence to oxygen tended to increase with time and was often associated with significant personal compromises. |
| Ek [41] | Sweden | The meaning of living with advanced COPD and LTOT when living alone | Patients with advanced COPD (n=4) | Pulmonary specialist clinics | Hermeneutic phenomenology; face-face (n=17) and telephone (n=15) interviews; field notes | Length of time using oxygen: 1 year (n=1), 2 years (n=3); all patients: 16–24 h·day$^{-1}$ | Oxygen was an aid that could be perceived as increasing the patients' freedom of movement, although it could also encroach on it. Problems associated with oxygen: tank weight, fear of explosion, dry mucous membranes. |
| Ek [42] | Sweden | The lived experience of severe COPD during the palliative phase of the disease | Patients with COPD in the palliative phase (n=8) | Hospital | Phenomenology; semistructured interviews | Receiving domiciliary oxygen ~16 h·day$^{-1}$ (n=6); refused oxygen because they felt it imposed limitations on their daily activities (n=2) | While oxygen therapy makes it easier to breathe, it also hampers social activities. |
| Elkinton [43] | UK | Symptoms experienced by COPD patients' in the last year; access to and contact with health services | Caregivers of patients with COPD (n=25): wife (n=4), daughter (n=13), son (n=6), sister (n=1), brother (n=1) | Community and research department | Theoretical framework not reported; semistructured interviews | Only 11 patients on domiciliary oxygen | Oxygen improves breathlessness. Oxygen perceived as a "lifeline". Dependence on oxygen causing lifestyle restrictions (*e.g.* being housebound or only able to go outside with portable oxygen). |

Continued

**TABLE 2** Continued

| First author [ref.] | Country | Focus | Participants | Setting | Theoretical approach and primary method of data collection | Patterns of oxygen use/ oxygen prescription | Findings (oxygen-related only) |
|---|---|---|---|---|---|---|---|
| Fraser [44] | USA | Experiences of older adults with severe COPD | Patients with severe COPD (n=10) | Community and hospital | Hermeneutic phenomenology; semistructured interviews | n=8 participants were oxygen dependent and n=2 used oxygen as needed | Adjusting oxygen depending on the level of breathlessness. In some circumstances, patients remove oxygen to increase mobility. |
| Goldbart [45] | UK | Views and experiences of LTOT of COPD patients, their caregivers and healthcare professionals who deliver these services | Patients (n=16); caregivers (n=6); HPs (n=9) | Community | Theoretical framework not reported; semistructured interviews (n=11) and focus groups (n=4) | Currently receiving or had previously received LTOT | Patients and carers reported the benefits of LTOT, including increased social activity, perceived improvements in health status and self-management in routine daily activities. Concerns were regarding stigma, dependency on LTOT and deterioration in health status. Staff accounts included negative perceptions, suggesting that LTOT was often inappropriately prescribed and under-used, but recommended active patient management to address this challenge. |
| Hasson [46] | Ireland | The potential for palliative care among people living with advanced COPD | Patients with advanced COPD (n=13) | Community | Theoretical framework not reported; semistructured interviews | Not specified | Fear of not being able to access their oxygen supply in case of breathlessness exacerbation. |
| Jaturapatporn [47] | Canada | Breathlessness experience, patterns and experiences of oxygen use | Patients with metastatic lung cancer (n=6), prostate cancer (n=1), lung metastasis with unknown primary (n=1) | Community | Theoretical framework not reported; semistructured interviews | Oxygen therapy initiated at the onset of breathlessness (n=4); oxygen initiated <88% saturation (n=3); oxygen initiated >88% saturation; no information (n=4) | Oxygen has more advantages than disadvantages. Advantages include increased functional capacity, patients' perceiving oxygen as a life-saving intervention, as well as a symptom management tool. Disadvantages were decreased mobility, discomfort related to the nasal prongs, barriers to accessing oxygen therapy and noise related to the equipment. |

Continued

**TABLE 2** Continued

| First author [ref.] | Country | Focus | Participants | Setting | Theoretical approach and primary method of data collection | Patterns of oxygen use/ oxygen prescription | Findings (oxygen-related only) |
|---|---|---|---|---|---|---|---|
| Kelly [48] | UK | HPs perceptions of oxygen therapy in palliative care | HPs (n=34): nurses (n=18), paramedics (n=6), doctors (n=4), pharmacists (n=5), other HP (n=1) | Mixed (university or workplace) | Interpretative phenomenology; semistructured interviews | Not specified | Most HPs were well informed about oxygen therapy. All recognised the role of oxygen in the palliative care setting as important. The overarching theme of compassion identified subthemes of “comfort”, “do anything and everything” and “family benefit”. However, the use of oxygen in the palliative care setting was not without its dilemmas, as additional subthemes of “controversy”, “doubt” and “dependency” illustrated. |
| Kelly [49] | UK | Respiratory patients’ and HPs’ experiences and perceptions of oxygen therapy | Patients (n=28); HPs (n=34) | Mixed (university or workplace) | Interpretative phenomenology; semistructured interviews | Current or previous use of LTOT (type not specified); hypoxic or borderline hypoxia (n=14); normoxic (n=11); borderline normoxic (n=2); unknown (n=1) | Patients used oxygen for breathlessness and as an enabler; they were grateful for oxygen and accepted it as part of the disease. HPs used oxygen because it helps patients, it works and it makes HPs feel better. Oxygen is not benign and a burden is evident with potential antecedents to beliefs revealed. |
| Lai [50] | China | Breathlessness experience and helpful interventions in Chinese patients with advanced lung cancer in the palliative care unit | Patients with advanced lung cancer (n=11) | Hospital (inpatients) | Theoretical framework not reported; semistructured interviews | Not specified | Oxygen was essential to help manage breathlessness. Oxygen therapy was also a burden and inconvenient. Impact on self-image. Association with addiction. |

Continued

**TABLE 2** Continued

| First author [ref.] | Country | Focus | Participants | Setting | Theoretical approach and primary method of data collection | Patterns of oxygen use/ oxygen prescription | Findings (oxygen-related only) |
|---|---|---|---|---|---|---|---|
| Landers [51] | New Zealand | Patients' experience with advanced COPD after a life-threatening event, with focus on end-of-life issues | Patients with advanced COPD (n=15) | Community (home and aged care) | Grounded theory; semistructured interviews | LTOT (n=9) | Requirement of LTOT as a transition point in care management. Preconceptions about the benefits of oxygen and its impacts on symptoms. Frustration about lack of improvement in energy level and mobility, as well as the practical burden of the equipment. LTOT was identified as a milestone that would result in more dependency. |
| Quinn-Lee [52] | USA | Oxygen use at the end of life and its role in contemporary palliative care practice | HPs (n=25) | Hospital | Theoretical framework not reported; survey (quantitative plus some open-end questions); not reported | Not applicable | Oxygen prolongs the dying process (43%). 96% of the families had a standard "comfort care" protocol for end-of-life patients that offered oxygen, regardless of whether the patient was breathless or not. Reasons that might lead staff to use oxygen: patient comfort, family request, emotional comfort of family, prolongation of life when that was a patient goal, emotional comfort of staff. Reasons that might lead staff not to use oxygen: oxygen did not seem to bring comfort, oxygen was an irritant to the patient, prolongation of natural death was not a patient/family goal, oxygen did not add to the emotional comfort of patient, family or staff. |

Continued

**TABLE 2** Continued

| First author [ref.] | Country | Focus | Participants | Setting | Theoretical approach and primary method of data collection | Patterns of oxygen use/ oxygen prescription | Findings (oxygen-related only) |
|---|---|---|---|---|---|---|---|
| Reinke [53] | USA | Transitions (defined as experiences patients and family members viewed as milestones in the evolution of their illnesses and therapies); comparison of these perceptions with perspectives of patient's physicians and nurses to provide insight about communication about end of life care | Patients (n=55); caregivers (n=36) (spouse/partner (n=20), relative (adult child, sibling, in-law) (n=12), friend (n=4)); HPs (n=56) | Community (home and aged care) | Grounded theory; semistructured interviews | All patients on LTOT (n=55) | COPD patients explained that oxygen therapy imposed further restrictions on activities. Wearing oxygen can be accompanied by social stigmas and lead to social isolation. In the theme "activity limitations/functional decline", patients also speak about the limitations imposed by oxygen. |
| Robinson [54] | UK | The experience of living with severe oxygen-dependent COPD | Patients with episodic breathlessness (n=10) | Not specified | Phenomenology; unstructured interviews | All patients on LTOT (n=10); at least one patient discussed a portable liquid oxygen system, another talked about the oxygen concentrator; length of time on LTOT 8–48 months (mean 22 months) | Most participants did not mention the impact oxygen had on their daily lives. One expressed negative views about being oxygen dependent. Others felt that oxygen had not been of much benefit to their breathing. Some participants discussed oxygen therapy positively. |
| Simon [55] | Germany | Patients' self-management strategies for episodic breathlessness | Patients with episodic breathlessness (n=51) | Hospital (outpatient) | Theoretical framework not reported; semistructured interviews | Patients on oxygen (n=14) | COPD patients found oxygen to be effective in relieving severe episodes of breathlessness. |
| Smallwood [56] | Australia, New Zealand, UK | Current beliefs and practices of prescription of oxygen therapy among respiratory and palliative medicine doctors | Doctors (n=440): respiratory medicine (n=177), palliative care (n=263) | Mixed | Theoretical framework not reported; survey (case vignette; with free-text comments) | Not applicable | Over the past decade and concordant with guidelines, fewer respiratory and palliative medicine doctors report prescribing POT, with less believing it reduces chronic breathlessness. The majority of palliative medicine doctors and just over half of respiratory physicians still believe that POT relieves breathlessness, with this proportion increasing slightly over time. The continued use of POT highlights the challenge of managing distressing, chronic breathlessness. |

COPD: chronic obstructive pulmonary disease; PH: pulmonary hypertension; HP: health professional; LTOT: long-term oxygen therapy; POT: palliative oxygen therapy.

### *Study design*

Data in the contributing studies were collected from published semistructured interviews (n=16) [35, 36, 38, 39, 42–44, 46–51, 53–55], combined interviews and focus groups (n=1) [45], combined quantitative methods and interview (n=1) [40], interviews, phone calls and field notes (n=1) [41], focus groups (n=1) [37], unstructured interviews (n=1) [54], survey combining quantitative methods with open-ended questions (n=1) [52], and survey combining case vignette with free-text comments (n=1) [56].

Approaches to data analysis included phenomenology (n=6) [41, 42, 44, 48, 49, 54], grounded theory (n=5) [35, 38, 40, 51, 53], symbolic interactionism (n=1) [37], constructivism and naturalistic theory (n=1) [36] or was not reported (n=9) [39, 43, 45–47, 50, 52, 55, 56].

### *Study focus*

More than half of the studies focused on the use of ambulatory oxygen or home oxygen or LTOT (n=12) [35–40, 45, 47–49, 52, 56], while a smaller proportion focused on advanced or severe COPD at the palliative stage or at the end of life (n=6) [42–44, 46, 51, 53]. The remaining studies focused on advanced COPD and LTOT (n=1) [41], severe hypoxic COPD (n=1) [54], breathlessness in advanced lung cancer (n=1) [50], and episodic breathlessness across different aetiologies (n=1) [55].

Length of oxygen therapy was reported in one study where patients (n=4) received oxygen 16–24 $\mathrm{h \cdot day^{-1}}$ for 1 year (n=1) or 2 years (n=3) [41]. In one study oxygen use lasted 8–48 months (mean 22 months) [54]; in another study the duration of therapy was not specified but oxygen was received for 16 $\mathrm{h \cdot day^{-1}}$ [42].

### ***Methodological quality of studies***

The qualitative studies scored generally well, ranging from 0.6 to 1.00, with a median (interquartile range) of 0.8 (0.2), with the majority of studies scoring low in the use of verification procedures and in reporting reflexivity. The surveys [52, 56] scored generally high at 0.9 and 0.8, with a median of 0.85.

### ***Themes***

The synthesis generated 60 line-by-line codes, 10 descriptive themes and three analytical themes (table 3). These include: 1) benefits and drawbacks of palliative oxygen use, 2) knowledge and perceptions of palliative oxygen use beyond the guidelines, and 3) longitudinal trajectories of palliative oxygen use.

### *Theme 1: Benefits and drawbacks of palliative oxygen use*

Participants reported various benefits for palliative oxygen use, but not without drawbacks and impacts on daily living. Four subthemes informed this broader theme.

#### Benefits

Most patients, caregivers and clinicians (health professionals (HPs)) identified psychological [38, 47] and therapeutic benefits of palliative oxygen use [45, 55], including a reduction in breathlessness [55].

> “You know, because honestly when you see someone’s lips going blue and they are trying to breathe and can’t, you know, it is horrible. You know, especially if it is your dad or your mum or somebody you love. It is horrendous. It is horrendous. So at least with the oxygen you quickly stick it up his nose and it helps a bit. It takes a while to kind of get in them or something but yeah.” [Caregiver] ([38], p. 35)
>
> “Some patients find oxygen helpful but I think this is not because of increasing the $S_{\mathrm{pO_2}}$, I think it is psychological and one can argue the pros and cons of this, although I consider it inappropriate to give oxygen therapy in these circumstances.” [HP] ([56], p. 254)

Patients reported palliative oxygen reduced their usage of health services [45], and along with their caregivers, noted improvements in sleep, independence and quality of life [45].

> “Prior to that I would about 1 or 2 hours and now I sleep all night so that’s made a big difference.” [Patient] ([45], p. 5)
>
> “It is not going to change his life but it has picked him up. It has given him a better quality of life.” [Caregiver] ([45], p. 6)

**TABLE 3** The three stages of thematic synthesis

| Analytical themes | Descriptive themes | Line-by-line coding | Illustrative quotes |
|---|---|---|---|
| **Benefits and drawbacks of palliative oxygen use** | Benefits (psychological or therapeutic or there is lack of benefits) | Beliefs | "No, I want some [oxygen]! I asked if I could [have oxygen] and the guy said to me, well you will need a lot. Because I know it is really good for your skin. And I am like, 'I would like some of that.' Because it is, some people go and sit in oxygen things for like an hour at lunch time." [Caregiver] [38] |
| | | General benefit | "I am willing to put up with the nuisance for the benefit of oxygen; the burden does not mean much." [Patient] [47] |
| | | Health service utilisation | I: "Have you been into hospital at all since you've been on the oxygen, been involved with the service?"<br>C: "Oh yeah, yeah. Yeah, but I haven't … three times I've been in … but this is the longest time … you know."<br>I: "The longest that you've not been in?"<br>C: "Yeah … touch wood!" [Patient] [45] |
| | | Reduces acute-on-chronic breathlessness | "When it gets worse I just come straight to the oxygen. … So you cannot stop it's going to be you cannot stop it. But you can help yourself like taking oxygen." [Patient] [55] |
| | | Reduces chronic breathlessness | "It [home oxygen] was a good thing for the fact that she weren't fighting for her breath." [Caregiver] [43] |
| | | Helps with sleep | "Prior to that I would about 1 or 2 hours and now I sleep all night so that's made a big difference." [Patient] [45] |
| | | Improves independence | "He will make a cup of tea now and that is a big step for us. I know it doesn't seem very much but it is a big step." [Caregiver] [45] |
| | | Improves quality of life | "It is not going to change his life but it has picked him up. It has given him a better quality of life." [Caregiver] [45] |
| | | Physiological advantages | "It is so easy to take your own pulse and it is 120 sometimes but after the oxygen for half an hour it starts climbing down again and that is the major thing." [Caregiver] [45] |
| | | Safety net or source of security | "There are many people you go [to] and they're settled and they're not anxious. They actually take the oxygen away and they say, 'Oh, I'll use it when I need it' … so you just think, 'Oh, it must be really a security blanket [for] when you're anxious'." [HP] [37] |
| | | Emotional comfort | "Some patients find oxygen helpful but I think this is not because of increasing the $S_{pO_2}$, I think it is psychological and one can argue the pros and cons of this, although I consider it inappropriate to give oxygen therapy in these circumstances." [HP] [56] |
| | | Improves carer anxiety or distress | "You know, because honestly when you see someone's lips going blue and they are trying to breathe and can't, you know, it is horrible. You know, especially if it is your dad or your mum or somebody you love. It is horrendous. It is horrendous. So at least with the oxygen you quickly stick it up his nose and it helps a bit. It takes a while to kind of get in them or something but yeah." [Caregiver] [38] |
| | | Lack of benefit | "I've been on oxygen three years and I still get progressively worse. I don't know if that is my fault or the illness." [Patient] [54] |
| | Burdens/harms | General burden | "I am willing to put up with the nuisance for the benefit of oxygen; the burden does not mean much." [Patient] [47] |

Continued

**TABLE 3** Continued

| Analytical themes | Descriptive themes | Line-by-line coding | Illustrative quotes |
|---|---|---|---|
| | | Heavy equipment | “Then I was going to lift the oxygen tanks into the car and I can’t handle that – I don’t have the energy for that.” [Patient] [41] |
| | | Reliance on carers | “She doesn’t think it’s a problem – the weight – because she doesn’t carry it, I put it in the car between us and she uses it as she needs to when we’re going along. I sort out all the oxygen, we have one in the car and this one in the house is a back-up. I have to check them all the time ‘cause she leaves them on.” [Caregiver] [35] |
| | | Caregiver burden | “When she is on it [oxygen], yeah. I wake up in the night, every hour and a half, to check her. She just knocks it off, it is off, and I don’t know how long it has been off and I put it on and she is half asleep and she will try and put it on and she thinks she has put it on and she will fall asleep again. And I don’t know if it is because of lack of oxygen she is not waking up or just tiredness. I put it on, go back to bed. Another hour I will come and it is off again. I said, what can keep it on I don’t know? So I don’t sleep too good because I am frightened it is going to come off and I don’t know the ramifications if it stays off for more than 4 hours, what will happen to her?” [Caregiver] [38] |
| | | Social embarrassment | “… it’s just that I feel that people would stare at you and it would make me feel very uncomfortable …” [Patient] [35] |
| | | Impact on self-perception | “Wearing an oxygen cannula just looks like someone addicted to drugs. How can I face others? They think that I am an addict.” [Patient] [50] |
| | | Shame | “I think I feel like it’s shameful because I have to do it because I smoked.” [Patient] [40] |
| | | Attracts judgement | “I never go out with oxygen. I tried to go out without it and it was too difficult. Finally, I just quit that. If I were out of town, it [oxygen] wouldn’t bother me around strangers. It’s my friends, and they’re all going to say, ‘What if you quit that smoking?’” [Patient] [40] |
| | | Attracts pity | “You get people looking at you and saying oh aren’t you brave coming out.” [Patient] [45] |
| | | Social burden | “I have seen people out with portable oxygen, but I suppose there’s stigma attached to it.” [Patient] [36] |
| | Impact on daily life (mobility, activities of daily living, social life) | Can increase or hinder daily activities | “I feel as though I’ve got some independence back whereas before I was 100% reliant on other people doing things.” [Patient] [45]<br>“I have kept not wanting it really because it takes away your independence.” [Patient] [45] |
| | | Makes travel hard | “I used to dance and travel; then I was diagnosed with COPD and oxygen therapy, everything stops – it’s like you are on a leash, tied to a regimen. I feel sad I can’t do the things I would like to do with my kids … go to the horse races. I haven’t done anything I like to do.” [Patient] [53] |
| | | Can increases or hinder freedom of movement | “I don’t find the oxygen too bad. At least you can wander around with it. It is much better than the bottles. You have got the freedom of the place.” [Patient] [54]<br>“Of course, you are limited by, I call it ‘the slime.’ Because everywhere we go there is a trail of plastic behind. So that is a limitation in itself. But it does, you know, it can go from anywhere in the unit, it can go without disconnecting from the oxygen. It means whatever he is going to do he can do a little bit easier.” [Caregiver] [38] |

Continued

**TABLE 3** Continued

| Analytical themes | Descriptive themes | Line-by-line coding | Illustrative quotes |
|---|---|---|---|
| | | Can increase or hinder social activities | "I can go on days out and things like that which I couldn't do before because if we did it would only be from A to B and not do anything, I would sit in the car whilst they were doing things … whereas now it means that I can go on a day out and go with them where they're going so that has made a big difference." [Patient] [45]<br>"My social life's just gone. I can't go out or anything you know, because I've gotta drag this with me." [Patient] [45] |
| | Safety concerns | Fire hazard | "And he was sat there with a massive big gas fire blazing, with an oxygen cylinder sat in front it, and a cigarette! … and you just think … you're going to end up killing yourself." [HP] [49] |
| | | Ignition | "We had a guy who went outside to the shed and use[d] an angle grinder. It all exploded in his face. He just forgot he had it on." [HP] [37] |
| | | Equipment | "Now while I'm sitting here talking to you I'm quite happy, but if I got up and went to walk somewhere I'd have to be very, very careful or I'd fall over or something or other. So I've adopted the policy during this cold weather that I just won't go outside." [Patient] [36] |
| | | Patients living alone | "For people who live on their own, that index of caution is just ratcheted up a little bit higher." [HP] [37] |
| | | Smokers | "Some patients are sensible when they smoke … and they'll go out and smoke and relatives will go out and smoke …" [HP] [37] |
| | | Personal aspects | "I'm supposed to go out with a bottle when I go shopping … but I don't take it out [with me] because I look at myself like I'm gonna be at target. If youngsters see me walking round with one of those [oxygen cylinder], they'll think, 'well there's an old guy, he is stuffed, we'll roll him [steal from him] … I don't want anybody to know I'm crook." [Patient] [36] |
| **Knowledge and perceptions of palliative oxygen use beyond the guidelines** | Knowledge of the evidence base | Patients defer to clinicians | "Because I've been told to do that …" [Patient] [49] |
| | | Initiating oxygen | "The initiation of oxygen therapy was just one more therapy that might help." [HP] [53] |
| | | Prescribing and adjusting use | "many HPs and doctors don't really feel competent to prescribe and adjust" [HP] [49] |
| | | Lack or mixed evidence to use of oxygen | "I've become more skeptical about oxygen because, there's been little evidence to actually demonstrate that it's effective." [HP] [48] |
| | | Oxygen does not do any harm | "it's just oxygen" [HP] [49] |
| | | Ethics of prescribing oxygen | "it just seems a little bit unethical" [HP] [48] |
| | Reactive prescribing outside of current guidelines (including compassionate decision making) | Difficulty following guidelines | "Also if we pick up patients who are using their oxygen because they are perhaps under-medicated and they need a review, they need to be supported. That is how we are picking up patients who are using oxygen because there is a gap in their management somewhere so we are passing patients across for COPD review or for pulmonary rehabilitation." [HP] [45] |
| | | Reactive prescribing | "I will typically provide information on the benefits/burdens of supplemental oxygen and allow families control of this, especially if it seems they need this." [HP] [52] |
| | | Resistance to change and culture | "Reflects on entrenched practice: 'anybody and everybody had an oxygen mask on, no matter what'." [HP] [49] |

Continued

**TABLE 3** Continued

| Analytical themes | Descriptive themes | Line-by-line coding | Illustrative quotes |
|---|---|---|---|
| | | Use in acute setting | "The patients you send to hospital, the first thing they do [in the ambulance] is put oxygen on before they even get to hospital." [HP] [37] |
| | | Oxygen at the end of life | "You wouldn't want anybody to die not being able to breathe … it must be awful to die with a sense of breathlessness, must be so frightening …" [HP: nurse] [48]<br>"They want to feel like they and we are doing something for their loved one. They think the patient will suffer or suffocate without it." [HP] [52] |
| | | Oxygen for chronic breathlessness | "Regarding prescribing oxygen for very frail patients who perceive symptom benefit from oxygen despite lack of objective evidence of hypoxaemia, it is often very difficult discussing not prescribing oxygen for home for them, as per guidelines, especially in an acute setting when they are currently on oxygen." [HP] [56] |
| | | Caregiver feels they are doing something | "… it's the relatives, because they see them struggling for breath, … I've been in situations where the patient's relatives are saying 'they've done nothing to help them', so they've [GPs] given the oxygen." [HP] [48] |
| | | HPs feel they are doing something | "… health professionals feel something's being done, because patients expect something to be done, and when it's not done can feel very abandoned …" [HP] [49] |
| **Longitudinal trajectories of palliative oxygen use** | Beliefs | Beliefs (factors) affecting adherence | "If you know it's there you seem to relax but if you say to yourself, 'I have no oxygen', then you'd start to panic I think and that's when the attacks come on." [Patient] [39]<br>"The advantages are it is keeping my husband alive. He can't live without it, we know that." [Caregiver] [38]<br>"It's probably going to prolong their life, maybe for a few hours, maybe a few days … that's more cruel in a way. I suppose another person might say, 'Well why are you doing that?'" [HP: nurse] [48] |
| | | Beliefs (factors) affecting nonadherence | "Most people who get portable oxygen, they just sit and look at it. It is never used and I think that is probably one of the most wasted resources really." [HP] [45]<br>"In some cases, oxygen equipment had just been lying in homes without being used." [HP] [45] |
| | Patterns of oxygen use | Adjusting oxygen while performing certain activities | "Well, I get short of breath … so I set the oxygen higher … After I've finished bathing and drying myself and dressing, I can put it back down." [Patient] [44] |
| | | Adjusting to oxygen | "The oxygen was difficult at first. I wondered how I would get the 15 hours in, but it is quite easy. But I have managed to purchase a portable liquid oxygen system." [Patient] [54] |
| | | Concurrent therapies | "I take three puffers a day and umm they help manage it I guess [the breathlessness], it's the morphine that helps me more than anything." [Patient] [36] |
| | | Duration of use | "Originally, I thought I would [eventually get] off the oxygen, when I first got on it, and I'm sure [the physician] knew I wouldn't, but he never said. But … I don't know … It's just been a gradual thing, you know, this is the way it's going to be." [Patient] [53] |
| | | Use escalates over time | "You know I'm very conscious of it and I think, well, it might be a day when I'm very bad and it maybe wouldn't have the same effect, so I respect it and I don't use it that much." [Patient] [40] |

Continued

**TABLE 3** Continued

| Analytical themes | Descriptive themes | Line-by-line coding | Illustrative quotes |
|---|---|---|---|
| | Re-assessment of oxygen use | Re-assessment caregivers | "To my mind that doctor shouldn't have kept writing those prescriptions out. He should have had her down the surgery or come down here to have a look at her. To see does she really need all those tablets, does she really needs all that oxygen." [Caregiver] [43] |
| | | Re-assessment HPs | "If someone was severely dyspneic today and we put oxygen in, I would get them to phone me if things hadn't resolved." [HP] [37] |
| | | Self-assessment patients | "Every time I tried to, I was just gasping for air – yeah. But the strangest thing is, by the second or third day I accidentally took it off just to see how I was going and I forgot – I left it off and I forgot. … and I thought, hello what's going on? So I put it back on again straight away. Then the next day I took it off, left it off for three hours or four hours, and the next day I took it off and left it off." [Patient] [36] |
| | Oxygen dependence | Dependency and addiction | "It does bother me to feel this way, because I wonder, am I addicted to it? See, I started at 1 and I am up to 4 liters now." [Patient] [40]<br>"… when patients are put on oxygen, sometimes after a time they can feel panicky if it's not on, and actually it just induces panic and fosters a further dependency." [HP] [48] |
| | | Fear that oxygen might run out | "I'm worried it's [ambulatory oxygen] going to runout, I can see the dial going down, so I don't like to go too far away from this one [long-term oxygen therapy system], in fact it restricts me in some ways because I can't go out for long." [Patient] [35] |
| | | Over-reliance | "Patients overuse oxygen …" [HP] [49] |

HP: health professional; COPD: chronic obstructive pulmonary disease; $S_{pO_2}$: peripheral oxygen saturation.

Clinicians reflected that palliative oxygen provided emotional comfort [56] or sense of security [37], while caregivers reported it eased anxiety and distress [38]. However, some patients reported a lack of benefits [54].

> "I've been on oxygen three years and I still get progressively worse. I don't know if that is my fault or the illness." [Patient] ([54], p. 41)

### Burdens/harms

Patients noted that handling and managing oxygen equipment was burdensome [41]. The judgement or pity associated with the need for palliative oxygen impacted on patient's self-perception and generated social stigma [35, 36, 40, 45, 50]. For others, the benefits of the oxygen outweighed these burdens [47].

> "Wearing an oxygen cannula just looks like someone addicted to drugs. How can I face others? They think that I am an addict." [Patient] ([50], p. 5)

> "… it's just that I feel that people would stare at you and it would make me feel very uncomfortable" [Patient] ([35], p. 4)

> "I am willing to put up with the nuisance for the benefit of oxygen; the burden does not mean much." [Patient] ([47], pp. 767–768)

Caregivers reported they take on the responsibility of handling and carrying oxygen equipment to reduce the burden for patients though this increased their responsibility and added to their caregiver load [35, 38].

> "She doesn't think it's a problem – the weight – because she doesn't carry it, I put it in the car between us and she uses it as she needs to when we're going along. I sort out all the oxygen, we have one in the car and this one in the house is a back-up. I have to check them all the time 'cause she leaves them on." [Caregiver] ([35], p. 4)

### Impact on daily life

Patients (and sometimes caregivers) who were extremely limited by breathlessness tended to report that palliative oxygen was beneficial, increasing the physical and social space available to them and enhancing their independence [38, 45, 54].

> "I feel as though I've got some independence back whereas before I was 100% reliant on other people doing things." [Patient] ([45], p. 6)

Conversely, for patients with higher levels of function, palliative oxygen was considered to hinder daily activities and restrict freedom of movement [45, 53].

> "I used to dance and travel; then I was diagnosed with COPD and oxygen therapy, everything stops – it's like you are on a leash, tied to a regimen. I feel sad I can't do the things I would like to do with my kids … go to the horse races. I haven't done anything I like to do." [Patient] ([53], p. 606)

### Safety concerns (clinicians, patients)

To clinicians, patients living alone were a prescribing risk [37]. This was amplified if the patient smoked, as this posed a fire hazard [49], particularly in larger households [37, 49]. Use of oxygen equipment alongside other tools or equipment where ignition was possible was also seen as a safety issue [37].

> "For people who live on their own, that index of caution is just ratcheted up a little bit higher." [HP] ([37], p. 271)

Oxygen equipment itself was a hazard due to its bulkiness [36], but concerns for safety also arose from the image it created. Patients were concerned that having an oxygen tank with them signalled vulnerability and the presence of their illness, making them a "target" [36].

> "I'm supposed to go out with a bottle when I go shopping … but I don't take it out [with me] because I look at myself like I'm gonna be at target. If youngsters see me walking round with one of those [oxygen cylinder], they'll think, 'well there's an old guy, he is stuffed, we'll roll him [steal from him] … I don't want anybody to know I'm crook." [Patient] ([36], p. 86)

### *Theme 2: Knowledge and perceptions of palliative oxygen use beyond the guidelines*

Knowledge of the evidence base and perceptions of palliative oxygen use influenced prescribing and decision making in various, often contradicting ways. Two subthemes informed this theme, drawing on data (largely) provided by clinicians.

#### Knowledge of the evidence base

Clinicians expressed scepticism about palliative oxygen outside of guideline recommendations, noting lack of evidence for its effectiveness in many populations [48]. Some considered that prescribing palliative oxygen to nonhypoxic patients was deceitful when it did not reflect the clinician's knowledge of the treatment [48].

> "it just seems a little bit unethical" [HP] ([48], p. 955)

Others considered it to be just another treatment option [53], causing no harm [49]. Of note, many clinicians expressed a lack of competency for assessing, prescribing and managing their patients' palliative oxygen [49].

> "it's just oxygen" [HP] ([49], p. 624)

> "[many HPs] don't really feel competent to prescribe and adjust" [HP] ([49], p. 623)

By contrast, patients had little prior knowledge of palliative oxygen prescribing and use, and deferred these clinical decisions to clinicians [49].

> "Because I've been told to do that" [Patient] ([49], p. 627)

#### Reactive prescribing outside of current guidelines

Clinicians had difficulties in following guidelines [45], sometimes resorting to reactive prescribing of palliative oxygen in response to patient [49] and caregiver/family needs and expectations [52].

> "… clinicians feel something's being done, because patients expect something to be done, and when it's not done can feel very abandoned …" [HP] ([49], p. 626)

> "I will typically provide information on the benefits/burdens of supplemental oxygen and allow families control of this, especially if it seems they need this." [HP] ([52], p. 11)

Clinicians also acknowledged that palliative oxygen may be prescribed to frail patients to palliate their breathlessness outside prescribing guidelines [56], often for compassionate reasons. This prescribing practice was often justified by the widespread use of oxygen in acute care settings [37] and especially at the end of life [48].

> "You wouldn't want anybody to die not being able to breathe … it must be awful to die with a sense of breathlessness, must be so frightening …" [HP] ([48], p. 954)

Resistance to change and practice culture [49] also influenced clinicians' prescribing and palliative oxygen use.

> "Reflects on entrenched practice: 'anybody and everybody had an oxygen mask on, no matter what'." [HP] ([49], p. 624)

### *Theme 3: Longitudinal trajectories of palliative oxygen use*

Once prescribed, adherence to palliative oxygen therapy is influenced by people's experience, beliefs, dependency and safety concerns, resulting in dynamic re-assessment and individualised patterns of use. Four subthemes informed this broader theme, incorporating patients', caregivers' and clinicians' views.

#### Beliefs

Patients', caregivers' and clinicians' beliefs influenced adherence [38, 39, 48] and nonadherence to prescribed palliative oxygen therapy [45].

> "If you know it's there you seem to relax but if you say to yourself, 'I have no oxygen', then you'd start to panic I think and that's when the attacks come on." [Patient] ([39], p. 792)

#### Patterns of oxygen use (patients)

Many patients reflected on their use of oxygen over time, having to become accustomed to its use at the beginning but finding it easier to use over time [54]. Patients reported titrating the oxygen flow rate to accommodate their activities of daily living [44]. Some were resigned to the fact that they would have to use palliative oxygen forever [53].

> "Well, I get short of breath … so I set the oxygen higher … After I've finished bathing and drying myself and dressing, I can put it back down." [Patient] ([44], p. 553)

#### Re-assessment of oxygen use (patients, caregivers, clinicians)

Caregivers were critical of the therapeutic oxygen monitoring process, noting that clinicians should provide more hands-on assessment of the dosage and need for palliative oxygen [43]. Clinicians encouraged self-monitoring as part of ongoing assessment for its effectiveness [37]. Patients reported that self-assessment sometimes resulted in their completely ceasing the therapy [36].

> "If someone was severely dyspneic today and we put oxygen in, I would get them to phone me if things hadn't resolved." [HP] ([37], p. 271)

#### Oxygen dependence (patients, clinicians)

For patients, increase in dosage was a concern, indicating they may be becoming addicted to palliative oxygen [40]. Clinicians noted that patients easily become over-reliant on palliative oxygen therapy [49], and that their dependency can also be linked to fear and anxiety that arises when oxygen is not on [48]. Patients made a conscious effort to reduce palliative oxygen use during periods of rest because they were worried that continuous use would result in ineffectiveness [40].

> "It does bother me to feel this way, because I wonder, am I addicted to it? See, I started at 1 and I am up to 4 liters now." [Patient] ([40], p. 752)

## Discussion

This is the first study to compare, contrast and synthesise patients', caregivers' and clinicians' perspectives on the use of palliative oxygen for the symptomatic relief of breathlessness in people with advanced life-limiting illnesses. The findings are presented within a proposed research agenda to advance the science of palliative oxygen use in this setting (table 4) [19].

### ***What is the true role of oxygen therapy in clinical practice?***

When considering the use of palliative oxygen for the relief of breathlessness, the goals of treatment need to be clearly defined based on patients' and caregivers' priorities [19].

#### *Function and activities of daily living*

Maintaining functionality and independence is crucial for people who are chronically breathless. This review found that palliative oxygen can facilitate or hinder their mobility, which strongly influences the net benefits of this therapy (weighing benefit and harms). Patients who are severely limited by chronic breathlessness and housebound are more likely to report an overall positive experience with palliative oxygen therapy. For this population, the burdens of palliative oxygen are small when compared with the gains in autonomy and freedom of movement. Conversely, patients who are less limited by their

**TABLE 4** Implications of key stakeholder's perspectives on palliative oxygen for clinical practice, education and future research

| Key stakeholder groups | Implications for … | | |
|---|---|---|---|
| | Clinical practice | Education | Future research |
| **Patients** | Patients should be included in the decision-making process when considering palliative oxygen [49].<br>If palliative oxygen is initiated, patients should be asked about impacts of therapy on them since benefits and harms will vary for each individual [35, 36, 38, 40, 41, 45, 47, 50, 54, 55].<br>Domains include mobility, ability to perform daily activities and impacts on social life or self-image [35, 36, 38, 40, 45, 50, 53, 54].<br>For people who do not have a caregiver, support should be offered so that safe, practical handling of equipment can be managed [35, 38]. | Patients should be informed about the hoped for benefits and likely harms of using palliative oxygen before therapy is initiated [38, 39, 45, 48].<br>Ongoing discussions about the net effect of the therapy may help to ensure optimal use while addressing concerns about oxygen dependence [40, 48, 49]. | Studies should prospectively evaluate the net effects of palliative oxygen on changes in functional status or activities of daily living to better define its role [38, 45, 53, 54].<br>Other patient-relevant outcomes include quality of life, sleep and psychological wellbeing [35, 36, 38, 40, 45, 47, 50].<br>Monitoring self-administration will help identify patterns of use and adherence [36, 44, 54].<br>Patterns of health service utilisation should also be evaluated to assess the impact of palliative oxygen on unplanned health service contact [45]. |
| **Caregivers** | The presence of a caregiver increases the likelihood of palliative oxygen being prescribed, lessening safety concerns [37].<br>Compassionate prescribing to reduce caregiver anxiety and distress at the end of life is often cited as a reason for use of oxygen outside guidelines [37, 38, 48, 49, 52, 56].<br>Patient–caregiver partnerships are important in how people optimise the use of palliative oxygen [35, 38]. | Caregivers should be offered advice about how to administer oxygen, including parameters for adjusting dose [43].<br>If therapy is initiated, caregiver needs should be regularly assessed and supported in their role [35, 38].<br>Although palliative oxygen may reduce breathlessness, its administration and supervision may create physical and psychological burdens for caregivers [35, 38]. | Studies should prospectively evaluate the benefits and harms of palliative oxygen on caregivers, especially if this support is provided over long periods of time, including measures of anxiety and distress [35, 38].<br>A dyadic approach, where possible, will provide further insights into the dynamics of negotiations between patients and caregivers. |
| **Clinicians** | Clinicians should systematically assess the impacts of palliative oxygen on patients and caregivers [35, 36, 38, 40, 45, 50, 53, 54].<br>Assessment should be multifaceted (activities of daily living, psychosocial wellbeing, sleep, safety), and should be conducted in relation to baseline breathlessness intensity and performance status [35, 36, 37, 38, 40, 45, 47, 50, 53, 54, 55].<br>Adherence should be assessed [36, 37, 43]. | Training modules should be developed to: improve clinicians' ability to recognise, assess and manage breathlessness, and guide clinicians' use of palliative oxygen [37, 45, 48, 49, 52, 53, 56].<br>Systematic assessment of chronic breathlessness (especially its impact on everyday life) will help improve patients access to evidence-based interventions that can be used with (or instead of) palliative oxygen.<br>If no caregiver is available, greater attention should be paid to the education of patients about using palliative oxygen [35, 38]. | Future interventions should further investigate the reasons for palliative oxygen prescribing [37, 45, 48, 49, 52, 53, 56].<br>Use acutely will continue to influence practice, so delineating the effectiveness of oxygen in acute-on-chronic compared with chronic breathlessness in prospective studies will help inform clinical practice [37]. |

breathlessness report that the oxygen equipment reduces their mobility and ability to engage in social activities. These findings align with the body of evidence suggesting that people with severe breathlessness prioritise maintaining their autonomy and "life space" (*i.e.* the actual physical and social space available to them) [41] until later stages of their disease [57–60].

### *Psychological benefit*

All groups in this review reported that palliative oxygen is sometimes helpful to reduce the psychological distress associated with chronic breathlessness, especially when experiencing acute exacerbations. This trust in the effectiveness of oxygen reduced the anxiety associated with breathlessness, breaking the breathlessness–anxiety–breathlessness cycle [61, 62]. Caregivers are often significantly distressed by patients' breathlessness [6], so the availability of palliative oxygen may help to ease their anxiety by believing something is being done, particularly at the end of life [63].

#### *Quality of life and health services utilisation*

Some patients reported improved quality of life and fewer hospitalisations as benefits experienced with palliative oxygen therapy [45]. Patients and caregivers also reported improvement in sleep [45]. This may be a direct result of small gains in function (due to enhanced blood oxygenation) or reduced anxiety associated with breathlessness. Improved function and interruption of the breathlessness–anxiety–breathlessness cycle may also help reduce deconditioning, which is a key contributing factor for disability associated with breathlessness [45, 60, 64–66].

### *What are the clinically relevant burdens or harms associated with oxygen administration?*

#### *Environmental issues*

For patients who tolerate higher degrees of exertion, palliative oxygen can hinder mobility and potentially lead to greater social isolation [19, 45, 53]. These patients report that the use of palliative oxygen may affect their entire personhood, posing physical, psychological and social challenges, and increasing reliance on others. Aspects related to equipment management and safety concerns feature prominently in the narratives of patients, caregivers and clinicians. Safety concerns involve tripping on equipment or fire hazards. The presence/absence of a caregiver can be a mitigating factor in how well people cope with these challenges daily and over the course of treatment.

#### *Psychological issues*

Psychological dependence on oxygen is a key harm reported by all groups in this review. Palliative oxygen has a psychological impact on patients and caregivers while using it, and on clinicians when deciding its appropriateness. Caregivers find palliative oxygen reassuring because it provides them with concrete tools to help patients with their breathlessness. For patients, however, palliative oxygen may carry a psychological and emotional burden as it restricts their social interactions and space [41]. Safety concerns can also be psychological when they are out and about in public, with patients reporting vulnerability and negative perceptions. This means burdens and harms need to be looked at in the broader context of the patient–caregiver partnership. For patients who do not have caregivers, these burdens will be amplified as patients would have to deal with them alone (*e.g.* when handling the equipment, being less mobile, in interactions with others, *etc.*).

### *Who are the drivers for oxygen prescribing by clinicians: patients or caregivers?*

#### *Evidence-based compared with reactive prescribing*

The drivers for prescribing palliative oxygen are complex. The net benefits of palliative oxygen for the relief of chronic breathlessness in people with advanced life-limiting illnesses who are not hypoxaemic are still unknown [8, 59] and clinicians are often unsure of the outcomes they are trying to achieve. Often, their focus will be symptom relief, but compassionate prescribing means palliative oxygen will be given for patient/caregiver support in the hope that it will not do much harm. This is particularly true towards the end of life, when decisions to initiate/maintain palliative oxygen are often driven by caregivers and clinicians, potentially to the exclusion of patients.

This review suggests that prescribing is often for compassionate reasons: to ease caregiver distress, because the person is at the end of life or because palliative oxygen might provide emotional comfort and a sense of security to either the patient or the caregiver. This, in part, may be a reflection of more intense breathlessness experienced by the patient in the last weeks/days of life [67, 68]. Addressing patients' and caregivers' distress is an important aspect of providing care at the end of life [69, 70] and a common goal of care for all parties involved. Although palliative oxygen may play a role in such situations, its use needs to be considered within a larger framework with other evidence-based interventions [71–75]. There is also an element of palliative oxygen being an intuitive therapy ("if you are out of breath it means you need more oxygen") and this needs to be addressed in clinical practice.

#### *Established practices*

This review found that established practice culture and (lack of) knowledge of current prescribing guidelines are contributing factors when initiating and assessing the use of palliative oxygen. Oxygen use in acute settings [7, 76] can be a major driver for clinicians to prescribe palliative oxygen outside of guidelines [77, 78]. Uncertainty about the evidence can also compound this practice. Importantly, improving the functional independence of the patient (*e.g.* their mobility or ability to perform daily activities) was not a stated consideration for clinicians when prescribing palliative oxygen. Although this aligns with current evidence that ambulatory oxygen compared with medical air in people with COPD does not improve function [59], it raises the question of how clinicians evaluate relevant outcomes for their patients and caregivers [19] when deciding treatment.

Patients defer to their doctors the decision of initiating palliative oxygen and there is a sense of “the doctor knows best”. Once prescribed, however, patients actively monitor the benefits/harms and reassess their need for palliative oxygen (when and in what circumstances), thus managing their oxygen use without seeking clinicians’ advice. For clinicians, knowledge of the evidence base is important when initiating and continuing palliative oxygen, and any lack of knowledge or uncertainty means palliative oxygen will be prescribed outside of the prescribing guidelines. Re-assessment is often not consistent.

### *Caregiver availability*

A large cohort study of people on home LTOT for chronic breathlessness at the end of life found that not having a caregiver significantly reduces the likelihood of being prescribed oxygen [63]. This review provides potential explanations for these findings, while confirming that caregiver availability is one of the key factors influencing palliative oxygen prescribing and adherence. Palliative oxygen is often prescribed to ease caregivers’ anxiety; it helps them to have something with which to respond when the patient was seen to be breathless. Clinicians feel more confident prescribing palliative oxygen to patients with an available caregiver, mainly due to the risks associated with its use. A new finding from the current review is that caregivers play a significant role in ameliorating the drawbacks of palliative oxygen use (*e.g.* assisting with equipment), thus helping patients cope better with the prescribed therapy. In many cases, patients would not be able to cope with the demands of the therapy alone, a factor that needs to be taken into account by clinicians when considering palliative oxygen therapy.

## *Implications for clinical practice and education*

The review’s findings have implications for clinical practice and education (table 4).

The findings suggest that the relevant outcomes of palliative oxygen therapy ought to be determined by and tailored to the individual(s), in the context of their clinical history, discussed at the start of therapy, and assessed over time to ensure that the intervention aligns with patients’ and caregivers’ needs and preferences. Acknowledging the burden (physical, emotional and psychological) experienced by patients and caregivers is important. Identifying the specific challenges and daily activities hindered by chronic breathlessness [60] may help to select patients that are more likely to derive benefit from palliative oxygen therapy, as would assessing desaturation associated with tasks that the patient finds important. Sleep assessments should also be routinely conducted. Safety concerns (environmental and psychological) should be discussed when therapy is initiated and as it progresses. These should include issues around the practical handling of equipment and home environment. Psychological assessment is critical for both patients and their caregivers, especially the impact of oxygen on their social interactions and independence. Establishing a shared understanding of the goals when considering prescribing outside the guidelines is important, especially at the end of life. Clinicians should be aware that their goals may not always align with those of their patients and caregivers, so eliciting patients and caregivers concerns should be a priority and incorporated in a shared decision-making process when prescribing palliative oxygen therapy. Once prescribed, clinicians should regularly assess oxygen use and monitor adherence. Burdens and harms should be assessed for the patient–caregiver unit and support offered to patients who do not have a caregiver to minimise those risks.

## *Strengths and limitations*

The rigorous methodological approach to synthesise the qualitative data and identify themes (*i.e.* generate findings) enabled a triangulated perspective of the use of palliative oxygen in people with advanced life-limiting illnesses. Identifying what is unique and shared across the populations of interest (patients, caregivers and clinicians) has provided significant insight into the experiences, painting a more comprehensive picture of what life is really like for patients using palliative oxygen, their caregivers and clinicians. Generating themes based on reported quotes means the findings are directly representative of patients and caregivers voices.

Incorporating palliative care in the search strategy means that people with late-stage disease who have qualified for LTOT but are not receiving palliative care may have been missed. The majority of the patient population in the included studies had COPD as the primary condition generating breathlessness compared with other diseases, which limits insights into the use of palliative oxygen for other patient populations. Combining the various conditions and healthcare settings may also limit applicability, and future studies should look to delineate the use of palliative oxygen in these settings. The original authors were not approached to provide clarification about the numbers of patients receiving LTOT across the studies. The synthesis relied exclusively on the use of raw data (*i.e.* quotes) and did not consider the themes generated by the authors of the original articles, which means issues not reflected in the quotes (but summarised in those themes) may have been missed.

### *Conclusions*

There are differing perceptions regarding the benefits and burdens of using palliative oxygen. Clinicians should be aware that oxygen use may generate differing goals of therapy for patients and caregivers. These perceptions should be taken into consideration when prescribing oxygen for the symptomatic relief of chronic breathlessness in patients who do not quality for LTOT. Future interventions should use outcome measures that are important to patients and caregivers, and make a difference to their wellbeing. Before initiating palliative oxygen, clinicians have an opportunity to explore the meaning of the therapy to patients and, separately, caregivers.

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