Healthcare experiences of adults with COPD across community care settings: a meta-ethnography

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The healthcare experiences of patients with COPD often fall short of what is expected and needed by these patients https://bit.ly/3UAAOQQ

Abstract

Background Studies investigating lived experiences of patients with COPD raise important concerns about interactions with healthcare professionals. Patients often describe feelings of guilt and shame associated with their COPD and may experience stigma and poor patient experience of care. The aims and objectives of the present study were to systematically scope and synthesise findings from peer-reviewed qualitative studies describing healthcare experiences of patients living with COPD across community care settings.

Methods A meta-ethnography was undertaken. Database searches were performed in Ovid MEDLINE, PsychINFO, Ovid Emcare, CINAHL Plus and Sociological Abstracts. Eligible qualitative studies were included. Study screening and data extraction was performed by two independent reviewers. A "line-of-argument" synthesis and deductive and inductive analysis was used to identify key themes, where the deductive element aligned to Wong and Haggerty's six key dimensions of patient experiences.

Results Data from 23 studies were included. Experiences and their meaning to patients were explored within the context of six domains of patient experience including access, interpersonal communication, continuity and coordination, comprehensiveness and trust. Inductive coding revealed emotion, stigma, identity and vulnerability shaped healthcare experiences of adults with COPD.

Implications Experiences often fell short of what was expected and needed in community settings. Adopting strategies to improve experiences of care in the community can be expected to improve self-management and contribute to improved health outcomes and quality of life. These strategies should take account of vulnerability, stigma and emotions such as guilt and blame that are potent affective drivers of the experience of care for patients with COPD.

Lessons for clinicians

- One of the key contributions of this review is highlighting how healthcare experiences can be shaped by emotion, identity and vulnerability and are clearly vital perspectives to understand the healthcare needs of people with COPD.
- Further studies are needed to understand the mechanisms underpinning the impact of judgemental attitudes and guilt related to smoking and smoking-related respiratory illness. It is important to understand the experience of trust and the meaning trust has to the patient with COPD.
- Future research should explore a broader scope of access, from perception of need through to healthcare consequences.

Introduction

COPD is the fourth leading cause of disability-adjusted life-years in people aged 50 to 74 years and third leading cause for those over 75 years of age [1]. Its prevalence is disproportionately higher among individuals in the lowest compared to highest socioeconomic groups (prevalence rates higher in men compared to women) [2, 3], mirroring rates of smoking in the community [4]. COPD commonly results in difficulties carrying out simple tasks such as walking or climbing stairs [5] and has substantial social impacts [6].

Delivery of evidence-based patient-centred care necessitates a detailed understanding of patients' perceptions of their healthcare experiences [7]. Research in patient experience has grown rapidly in the past decade, with evidence suggesting patient experiences of care are associated with outcomes including safety, clinical effectiveness, therapy adherence and engagement with preventive care [8]. The patient experience encompasses a range of interactions and relationships between patients and the healthcare system, including structural elements of care as well as affective and relational components [9].

WONG and HAGGERTY [10] suggest six dimensions of patient experience as most relevant to patients in primary care settings. These dimensions were identified based on manually categorising items from 17 different instruments and surveys assessing patient experiences in primary healthcare and encompass the following: accessibility of care; interpersonal communication; continuity and coordination; comprehensiveness of services; trust; and patient-reported impacts [10].

Understanding patient perspectives of care is an essential consideration in the delivery of good clinical care. Quantitative studies of COPD patients' experiences of care reveal significant gaps in the delivery of important aspects of patient care, while qualitative studies have suggested care experience does not always meet patients' expectations [11–16]. Negative healthcare experiences may impact provision of evidence-based care and exacerbate patient perceptions of inequality and feelings of stigmatisation [17].

Care for people with COPD can be managed effectively in the community by general practitioners either independently or collaboratively with respiratory specialists providing outpatient care and through referral to community pulmonary rehabilitation [18]. The experience of care in these settings can influence ability to self-manage COPD and is important for reducing the need for acute and inpatient hospital services [12, 19]. A key care objective is to improve quality of life [20], by supporting patients with COPD to self-manage their condition and offer assistance through appropriate referral where appropriate [20].

People who smoke can be particularly vulnerable to poor patient experience in healthcare settings, particularly those with lower socioeconomic status [13] and those living with chronic, smoking-related illnesses [21]. This is particularly relevant in COPD as many people report feelings of guilt and shame about smoking and "self-inflicted" smoking-related disease [22, 23], and this might lead to experiences of stigma in healthcare settings which exacerbate poor patient experience of care [21].

Individual qualitative studies have been valuable in revealing insights into the lived experiences of people with chronic conditions including their experience of healthcare. Meta-ethnography is an approach to the synthesis and interpretation of qualitative research findings from different studies as they relate to a target experience or phenomenon [24, 25]. Compared to meta-analytic and integrative reviews, it is an interpretive endeavour aligning with an interpretivist framework [24] and is especially useful when researchers are interested in conceptual or theoretical understandings of a particular phenomenon [26].

This review aimed to identify and synthesise findings from qualitative studies describing the healthcare experiences of people living with COPD, and to compare experiences (where possible) between current and former smokers using meta-ethnography methodology.

Methods

The review methodology followed the seven steps for meta-ethnography described by NOBLIT and HARE [24] and others [27, 28]. These steps include: 1) identifying a refined research question; 2) defining focus of synthesis and locating relevant studies; 3) reading the studies; 4) determining how the studies are related; 5) translating studies into one another; 6) synthesising translations; and 7) expressing the synthesis [24]. Reporting followed eMerge recommendations for meta-ethnography [29] and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [30]. The methodology was registered on PROSPERO (ID: CRD42021251676).

Selection of articles
Eligibility criteria

Full text qualitative studies describing experiences of care of patients living with COPD were eligible for inclusion. Our definition of experience of care drew upon that described by WONG and HAGGERTY [10]. Studies must have been published in academic journals and may have drawn upon any interpretative methodology (*e.g.* phenomenology, grounded theory). Owing to their unique context, studies describing experiences of hospital emergency, inpatient or palliative care settings were not considered.

A search strategy was developed with the guidance of an academic librarian. Search terms included controlled vocabulary, keywords and synonyms related to COPD, patient experience of care and qualitative methodologies. Papers were not restricted by year of publication [31]. Database searches were conducted from inception to February 2021 for MEDLINE, PsychINFO, EMCARE, CINAHL and Sociological Abstracts. The final search strategy for each database is presented in the online supplementary File 1. Titles and abstracts were exported into Covidence software for screening and duplicates removed. Two reviewers then independently reviewed the title and abstracts to identify studies meeting inclusion criteria for full text screening (S. Madawala, C. Barton, C.R. Osadnik and K. Kasiviswanathan). Any disagreements were resolved *via* consensus or by discussion with a third reviewer. Full text articles were retrieved and read by two authors who made a final decision on inclusion based on the principles of intensity sampling (to include information-rich studies and exclude those with insufficient detail and/or depth [32]). Reference lists of included studies were hand searched and footnotes traced *via* citation searching [25, 33]. Results from the search were reported in a PRISMA flowchart (figure 1).

Data extraction and analysis

The lead author (S. Madawala) read the included studies "intensely and actively", multiple times [34], and maintained a reflective journal for auditing purposes and reflexivity [35]. Key elements of studies were noted, including use of metaphors and key concepts, to optimise theoretical sensitivity and assist with subsequent identification of themes.

A standardised template was used to extract data related to study context, data collection method, description of participants, results and conclusions (see supplementary File 2). The results and discussion section of included studies were then imported into QSR NVivo for secondary synthesis. Meta-ethnographies describe data as first-order, second-order and third-order constructs [24, 27, 36]. First-order constructs are the research participants' accounts, second-order constructs are the original interpretations of the first-order constructs and third-order constructs are the interpretations formed in the synthesis regarding the second-order constructs. Second-order constructs are the principal "raw data" for meta-ethnographies [36].

QSR NVIVO was used to manage the synthesis of data, supporting the authors to interpret results code and formulate themes across studies. NOBLIT and HARE [24] suggests developing a list of metaphors/ideas (phrases or themes) from each study and juxtaposing them by examining the relationships between the metaphors in each study. Common and recurring concepts in each study were identified using this method. A concept is a "meaningful" idea developed by comparing that can explain rather than describe the data. The author constantly examined key concepts within and between studies, comparing them for the absence and presence of key concepts.

Similarities and differences were highlighted between concepts/metaphors to assist with forming further conceptual categories and to explore each of the study aims. The research studies were organised in different orders to assist with this, such as chronological order, by smoking status and by health setting, allowing the researcher to perform this comparing and contrasting across the settings of interest and over time.

Maintaining awareness of the researcher's position (reflexivity) is important in meta-ethnography research. The primary researcher (S. Madawala) is a nonsmoker, who has completed an undergraduate psychology degree and has conducted this meta-ethnography as part of a PhD programme. The researcher has no direct experience of airways disease, either personally or in the care of others. S. Madawala can be viewed as being an outsider in relation to concepts of smoking and COPD. However, S. Madawala is a consumer of health services and is undertaking her PhD within an academic department of general practice, and this potentially reflects an insider perspective. As ACKER [37] highlights, this debate cannot be fully resolved. The researcher identifies as having an outsider perspective in relation to these participants but aims to approach all stages of investigation including analysis of data as empathetic and independent from the medical establishment.
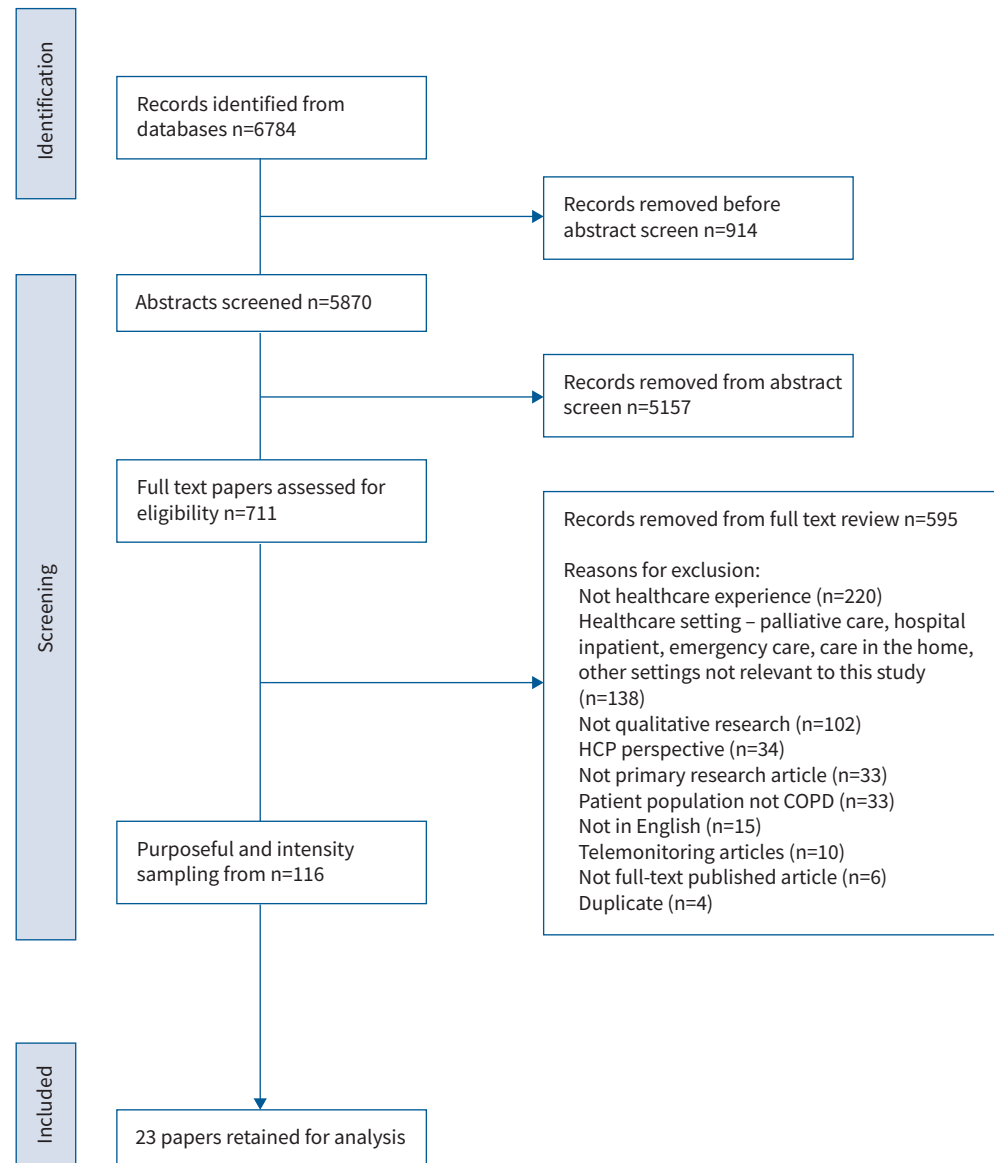
FIGURE 1 PRISMA flow diagram showing selection of papers for inclusion.

Team discussions and journaling occurred frequently to assist in maintaining reflexivity, and to identify alternate explanations and avenues for further exploration.

Data analysis was conducted *via* a "line-of-argument" synthesis – an interpretative process that compares and juxtaposes translated themes and sub-themes with secondary themes of original authors. Deductive and inductive analysis was used to identify key themes, with the deductive element aligned to WONG and HAGGERTY's [10] six key dimensions of patient experiences (refer to table 1 for definitions). Inductive analysis was conducted to organise and describe experiences that were not accounted for by WONG and HAGGERTY's [10] model but contributed to the patient experience. Quality appraisal of included studies was determined using the approach of ATKINS *et al.* [28], as outlined in table 2 (see results in supplementary file 3).

Results

116 studies met the broad inclusion criteria for the review. Intensity sampling was used to select the final set of 23 "information-rich" studies included in the synthesis. Excluded studies are listed in supplementary file 4.

TABLE 1 Definition of WONG and HAGGERTY's [10] patient experience domains used in the assessment of patient experiences of care	
Patient experience domain	**Definition**
Access	Access can be broadly defined as the ease and ability for consumers and community groups to access a provider, service or an institution
Interpersonal communication	The extent to which patients are involved in making decisions about their treatment
Continuity and coordination	Continuity is the patients' experience of care over time. Coordination is the provision and organisation of health services and information to meet a patient's health needs
Comprehensiveness of services	The provision, either directly or indirectly, of a full range of services to meet patients' or clients' healthcare needs
Trust	The expectation that the other person will behave in a way that is beneficial and that allows for risks to be taken based on this expectation and the expectation that the other person will behave in a way that is beneficial and that allows for risks to be taken based on this expectation [10]
Patient-reported impacts	Patients' or clients' ability or readiness to engage in health behaviours that will maintain or improve their health status

Included studies were published between 2000 and 2020 with a predominance of healthcare settings from the UK (n=6), Norway (n=5), Australia (n=3), Canada (n=2) and Denmark (n=2) (see table 3 for study characteristics). Sample size ranged from 8 to 37, with men represented slightly more than women. Five studies described healthcare experiences in primary care settings [38–44], eight studies discussed experiences within community pulmonary rehabilitation settings [23, 41, 45–51] and one study reported on experiences from an outpatient care setting [52]. Eight studies described experiences across or within a general healthcare setting [15, 53–57] and one study within the telehealth setting [58].

The overall quality of included studies was high. The most common issues identified included lack of description of the role of the researcher, which is important for maintaining reflexivity in qualitative studies.

Access

Issues in access to care were a common concern for patients with COPD and were reported widely in the literature across primary care, specialist care and pulmonary rehabilitation. Good accessibility to care provided patients with a sense of security when symptoms worsened or when uncertainty existed regarding the steps to care [57]. Barriers to accessing care reported by patients with COPD included both service and system factors like distance to services, hours of availability and number of appointments available, and costs of services, as well as patient-related factors such as ability to pay for services, time and ability to travel to appointments, health and emotional factors, perceptions of availability and acceptability of care.

> My last experience of going to the doctors … I phoned up and he said well come down. Oh and the pain that I felt walking into the, waiting, getting there and waiting …. I found it quite heartless really. That he, you know, expecting me to go all the way down there. [43]

TABLE 2 Quality appraisal criteria
1. Is this study qualitative research?
2. Are the research questions clearly stated?
3. Is the qualitative approach clearly justified?
4. Is the approach appropriate for the research questions?
5. Is the study context clearly described?
6. Is the role of the researcher clearly described?
7. Is the sampling method clearly described?
8. Is the sampling strategy appropriate for the research question?
9. Is the method of data collection clearly described?
10. Is the data collection method appropriate to the research question?
11. Is the method of analysis clearly described?
12. Is the analysis appropriate for the research question?
13. Are the claims made supported by sufficient evidence?

TABLE 3 Characteristics of included studies

Authors (year) [ref.]	Sample	Healthcare setting	Data collection	Type of methodology	Quality appraisal score using Atkin's quality appraisal tool
BAUER and SCHIFFMAN (2020) [38]	28 patients (12 men, 16 women), Mean of 4 comorbidities, 6 current smokers, 18 ex-smokers, 4 nonsmokers	Primary care	Semi-structured interviews	Thematic analysis	12
ELLISON et al. (2012) [39]	14 patients (7 men, 7 women), 7 current smokers and 7 ex-smokers	Primary care	In-depth semi-structured interviews (40 to 60 min)	Thematic analysis	13
FOTOKIAN et al. (2017) [54]	15 patients with COPD	General healthcare setting	In-depth semi-structured interviews (30–100 min)	Grounded theory	13
GORST et al. (2016) [58]	8 patients (5 women, 3 men)	Telehealthcare	Face-to-face semi-structured interviews (mean=45 min)	Interpretative Phenomenological Analysis (IPA)	13
GUO and BRUCE (2014) [45]	25 participants (12 women, 13 men), 8 current smokers, 16 nonsmokers, 1 experimenter	Pulmonary rehabilitation	Focus group discussions using a semi-structured topic guide	Thematic analysis	12
HALDING et al. (2018) [40]	11 patients (6 men, 5 women), 4 answered YES to smoking	Primary care	Semi-structured interviews (45–90 min)	Content analysis	13
HALDING et al. (2010) [46]	18 participants (13 men, 5 women), 11 were ex-smokers and 5 were current smokers	Pulmonary rehabilitation	33 qualitative interviews (40–90 min), 2 sessions with each participant	Interpretive phenomenology	12
HALDING et al. (2011) [23]	18 participants (13 men, 5 women), 11 were ex-smokers and 5 were current smokers	Pulmonary rehabilitation	33 qualitative interviews (40–90 min), 2 sessions with each participant	Qualitative content analysis	12
HARB et al. (2017) [41]	26 patients (11 men, 15 women), 10 had arthritis, 7 asthma, 5 hypertension, 5 obstructive sleep apnoea, 5 diabetes, 4 osteoporosis, 3 cardiovascular disease, 2 hypercholesterolaemia and 17 other	Primary care setting and specialist care	Semi-structured in-depth interviews (~45 min)	Thematic analysis using treatment-burden framework	12
HELLEM et al. (2012) [47]	11 participants (3 men, 8 women), all had smoking history except 1	Pulmonary rehabilitation	In-depth interviews and focus group discussion	Content analysis, phenomenological approach	12
KAYYALI et al. (2018) [42]	18 patients (11 women, 7 men)	Primary care setting	Semi-structured interviews	Thematic analysis using inductive/deductive approaches	12
KEATING et al. (2011) [48]	37 patients (18 men, 19 women), 10 current smokers, all had at least 1 comorbidity (1–7)	Pulmonary rehabilitation	Semi-structured interviews	Thematic analysis	13
LINDGREN et al. (2014) [15]	8 participants (3 male, 5 female), 7 ex-smokers and 1 smoker	General healthcare setting	60 to 110 min interviews	Phenomenological–hermeneutical approach	12
LUCKETT et al. (2017) [49]	20 participants (9 women), 15 had COPD	Pulmonary rehabilitation	Semi-structured interviews (22–70 min)	Phenomenology	13
MOORE et al. (2012) [50]	24 participants (14 men, 10 women)	Pulmonary rehabilitation	Semi-structured interviews (mean 1 h)	Thematic analysis	13
OLIVER (2001) [44]	16 patients (12 men)	General practice	Semi-structured interviews (45–85 min)	Thematic analysis	13

TABLE 3 Continued					
Authors (year) [ref.]	Sample	Healthcare setting	Data collection	Type of methodology	Quality appraisal score using Atkin's quality appraisal tool
Robinson (2005) [56]	10 patients	General healthcare setting	Unstructured interviews	Qualitative phenomenological approach	10
Shipman et al. (2009) [43]	16 patients (9 men), 10 patients had comorbidities including heart disease, rheumatoid arthritis, diverticulitis, osteoporosis and diabetes mellitus	GP and hospital	In-depth qualitative interviews	Framework approach	12
Sully et al. (2012) [51]	23 patients	Pulmonary rehabilitation	Focus group discussions (45 to 60 min)	Grounded theory complemented with content matrix	13
Wodskou et al. (2014) [57]	34 patients (15 men, 19 women)	General healthcare setting	Focus groups and semi-structured interviews	Inductive content analysis	12
Hopley et al. (2009) [52]	9 patients (almost equal number of men and women), 7 ex-smokers, 1 current smoker	Specialist care	In-depth semi-structured interviews	General inductive approach with emerging themes	12
Andersen et al. (2018) [53]	10 patients (7 women, 3 men)	General healthcare setting	Repeated in-depth ethnographic interviews and patient observations	Phenomenological–hermeneutical approach	12
Korpershoek et al. (2016) [55]	15 patients (8 male, 7 female)	General healthcare setting	Semi-structured in-depth individual interviews	Grounded theory	13

Limited hours of availability prevented patients from accessing GP care in a timely manner in general practice. Frustrations were expressed in regard to wait times [41]. "It really frustrates me. You might be [at the medical centre to see the GP] for medication … you've still got to wait for 15 sick people, and you don't know what [illnesses] you're picking up [in the waiting room]".

Regular appointments were seen as appropriate to maintain regular contact with health professionals in a manageable manner, but limited appointments when they were needed for urgent visits negatively impacted experience of care [53].

> And if I suddenly wake up and feel very poor, for example at 10 am, then it's over. I try calling (the GP's office) to get an appointment. But it is simply impossible: "We can't today, he is busy".
> (Female patient, focus group with patients participating in hospital-based pulmonary rehabilitation) [57]

Physical and emotional factors impacted ability to seek or reach care. Concerns about pain, other health problems and exacerbation of respiratory symptoms were common problems impacting access and the experience of care. Experiencing breathlessness and fatigue "could dissuade patients" from making any contact [53], while patients also expressed uncertainty about when to contact the GP and not wanting to "bother" the GP.

> Because my chest was very bad we sort of put it off for a month and then I just never got around to going back again. [48]

Participants reported concealing their health status, the diagnosis of COPD and their unsuccessful smoking cessation attempts from healthcare providers. Participants considered smoking to be an additional reason for self-blame and isolation, leading to delaying seeking medical treatment.

> I think a lot of the COPDs who still smoke do harbour certain emotions … They blame themselves, and get angry with anyone who tries to influence their smoking. It gets on their nerves, because they know smoking is wrong. They kind of isolate themselves due to the feeling of being losers, because they think of themselves as having failed. [23]

The ability to pay for services was a key concern for patients, particularly those with multiple chronic illnesses. Reducing the frequency of visits or choosing not to take medications were strategies described by participants with limited ability to pay for healthcare visits [38].

In relation to specialist care services, some reported waiting several months to see a less expensive doctor due to unaffordable care [41].

Time and travel costs were additional barriers to accessing specialist (outpatient) respiratory care. Despite this, while cost was a concern, participants reported they were willing to accommodate this considering the importance to them of accessing care from a specialist for serious health concerns [52].

> Well we're only on the pension. It's the only income that we have. Well, it's not a barrier because if you've got to do it then you've got to do it. [52]

> It's more expensive. But if I had to go to a specialist because there was a concern, and I had to wait six months to get one [public specialist] and I could get a private guy in a week, I would … if it was serious. [52]

The benefits of participating in pulmonary rehabilitation were understood by participants, but travel and ability to pay for private services was a barrier to access. In some instances, participants reported attending most medical appointments except for pulmonary rehabilitation classes [41]. The availability of a family member or carer to attend with and readiness to participate were also described by participants as barriers to accessing care [41, 45, 50].

Fear of exercise and shortness of breath, discomfort with the notion of going to "the gym", and concerns of contracting "germs" when attending a hospital-based outpatient programme were also identified as impeding participants' readiness to participate in or complete a pulmonary rehabilitation programme.

Telehealth and tele-rehabilitation were mostly reported as positive developments that were acceptable to patients and improved access to healthcare and pulmonary rehabilitation for COPD, addressing many of the access barriers described above [58].

Interpersonal communication

Concerns about being taken seriously by healthcare professionals, delaying contact and difficulty explaining the severity of symptoms were common interpersonal communication concerns of patients with COPD. "Being heard" was described as an important experience contributing to better self-management. This was especially important for patients who experienced several exacerbations each year.

Where patients reported a high degree of confidence in healthcare professionals, patients were more readily engaged with their practitioner and self-management. But when patients felt judged or like they were not heard by their healthcare providers, their experience of care was negatively impacted.

> Actually, the most important thing is recognition, early recognition of a pneumonia and that someone listens to you at the moment you think something is wrong. [55]

While there was support for telehealth from COPD patients, the importance of in-person care was also emphasised within the telehealth context [58]. "No [telehealth is not as good as in-person care], it's a bit personal, I think. With face to face you can see how people react when you tell them things [laughs]. You've only got to look at somebody's eyes to see" [58]. Similarly, participants had reported telephone interviews (not telehealth) enabled them to develop "good" relationships with their GP; however, having the option to visit the clinic provided reassurance.

Patients with COPD wanted healthcare providers to be "caregivers, coaches and group leaders" and to show "caring and competence". These traits were perceived as supportive and relieved the patient's tension [46]. However, participants in some studies described medical professionals as "conceited, uncaring, mostly concerned with money, or not listening to what they had to say" [41].

> There's no interaction, because he just sits there: "How ya [sic] feeling?", "What's been happening?" And that's it and I go … He's just indifferent. [41]

In contrast, patients who experienced empathy and cooperation from their doctors perceived their care to be better and allowed patients to more fully participate in their own care [57]. Some studies attribute the success of the doctor–patient relationship to the level of empathy and concern expressed by the doctor at the time of diagnosis, as this was described as a particularly important time for the patient with COPD [44].

Knowledge, or availability of information was a "major" issue highlighted by patients. Being cared for by a health professional with a high degree of knowledge about respiratory health was important. This was something that primary care patients valued about participation in pulmonary rehabilitation.

Jargon, lengthy information and an inability to focus due to COPD were barriers to patients understanding information about their condition. Patients understood COPD was often caused by smoking and that COPD affected their lungs and breathing. However, patients in these studies reported that they had not been given enough information about medication and had developed erroneous beliefs [41].

There were instances when patients applied inappropriate self-treatment techniques, especially in cases where participants were unable to follow recommended lifestyle practices, such as quitting smoking. "I just started taking 50 mm [sic] of corticosteroids, as well as the antibiotics that I got there, and then I decreased the corticosteroid dose, based on my recovery. I was successful twice, but not the third time". [54]

Participants reported making decisions based on their beliefs and knowledge regarding their own care and treatment. In some instances, the decisions were useful and reasonable. In other instances, they attempted to make decisions that were contrary to their care, which resulted in poor disease control [54].

> This time, the doctor told me to buy the device (BiPAP) for home use, but I am not in a bad mood. I think that the device is for those who are in a very bad mood. [54]

Many patients with COPD felt they were not sufficiently involved in the decision-making process related to their care, including the prescription of medications for their respiratory conditions [42]. However, there

were others who did not want to be involved in the decision-making, "relying" on or trusting the healthcare professional to make the best decision without feeling a need to be involved [42].

An optimistic, positive attitude from allied health professionals, that is someone who brought humour and enjoyment was appreciated by participants and was important for participants' motivation to participate in programmes like pulmonary rehabilitation. Participants stated it was important to adopt a positive attitude themselves but they required assistance with "seeing life in a different way" and to keep motivated to finish health programmes [47].

> The physiotherapist needs to be good at teaching, not take herself too seriously, laugh a little at herself, care about each individual, and take care of everyone [47].

> I end up feeling sort of lonely in this situation … maybe I had felt that … no, what should I say … I don't know … but … (long pause) … no, I don't know … it's clear that my physiotherapist is a person who is very close to me. I don't see my doctor or nurse or others very often, so you could say that he is quite close. [47]

Caring, reassuring and professional competency was cited as important by participants within the pulmonary rehabilitation setting, and this was demonstrated through physical assessments, informative lectures and guidance and medication administration [46]. Patient engagement was particularly well achieved within the context of community pulmonary rehabilitation programmes.

> It's not just about learning to live with COPD, learning to exercise and so on. In the PR course, I benefited from the medical treatment, supervision and advices of experts. [46]

Participants who were more actively engaged with health professionals identified and understood the different roles between GPs and specialists. GPs were perceived to be more person-centred, while specialists were acknowledged for their subject-specific expertise [49].

> Because your GP just doesn't have that knowledge, and they don't have the expertise. And they [respiratory specialists] are across new developments and treatment.

> (P07, man with COPD) [49]

Participants also felt that there was minimal counselling provided regarding inhalers and indicated more advice and counselling were likely to increase confidence in using medications. Some patients indicated having received no counselling. [42]

> Counselling only involved basic use of the inhalers, lasted for a few seconds.

> I was told nothing after I received my medicines.

Continuity, comprehensiveness and coordination of care
Coordination was described as "good" or "coherent" when participants were referred to different parts of the healthcare system by healthcare professionals proactively.

Effective professional cooperation among healthcare professionals was highly valued by participants, with some reporting a smooth flow of information while others disagreeing [57]. Poor communication presented significant problems at follow-up, and errors in care that arose during transitional phases were particularly distressing to patients. The specific problems that occurred were often not specified, but some participants indicated a need for a "coordinator" to take responsibility to "optimise" the process of care.

Initiating follow-up appointments was viewed by participants as the role of the healthcare professional; however participants often felt the responsibility was left to them, which contributed to negative experiences of care [40, 57]. Long-term relationships with doctors were important for patients across primary care [57] and pulmonary rehabilitation settings [46, 47].

The continued relationship between healthcare providers and patient was emphasised by participants as highly valuable to participants (including those participating in an exercise programme) [47]. Participants emphasised the importance of relationships and this was reflected in their need to be seen, heard, understood and taken seriously.

> It's not just that you implement an exercise programme, finish and say goodbye! But that you are given a little extra time and are valued. This is very important for a person. It increases your quality of life and gives you extra motivation. If other people care, then you feel more valued … After all, everybody wants to be seen, don't they? [47]

Information or referral to pulmonary rehabilitation programmes was not consistent and patients may not be aware of pulmonary rehabilitation or what to expect from it. This impacted upon attendance and completion of pulmonary rehabilitation programmes.

> After talking to a friend who had done the programme, I was the one who brought up the subject with my doctor. He seemed sceptical and he told me, "Well yes, you could go there as an inpatient to get some rest". I don't think he knew about all the exercises we do here! [51]

Appropriate healthcare and social services were reported as important needs requested by the patients [57] and were important for patients to self-manage their condition and avoid hospitalisation. Difficulties arose for participants when they were denied access to services due to ineligibility, hindering the care of patients and negatively impacting the experience of care [57].

Importantly, it was acknowledged that care needs and expectations of adequate care are personal to the patient and families, who have specific resources to cope and require different care and services.

Trust

While some patients reported placing high value in participating in decisions relating to their care [42, 54], participants who trusted their healthcare professional did not find it necessary to participate in health-related decisions and were less likely to need or want to engage in shared decision-making.

The importance of support received from participating in a pulmonary rehabilitation programme was clear from patient statements such as "We gained enormous trust and a sense of security". The shared understanding and fellowship gained through attending the programme was attributed to gaining this trust and security [46], although others found challenges in achieving that same sense of belonging, which impacted upon their ongoing participation and completion of pulmonary rehabilitation.

Trust in health professionals is important to older patients with COPD. Respiratory specialists or physicians tended to be the most trusted health professionals compared to nurses or general practitioners [54]; however, continuity of care was important for developing a trusting relationship. Trust was promoted when health professionals presented an open, respectful communication style [40].

> … you could talk about anything. Almost like a buddy […]. He was just so good at talking to us, we just really understood it all. Then he said: "There's this one thing. If a COPD patient comes to me and says he is not anxious or nervous or anything, he lies. For that comes with the territory." I really liked hearing that. [40]

Patient-reported impacts and inductive coding

Participants expressed strong emotions arising from their health concerns and their experiences of care. These included frustration, fear, depression, anger and for some, ultimately, acceptance of the disease. Participants reported that medical professionals often did not understand the impact being short of breath had on participant's daily lives, and this lack of understanding and the emotions associated with this impacted their ability or readiness to engage in health behaviours that could maintain or improve their health status and their experience of care.

> I really find it frustrating, it really drives me mad, the frustration of not being able to do what I want to do, when I want to do it. [56]

Importantly, participants linked these strong emotions, particularly depression and guilt, to decisions to delay attempts to quit smoking. The participant was still hopeful that [something] could be done, even though they had accepted the damage that had occurred [56].

Participants experienced a change in identity as a result of the diagnosis of COPD and perceived a change in the way others viewed them [39]. Receiving a diagnosis of COPD was perceived by some as being stigmatising in and of itself.

[…] my God, have I got COPD? […] I had a hard time believing it. […] "I haven't got any COPD, you must just write asthma", cause I felt it was really terribly degrading. [15]

Participants described noticing physical changes and changes in social roles, and described perceptions of one's identity changing to "the person with COPD". This change in identity was linked to emotions such as guilt and self-blame [40].

Well, and then there's the guilt, you know? I really felt that so strongly at first. Didn't want to tell anyone. [40]

These emotions were the source of internal struggles, and all the while patients were conscious of COPD as being self-inflicted. This impacted their relationships with care providers, and some described feelings of not being taken seriously as a result, "… that as a group we sort of have a feeling that we are not taken as seriously as others? Maybe there's something there?" [40]. Another participant in this same study also described feeling guilty "occupying a bed" in hospital, which impacted upon decisions to seek (access) timely and appropriate care [40].

Participants reported feeling "taken advantage of" and "exploited" in response to the public health campaigns related to tobacco smoking [23]. While they assumed responsibility for smoking, many expressed that societal expectations differed now to when participants began smoking and this also shaped their healthcare experiences [15].

After such a long time, is it really possible? […] nobody said then that smoking was dangerous. But that's no excuse for me waiting so long before I gave it up. […] I get so annoyed with myself, to think I was so stupid. [15]

Fear was a common emotion described by participants. Fear of worsening health and fears of hospitalisation could trigger negative emotions, but some patients were able to use this fear as a motivator to quit smoking, while fear for the future was a motivation for engaging in pulmonary rehabilitation [47].

I know that if I don't exercise and move, I'll get much worse. The health professionals say so too … that I could end up sitting on the sofa with an oxygen tank. [47]

Two studies reported on the difficulty of quitting smoking that can be experienced by patients with COPD [41, 56]. The process of quitting smoking was described as emotionally draining including experiences of anxiety, frustration and low mood.

My GP said I should give it up, but I didn't and I became more and more breathless. As time went by I had more and more chest infections. [56]

Barriers to quitting included the fear of losing the ability to control feelings of stress, concerns about weight gain, anxiety, and experiences of physical and psychological dependence. Some did not see the use in quitting at the time of receiving a diagnosis of COPD.

When I first felt poorly I didn't stop smoking. You are like an alcoholic, one cigarette and off you go again. [56]

You feel so pathetic when you can't stop. All you think of is that cigarette. [56]

A self-judgemental attitude presented difficulties for participants in accepting their diagnosis and complying with doctor's advice to quit smoking. Being given a diagnosis of COPD was often described as a difficult time for participants who reported feeling "labelled" as a smoker as part of their diagnosis [15].

Participants experienced considerable vulnerability, which could be attributed to stigmatisation, lack of understanding and lack of acceptance from others due to the pervasive belief that COPD is a self-inflicted condition resulting from their smoking.

In contrast, within the pulmonary rehabilitation setting, participants reported feeling safe and motivated when exercising in a group [47]. Exercising with others appeared to alleviate experiences of stigma such as being viewed as different or needing to cover symptoms and reduce drawing attention to themselves.

Discussion

This meta-ethnography is a comprehensive review to evaluate healthcare experiences of patients with COPD outside hospital and palliative care settings. This addresses an important gap in the literature and draws together diverse findings from studies of "lived experience" of people with COPD [31, 59, 60]. The findings highlight a multitude of factors that impact upon patients' healthcare experiences including affective factors (*e.g.* stigma, vulnerability) and relational factors (*e.g.* healthcare provider communication and trust) in addition to extrinsic and environmental factors such as availability of appointments, distance to health services and cost. In order to optimise care delivery, personalised approaches that account for such complexity must be considered.

Much of the literature has limited its investigation of experience of care to issues of access and interpersonal communication. Issues of access related to both supply side drivers such as physical barriers like distance of specialist services and pulmonary rehabilitation, cost of services, difficulty getting access to timely appointments due to waiting lists and the availability of appointments. Time constraints encountered during consultations meant that concerns of patients might not be met. Perceptions of these were further influenced by feelings of blame and guilt and felt stigma and manifested in statements such as not wanting to bother the doctor. The ability to afford services, health status, fatigue and emotion (*e.g.* fear of stigmatisation) further influenced experience of access. Additional issues relating to suboptimal interactions with healthcare providers were impacted by fear of judgement and stigmatisation. Stigma is known to negatively impact engagement with health services [61] and is problematic among people with COPD, and in particular those who continue to smoke, due to feelings of unworthiness, guilt or shame of being unable to stop smoking [21, 62]. The studies in this review tended to view access within a restricted scope, and we recommend that future research should explore a broader conceptualisation of access, from perception of need through to healthcare consequences [63].

Interpersonal communication emerged as a strong theme in many of the studies and impacted effective self-management of the condition. Self-management is a critical component of good preventive medicine in COPD, and patients' desire to have their concerns validated by healthcare professionals and to feel "heard" was very important. Central to this issue was the importance of developing trustful relationships with clinicians. This has been previously reported between patients and doctors [40, 43, 54]. In our study several examples of effective communication emerged contributing to positive experiences of care, especially from studies in pulmonary rehabilitation settings [46, 47]. These programmes typically involve prolonged duration of engagement between patient and therapists with specialist knowledge, and also involve patient exposure to people living with similar conditions. This engagement and the sense of peer support that comes with this is particularly important in the experience of community pulmonary rehabilitation programmes. Disentangling the two factors from each other is difficult; however, positive impacts upon patient engagement and care experiences strengthen the importance of this therapy option as an effective, patient-centric health service. The continuity of care, and coordination of care, between patient and therapist is also likely to influence this finding [64]. Continuity of therapeutic relationships was rated important among participants in several studies included in this review and across settings (*e.g.* [40, 54]). It was important for patients to gain sufficient knowledge of their illness and understanding of the treatment options [41, 48].

Finally, trust emerged as an issue that received relatively little attention in the literature despite high importance described by patients. Trust is a multi-faceted component of the patient experience and was linked to many other domains of patient experience including shared decision-making [42], interpersonal communication [55] and continuity of care [43]. Further exploration of the role of trust in care experience of patients with COPD is needed as this was often linked to an outcome (*i.e.* patient satisfaction) rather than as part of a broader exploration of the patient's experience of care. It is also important to understand the experience of trust and the meaning trust has to the patient with COPD, and how smoking impacts upon the experience of trust [21].

One of the key contributions of this review is highlighting how healthcare experiences can be shaped by emotion, identity and vulnerability and are clearly vital perspectives to understand the healthcare needs of people with COPD. These patient-reported impacts of care were evident in our synthesis; however they do not feature within WONG and HAGGERTY's [10] model of patient experience. Excluding these elements are a limitation of generic models of healthcare experience, and there is value in developing illness-specific criteria for complex conditions such as COPD that incorporate these elements [65].

One important consideration in the context of the care experience of patients with COPD are stigmatising experiences of smoking and fear of stigmatisation, including in healthcare settings [23]. Further studies are

needed to understand the mechanisms underpinning the impact of judgemental attitudes and guilt related to smoking and smoking-related respiratory illness on the care experience for patients with COPD in the community. Anti-stigmatisation campaigns have been initiated in some countries in relation to lung cancer and may be beneficial for patients living with COPD.

Strengths and limitations

Qualitative studies, providing rich accounts of patients' encounters with health professionals in community and outpatient settings, were selected due to their ability to reveal nuanced insights from the perspective of patients with COPD. Meta-ethnography is not the only option to synthesise the relevant research in this field, but, unlike other qualitative synthesis approaches, a key strength of meta-ethnography is its focus on "information-rich" insights from relevant studies. This approach brings vital perspectives of sociology and psychology into the respiratory medicine domain, with potential to reveal additional important patient-focused insights that can improve provision of care to this group.

Synthesising qualitative studies by selecting information-rich papers, focusing the synthesis on first-order and second-order constructs and writing a consistent story that remains faithful to the original studies, is a challenge in meta-ethnography. We adhered to rigorous methodological standards including use of several authors to select appropriate studies for inclusion and reflexive journaling to ensure confirmability. Despite this time-intensive process, potentially relevant insights may have been overlooked as they were not described in the papers selected for inclusion in the analysis or concepts not explored more thoroughly during interviews with participants in the original studies. For example, we coded broadly for concepts such as interpersonal communication, but this is not the same as involvement in decision-making, where issues of voice, understanding, power and agency may interact as part of the experience of care. Further to this, demographic and socio-cultural factors such as ethnicity and sex were not well explored in the studies included in our review but have been identified as factors impacting experience of care in other settings and for patients with other clinical conditions such as cardiovascular disease. Future studies addressing the influence of these on care experiences would be valuable. Finally, we selected studies that described studies conducted before the emergence of the COVID-19 pandemic and so have not considered the impacts on health service provision that have occurred in many countries as a result of the pandemic.

Conclusions

This study drew upon a broad model of healthcare experience to synthesise understanding from qualitative accounts of the experience of care in community settings for patients with COPD. The healthcare experiences of this group often fell short of what was expected and needed by these patients. The model's six domains of care experience were useful for assessing and describing many elements of the healthcare experience important for patients with COPD; however, future studies should also account for the impact of vulnerability, stigma and emotions such as guilt and blame that were potent affective drivers of the experience of care. Future research should focus on further investigating the impact of key patient experience issues described in this review, particularly those that were associated with improving self-management to contribute to improved health outcomes and quality of life for this group.

References

1   Abrams EM, Akombi B, Alam S, et al. Global burden of 369 diseases and injuries in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. The Lancet 2020; 396: 1204–1222.
2   Safiri S, Carson-Chahhoud K, Noori M, et al. Burden of chronic obstructive pulmonary disease and its attributable risk factors in 204 countries and territories, 1990–2019: results from the Global Burden of Disease Study 2019. BMJ 2022; 378: e069679.

3   Adeloye D, Song P, Zhu Y, *et al.* Global, regional, and national prevalence of, and risk factors for, chronic obstructive pulmonary disease (COPD) in 2019: a systematic review and modelling analysis. *Lancet Respir Med* 2022; 10: 447–458.

4   Australian Institute of Health and Welfare (AIHW). Australia's Health 2018. Australia's health series no. 16. AUS 221. Canberra, Australian Institute of Health and Welfare, 2018.

5   Jolley CJ, Moxham J. A physiological model of patient-reported breathlessness during daily activities in COPD. *Eur Respir Rev* 2009; 18: 66–79.

6   Barton C, Effing TW, Cafarella P. Social support and social networks in COPD: a scoping review. *COPD* 2015; 12: 690–702.

7   Gardner K, Parkinson A, Banfield M, *et al.* Usability of patient experience surveys in Australian primary health care: a scoping review. *Aust J Prim Health* 2016; 22: 93–99.

8   Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open* 2013; 3: e001570.

9   Agency for Healthcare Research and Quality. What Is Patient Experience? www.ahrq.gov/cahps/about-cahps/patient-experience/index.html Date last accessed: 27 October 2022. Date last updated: August 2022.

10   Wong ST, Haggerty J. Measuring patient experiences in primary health care: a review and classification of items and scales used in publicly-available questionnaires. Centre for Health Services and Policy Research (CHSPR). http://dx.doi.org/10.14288/1.0048528 Date last accessed: 31 October 2022. Date last updated: May 2013.

11   Berger BE, Kapella MC, Larson JL. The experience of stigma in chronic obstructive pulmonary disease. *West J Nurs Res* 2011; 33: 916–932.

12   Philip K, Gaduzo S, Rogers J, *et al.* Patient experience of COPD care: outcomes from the British Lung Foundation Patient Passport. *BMJ Open Respir Res* 2019; 6: e000478.

13   Boland VC, Mattick RP, McRobbie H, *et al.* "I'm not strong enough; I'm not good enough. I can't do this, I'm failing" – A qualitative study of low-socioeconomic status smokers' experiences with accessing cessation support and the role for alternative technology-based support. *Int J Equity Health* 2017; 16: 196.

14   Chang YY, Dai YT, Chien NH, *et al.* The lived experiences of people with chronic obstructive pulmonary disease: a phenomenological study. *J Nurs Scholarsh* 2016; 48: 466–471.

15   Lindgren S, Storli SL, Wiklund-Gustin L. Living in negotiation: patients' experiences of being in the diagnostic process of COPD. *Int J Chron Obstruct Pulmon Dis* 2014; 9: 441–451.

16   Lindqvist G, Hallberg LR. 'Feelings of guilt due to self-inflicted disease': a grounded theory of suffering from chronic obstructive pulmonary disease (COPD). *J Health Psychol* 2010; 15: 456–466.

17   Earnshaw VA, Quinn DM, Park CL. Anticipated stigma and quality of life among people living with chronic illnesses. *Chronic Illn* 2012; 8: 79–88.

18   Starfield B, Shi L, Macinko J. Contribution of primary care to health systems and health. *Milbank Q* 2005; 83: 457–502.

19   Higginson R, Parry A. Managing chronic obstructive pulmonary disease in the community setting. *Br J Community Nurs* 2018; 23: 6–12.

20   Bellamy D, Bouchard J, Henrichsen S, *et al.* International Primary Care Respiratory Group (IPCRG) Guidelines: management of chronic obstructive pulmonary disease (COPD). *Prim Care Respir J* 2006; 15: 48–57.

21   Madawala S, Enticott J, Sturgiss E, *et al.* The impact of smoking status on anticipated stigma and experience of care among smokers and ex-smokers with chronic illness in general practice. *Chronic Illn* 2022; in press [https://10.1177/17423953221101337].

22   Barr RG, Celli BR, Martinez FJ, *et al.* Physician and patient perceptions in COPD: the COPD Resource Network Needs Assessment Survey. *Am J Med* 2005; 118: 1415.

23   Halding AG, Heggdal K, Wahl A. Experiences of self-blame and stigmatisation for self-infliction among individuals living with COPD. *Scand J Caring Sci* 2011; 25: 100–107.

24   Noblit GW, Hare RD. Meta-ethnography. Thousand Oaks, CA, SAGE Publications, Inc., 1988.

25   Sandelowski M. Metasynthesis of qualitative research. *In:* Cooper H, Camic PM, Long DL, *et al.*, eds. APA Handbook of Research Methods in Psychology, Vol. 2. Research Designs: Quantitative, Qualitative, Neuropsychological, and Biological. Washington, DC, American Psychological Association, 2012; pp. 19–36.

26   Sattar R, Lawton R, Panagioti M, *et al.* Meta-ethnography in healthcare research: a guide to using a meta-ethnographic approach for literature synthesis. *BMC Health Serv Res* 2021; 21: 50.

27   Cahill M, Robinson K, Pettigrew J, *et al.* Qualitative synthesis: a guide to conducting a meta-ethnography. *Br J Occup Ther* 2018; 81: 129–137.

28   Atkins S, Lewin S, Smith H, *et al.* Conducting a meta-ethnography of qualitative literature: lessons learnt. *BMC Med Res Methodol* 2008; 8: 21.

29   France EF, Cunningham M, Ring N, *et al.* Improving reporting of meta-ethnography: The eMERGe reporting guidance. *Psychooncology* 2019; 28: 447–458.

30   Shamseer L, Moher D, Clarke M, *et al.* Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. *BMJ* 2015; 349: g7647.

31   Rose S, Paul C, Boyes A, *et al.* Stigma-related experiences in non-communicable respiratory diseases: a systematic review. *Chron Respir Dis* 2017; 14: 199–216.

32   Suri H. Purposeful sampling in qualitative research synthesis. *Qualitative Res J* 2011; 11: 63–75.

33   Cooper HM. Research Synthesis and Meta-Analysis: A Step-by-Step Approach. 5th Edn. Thousand Oaks, CA, SAGE Publications, Inc., 2017.

34   Lee RP, Hart RI, Watson RM, *et al.* Qualitative synthesis in practice: some pragmatics of meta-ethnography. *Qualitative Res* 2014; 15: 334–350.

35   Lincoln Y, Guba E. Naturalistic Inquiry. Newbury Park, CA, SAGE Publications, 1985.

36   Toye F, Seers K, Allcock N, *et al.* 'Trying to pin down jelly' – exploring intuitive processes in quality assessment for meta-ethnography. *BMC Med Res Methodol* 2013; 13: 46.

37   Acker S. In/Out/Side: positioning the researcher in feminist qualitative research. *Resources for Feminist Research* 2001; 28: 153–172.

38   Bauer WS, Schiffman RF. Factors influencing self-management of chronic obstructive pulmonary disease by community-dwelling adults. *West J Nurs Res* 2020; 42: 423–430.

39   Ellison L, Gask L, Bakerly ND, *et al.* Meeting the mental health needs of people with chronic obstructive pulmonary disease: a qualitative study. *Chronic Illn* 2012; 8: 308–320.

40   Halding AG, Aarsheim EI, Dolmen NM, *et al.* COPD transitions in health and self-management: service users' experiences from everyday life. *Int J Chron Obstruct Pulmon Dis* 2018; 13: 2075–2088.

41   Harb N, Foster JM, Dobler CC. Patient-perceived treatment burden of chronic obstructive pulmonary disease. *Int J Chron Obstruct Pulmon Dis* 2017; 12: 1641–1652.

42   Kayyali R, Gebara SN, Hesso I, *et al.* Shared decision making and experiences of patients with long-term conditions: has anything changed? *BMC Health Serv Res* 2018; 18: 763.

43   Shipman C, White S, Gysels M, *et al.* Access to care in advanced COPD: factors that influence contact with general practice services. *Prim Care Respir J* 2009; 18: 273–278.

44   Oliver SM. Living with failing lungs: the doctor–patient relationship. *Fam Pract* 2001; 18: 430–439.

45   Guo SE, Bruce A. Improving understanding of and adherence to pulmonary rehabilitation in patients with COPD: a qualitative inquiry of patient and health professional perspectives. *PLoS One* 2014; 9: e110835.

46   Halding AG, Wahl A, Heggdal K. 'Belonging'. 'Patients' experiences of social relationships during pulmonary rehabilitation. *Disabil Rehabil* 2010; 32: 1272–1280.

47   Hellem E, Bruusgaard KA, Bergland A. Exercise maintenance: COPD patients' perception and perspectives on elements of success in sustaining long-term exercise. *Physiother Theory Pract* 2012; 28: 206–220.

48   Keating A, Lee AL, Holland AE. Lack of perceived benefit and inadequate transport influence uptake and completion of pulmonary rehabilitation in people with chronic obstructive pulmonary disease: a qualitative study. *J Physiother* 2011; 57: 183–190.

49   Luckett T, Phillips J, Johnson M, *et al.* Insights from Australians with respiratory disease living in the community with experience of self-managing through an emergency department 'near miss' for breathlessness: a strengths-based qualitative study. *BMJ Open* 2017; 7: e017536.

50   Moore L, Hogg L, White P. Acceptability and feasibility of pulmonary rehabilitation for COPD: a community qualitative study. *Prim Care Respir J* 2012; 21: 419–424.

51   Sully JL, Baltzan MA, Wolkove N, *et al.* Development of a patient needs assessment model for pulmonary rehabilitation. *Qual Health Res* 2012; 22: 76–88.

52   Hopley M, Horsburgh M, Peri K. Barriers to accessing specialist care for older people with chronic obstructive pulmonary disease in rural New Zealand. *J Prim Health Care* 2009; 1: 207–214.

53   Andersen IC, Thomsen TG, Bruun P, *et al.* Between hope and hopelessness: COPD patients' and their family members' experiences of interacting with healthcare providers – a qualitative longitudinal study. *Scand J Caring Sci* 2018; 32: 1197–1206.

54   Fotokian Z, Mohammadi Shahboulaghi F, Fallahi-Khoshknab M, *et al.* The empowerment of elderly patients with chronic obstructive pulmonary disease: managing life with the disease. *PLoS One* 2017; 12: e0174028.

55   Korpershoek Y, Vervoort S, Nijssen L, *et al.* Factors influencing exacerbation-related self-management in patients with COPD: a qualitative study. *Int J Chron Obstruct Pulmon Dis* 2016; 11: 2977–2990.

56   Robinson T. Living with severe hypoxic COPD: the patients' experience. *Nurs Times* 2005; 101: 38–42.

57   Wodskou PM, Høst D, Godtfredsen NS, *et al.* A qualitative study of integrated care from the perspectives of patients with chronic obstructive pulmonary disease and their relatives. *BMC Health Serv Res* 2014; 14: 471.

58   Gorst SL, Coates E, Armitage CJ. "It's sort of a lifeline": Chronic obstructive pulmonary disease patients' experiences of home telehealth. *Health Psychol* 2016; 35: 60–68.

59   Evans-Polce RJ, Castaldelli-Maia JM, Schomerus G, *et al.* The downside of tobacco control? Smoking and self-stigma: a systematic review. *Soc Sci Med* 2015; 145: 26–34.

60 Lippiett KA, Richardson A, Myall M, *et al.* Patients and informal caregivers' experiences of burden of treatment in lung cancer and chronic obstructive pulmonary disease (COPD): a systematic review and synthesis of qualitative research. *BMJ Open* 2019; 9: e020515.

61 Walker S, Andrew S, Hodson M, *et al.* Stage 1 development of a patient-reported experience measure (PREM) for chronic obstructive pulmonary disease (COPD). *NPJ Prim Care Respir Med* 2017; 27: 47.

62 Wilson JS, Elborn JS, Fitzsimons D. 'It's not worth stopping now': why do smokers with chronic obstructive pulmonary disease continue to smoke? A qualitative study. *J Clin Nurs* 2011; 20: 819–827.

63 Levesque J-F, Harris MF, Russell G. Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *Int J Equity Health* 2013; 12: 18.

64 Banfield M, Gardner K, McRae I, *et al.* Unlocking information for coordination of care in Australia: a qualitative study of information continuity in four primary health care models. *BMC Fam Pract* 2013; 14: 34.

65 Hodson M, Andrew S, Michael Roberts C. Towards an understanding of PREMS and PROMS in COPD. *Breathe* 2013; 9: 358–364.