

# Healthcare experience of adults with COPD during the COVID-19 pandemic: a rapid review of international literature

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## ABSTRACT

**Background** People living with chronic obstructive pulmonary disease (COPD) are a group who may be particularly vulnerable to COVID-19. This vulnerability has been associated with increased anxiety or fear about exposure to the virus, which may also impact upon experience in healthcare settings.

**Aim/objectives** The aim of this narrative mixed-methods review was to systematically scope, identify and synthesise findings from peer-reviewed qualitative, quantitative and mixed-methods studies published in academic journals describing the healthcare experiences of adults living with COPD independently in the community, following the emergence of COVID-19 in December 2019–June 2022.

**Methods** Databases including Ovid MEDLINE, PsychINFO, Ovid Emcare and CINAHL Plus were searched. Studies were uploaded to Covidence to support selection and appraisal of studies. Studies were appraised for quality using the Mixed Methods Appraisal Tool. A narrative synthesis of these themes was provided, and qualitative and quantitative findings are interpreted together in the discussion.

**Findings** The quality and experience of care for patients with COPD was impacted through the COVID-19 pandemic. Innovations and adoption of technologies such as telehealth and telerehabilitation were well received and mitigated the potential implications of severe disruption to care access to some extent. Patients feared feeling forgotten and experienced isolation and anxiety; however, telerehabilitation and exercise through modalities such as Zoom classes help support social connection and physical activity.

**Implications** These innovations are likely to be useful to be offered to patients on an ongoing basis, and education and standardised protocols around their use will benefit healthcare providers and patients alike.

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## BACKGROUND

The onset of the coronavirus pandemic occurred due to COVID-19, caused by the infectious SARS-CoV-2, and was declared to be of international and public concern by the WHO in early 2020.<sup>1</sup> People living with chronic obstructive pulmonary disease (COPD) are a group who may be particularly vulnerable to

## WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ People living with chronic obstructive pulmonary disease have reported feeling anxious about COVID-19 because of feeling afraid of being denied care.

## WHAT THIS STUDY ADDS

⇒ The rapid review found patients feared feeling forgotten and experienced isolation and anxiety; however, telerehabilitation and exercise through modalities such as Zoom classes help support social connection and physical activity. Adoption of telehealth and telerehabilitation was well received and mitigated the potential implications of severe disruption to care access to some extent.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ These innovations are likely to be useful to be offered to patients on an ongoing basis, and education and standardised protocols around their use will benefit healthcare providers and patients alike. There is a need for future research to more thoroughly investigate key patient issues highlighted in this review and their impact on self-management and health outcomes.



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COVID-19. This vulnerability has been associated with increased anxiety or fear about exposure to the virus, which may also impact upon experience in healthcare settings.<sup>2</sup> Further to this, smoking as a major cause of COPD was identified in early evidence as a further risk factor for contracting COVID-19 and one study found patients with COPD who are smokers were more likely to have adverse outcomes after contracting COVID-19.<sup>3</sup>

Studies of the lived experiences of patients with COPD prior to the emergence of COVID-19 had highlighted important concerns about interactions with healthcare professionals and experience of care which may impact upon health outcomes.<sup>4–10</sup> Understanding experience of care from the perspective of patients is essential to provision of high-quality, evidence-based care that

is patient centred.<sup>11 12</sup> Changes in healthcare provision introduced in response to the COVID-19 pandemic may have impacted the healthcare experience of adults with chronic respiratory illness.

Patient experience describes the range of interactions and relationships between patients and different components of the healthcare system.<sup>13 14</sup> During the COVID-19 pandemic, changes in healthcare services and community measures were implemented impacting the healthcare experience of adults.<sup>15</sup> This is concerning as positive healthcare experiences such as having regular contact with health services can positively impact the health outcomes of patients living with chronic conditions such as COPD.<sup>16</sup> The implementation of lockdown restrictions in several jurisdictions, quarantine policies and social distancing measures may have limited access to health services, leaving many individuals unable to access their healthcare needs.<sup>15</sup>

People living with COPD have reported feeling anxious about COVID-19, feeling afraid of being denied care<sup>17</sup> and have faced difficulties accessing medications.<sup>18</sup> A qualitative study found accessing timely healthcare services was a major concern stemming from long waiting times to see a general practitioner (GP) and for ambulances to arrive.<sup>19</sup> In contrast, changes in care delivery, such as greater use of telehealth, and widespread use of information communications technology to deliver healthcare services as a substitute for face-to-face care during the COVID-19 pandemic<sup>20–22</sup> may have increased access to healthcare services and satisfaction with care<sup>21</sup> and may be particularly valuable for patients with COPD in overcoming access issues relating to physical health barriers arising from symptoms of COPD.

### Aim(s) and objectives

The aim of this study was to systematically scope, identify and synthesise findings from peer-reviewed qualitative, quantitative and mixed-methods studies published in academic journals describing the healthcare experiences of adults living with COPD independently in the community, following the emergence of COVID-19 in December 2019 to the present time. Specifically, we aim to (1) identify the scope (number) of articles investigating patient experience among patients with COPD; (2) compare and contrast the patient experiences of adults with COPD in different healthcare settings; (3) synthesise descriptions of the impact of changes to healthcare experience on patient well-being and health outcomes.

### METHOD

A rapid review was undertaken to systematically identify and then synthesise evidence from peer-reviewed research published between January 2020 and June 2022, which described healthcare experiences of patients living with COPD independently in the community during the COVID-19 pandemic. Rapid review methodology was used due to the rapidly changing nature of the healthcare

environment, short time frame that changes have been in place and the need to identify strategies that support positive healthcare experience, but are compliant with emergency public health orders and minimise risk of infection to patients and healthcare staff. As we progress to a 'COVID-19 normal' environment, there is a need for rapid synthesis of the evidence to support the provision of healthcare for this particularly vulnerable group to protect them from the continuing pandemic.

A rapid review seeks to be rigorous and systematic, but the breadth or depth of the processes are limited to shorten the time scale needed to complete the review.<sup>23</sup> A systematic search of the literature was undertaken; however, this was limited in time frame (36 months) and we have not attempted to undertake meta-analysis or meta-synthesis of findings. A narrative, mixed-methods synthesis of key findings from identified literature was reported instead. The methodology was registered on PROSPERO (ID: CRD42022341168).

### PATIENT AND PUBLIC INVOLVEMENT

Evidence from 'lived experience' qualitative research and pilot work by supervisor (CB) suggested a need for exploration of these issues.

### Selection of articles

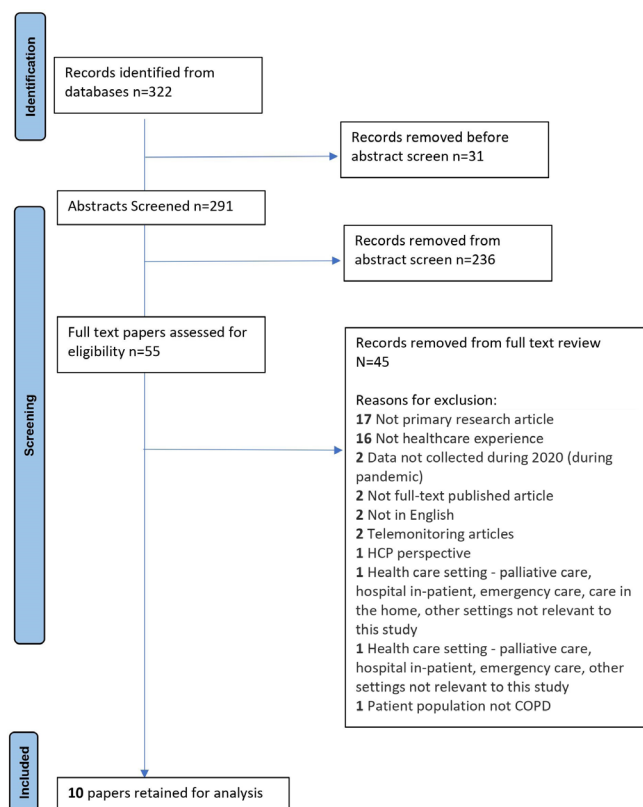
#### Eligibility criteria

Peer-reviewed qualitative, quantitative and mixed-methods studies published in academic journals or reports, drawing upon experiences of care of patients living with COPD, were included during the COVID-19 pandemic. Our definition of experience of care draws upon that described by Wong and Haggerty<sup>14</sup> and encompasses six domains of experience (see online supplemental table 1).

All peer-reviewed quantitative, qualitative and mixed-methods studies published in academic journals or reports written in English on the healthcare experience for adults with chronic lung disease (COPD, emphysema, chronic bronchitis) were included. Studies where data were collected before 2020 (not during pandemic) and experiences on lung cancer, pulmonary fibrosis and asthma were excluded.

#### Information sources

We searched the following databases for literature published between January 2020 and June 2022: Ovid Medline, PsychINFO, Emcare and CINAHL. A preliminary, broad-based search of PubMed was used to help define the scope of literature to be included in the review and refine the research question. The final search strategy was then developed with the guidance of a university subject librarian. We incorporated searches for illness conditions (COPD, chronic bronchitis, emphysema), patient experience of care<sup>14</sup> and COVID-19 (see online supplemental appendix 1).<sup>24</sup>



**Figure 1** Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram showing selection of papers for inclusion. COPD, chronic obstructive pulmonary disease; HCP, healthcare provider.

The title and abstracts of papers identified from these searches were uploaded to Covidence to support selection and appraisal of studies for inclusion. Initially, duplicates were removed and then two reviewers screened titles and abstracts to exclude studies that were out of scope or did not meet inclusion criteria (SM and AQ). The full text of remaining studies was downloaded and reviewed by the lead author (SM) and a second reviewer to determine if it met inclusion criteria. Any disagreements were resolved through discussion with CB.

Additional hand searching of reference lists of included studies was used to identify any further papers not identified in our electronic search. Steps in selection and inclusion or exclusion of studies are presented in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow chart (see figure 1).

### Data extraction and synthesis

This review follows recommendations for conducting and reporting a review and independent syntheses of qualitative and quantitative studies, where qualitative and quantitative findings are interpreted together in the discussion.<sup>25</sup>

Studies were appraised for quality using the Mixed Methods Appraisal Tool (MMAT) by two independent reviewers (SM and JYL) (see online supplemental

appendix 2 for results)<sup>26</sup> and disagreements were resolved through discussion.

The data extracted from the full text of included studies were relevant extracts of text reporting on experiences of care. We developed a custom data extraction form to support this process (see online supplemental appendix 3). Extracted data were examined for common characteristics and themes within the six domains of experience of care described by Wong and Haggerty<sup>14</sup> (see online supplemental table 1). A narrative synthesis of these themes is provided.<sup>25</sup>

### RESULTS

The initial search identified 10 papers meeting inclusion criteria (see online supplemental table 2 for study details). Papers were published from predominantly high-income countries including the UK (n=4), Canada (n=2), Denmark (n=1), Italy (n=1) and Spain (n=1). One study was published from China. Studies were published between 2020 and 2022 and presented data collected during the pandemic from January 2020 onwards (see online supplemental table 2). Studies included between n=13 and n=963 participants diagnosed with COPD. One study<sup>27</sup> reported findings from 68 032 404 participants, the highest number, but it was not mentioned how many were adults with COPD. Four studies used qualitative methods,<sup>2 19 28 29</sup> four quantitative<sup>18 27 30 31</sup> and two used mixed methods<sup>22 32</sup> (see online supplemental table 2). Based on MMAT scoring, there were no concerns about the quality of papers and a sensitivity analysis was not undertaken.

We synthesised findings of healthcare experiences within the dimensions described by Wong and Haggerty (see online supplemental table 1). Several studies addressed issues associated with barriers to access to care and fewer addressed other aspects of the care experience such as interpersonal communication, continuity, coordination, comprehensiveness and trust. The findings of our synthesis of these papers are reported in online supplemental table 1.

There was considerable disruption to care which caused concern to patients. Concerns about the ability of health services to function during the COVID-19 pandemic were common, and trust between doctor and patient was undermined if patients felt COVID-19 protective measures were taken lightly. Despite this, the majority of studies reported their participants' general health and self-management of their lung condition was similar or better during the pandemic and through any regional lockdown.

A key feature of the healthcare experience was the rapid adoption of telehealth and telerehabilitation across many healthcare settings. These were generally well received by patients with COPD. The virtual format allowed patients to discuss health matters with their healthcare provider (doctor, nurse or physiotherapist) without the risk of being exposed to COVID-19, which was a significant



source of fear for patients. Telehealth also provided continuity of care in an environment safe from COVID-19, a factor which was particularly important to people with COPD who were especially vulnerable to contracting COVID-19 infection.

... I found a lot of availability at my pulmonologist, who continued to follow us by phone. Getting out of the house was tiring ...<sup>29</sup>

Patients were accepting of having instructors guide them through online exercise classes and felt encouraged being able to see some of the same people when they were otherwise highly socially isolated or shielding. Despite the value of telehealth, disruptions to healthcare access were a common problem and cancelled appointments were a major concern for participants with COPD. However, access to medication did not seem to be a major issue impacting those with COPD.

Participants have reported difficult emotions including feeling forgotten, when facing difficulties accessing a GP due to the pandemic and restrictions.

The doctor wouldn't see me [...] I just got a text message saying that my appointment was cancelled [...] the general practitioner was only dealing with life-threatening conditions.<sup>2</sup>

Participants reported that being unable to have informal support from family members during the consultation presented challenges with communicating for the patient with COPD. However, comparatively, the positive approach and support received from the healthcare staff at the rehabilitation programme were perceived as motivational influence.<sup>28</sup>

Despite these challenges, patients with COPD tended to be able to self-manage their lung condition well throughout the pandemic and benefited from reductions in viral infections which are triggers for COPD exacerbation. Interventions to reduce spread of COVID-19 in the community were beneficial to those with COPD.<sup>30</sup>

More than half (65%) of respondents in the study from Philip *et al*<sup>18</sup> reported interest in accessing more information about managing their lung condition in regard to COVID-19, decision-making awaiting a COVID-19 infection (49%) and concerns about maintaining mental well-being (31%).<sup>18</sup> Both online and telephone services were used to obtain information about COVID-19 (National Health Service (NHS) website and NHS telephone, UK study); however, comparatively, only a minor percentage of respondents reported using the online website (3%–9% of people over 60 years old compared with 23%–25% of those under 40 years old).

## DISCUSSION

We conducted a rapid review to explore the patient experience of adults with COPD during the COVID-19 pandemic. Considering the healthcare needs of this group, changes that occurred in health service provision

due to the COVID-19 pandemic may have had particularly high impact on this vulnerable group. Adults with COPD in lockdown-impacted regions reported difficulties accessing GPs due to the pandemic and restrictions, thus leaving patients feeling forgotten by the healthcare system in general. Accessing telehealth has been crucial to receiving healthcare services and this is an innovation which contributed to positive healthcare experiences for many patients with COPD.

Broadly, similar concerns have been reported by patients in studies reporting experiences from chronic illnesses including diabetes and chronic heart conditions.<sup>33–35</sup> These include difficulty in accessing services during the pandemic, the usefulness of telehealth to a certain extent and the need for continuity of care.

Patients were satisfied with the usefulness of rehabilitation programmes delivered via telehealth and also expressed the need for greater education to provide more knowledge about self-management of COPD especially during the early stages of the pandemic. Similarly, pulmonary rehabilitation services were able to be successfully adapted using technology platforms such as Zoom and were found to be particularly useful<sup>28</sup>; however, managing the technology was a challenge reported by some patients in this setting. Importantly, participants appeared to be more willing to attend a greater number of sessions per week when classes were held via video.

Patients with chronic health conditions like COPD often experience better health outcomes when patient-centred care approaches such as good communication<sup>19 22 28</sup> and adequate time can be spent with a trusted healthcare provider.<sup>2</sup> Having direct telephone access for urgent questions was an important activity for remote specialist care consultations.<sup>22</sup> Patients appreciated the availability of a pulmonologist and the continuity of follow-up, and this was described as a positive patient experience by participants.<sup>29</sup> In contrast, cancelled appointments posed a major concern and presented as disruptions to care for participants,<sup>18 32</sup> while difficulties accessing healthcare services such as GPs and rehabilitation therapy left patients fearing disability.<sup>2</sup>

These experiences left adults with COPD feeling 'forgotten' and not adequately involved in the decision-making between themselves and healthcare providers. These feelings only appeared to be worsened by feelings of uncertainty brought about by the pandemic.<sup>19</sup> Studies prior to the pandemic have raised concerns about the difficulties adults with COPD can face accessing timely care,<sup>4</sup> feeling as though they are not heard, finding difficulties with being referred to a comprehensive range of services,<sup>5</sup> and these experiences and sense of feeling forgotten are likely to have been exacerbated through the pandemic and impacted negatively upon the experience of care during this time. Importantly, in cases where participants relied on a close family member to assist in communicating with the doctor, this was described as a major difficulty when consultations were limited to just the patient.

Several issues were reported regarding the comprehensiveness of services and care provided to adults with COPD during the pandemic due to the over-riding COVID-19 cases. Participants reported being denied care,<sup>29</sup> and fear of being denied care was a source of anxiety and stress for patients.<sup>19</sup> There were reports of reduced treatment options from respiratory specialists; however, there has been relatively little information published on continuity of care during the pandemic and papers had only explored this in the specialist care setting. Similarly, impacts on coordination of care were only reported in the context of pulmonary rehabilitation setting.<sup>28</sup> Further research involving patients treated principally in primary care and community settings is needed to understand how coordination of care was impacted through the pandemic and the impact this may have on longer-term health outcomes and disease control.

There has been relatively little published on trust in health professionals through the pandemic among patients with COPD. Trust is an important component contributing to the doctor–patient relationship<sup>2</sup>; it will be important to understand the impact of rapidly changing health policy settings had on trust, particularly in the context of rapidly developed, but essential, vaccine treatment for COVID-19. Feeling safe, comfortable and calm when talking to a healthcare professional about risks of being infected with coronavirus were important emotions to manage for participants.<sup>2</sup> Further research investigating the impact of experiences of stigma relevant to the COVID-19 context such as wearing a mask or having a mask exemption can be further explored.

Patients' need for knowledge regarding their health and management of their condition was well reported. Patients with COPD seemed to adopt health behaviours that positively impacted their health status and adhere to social distancing advice.<sup>29</sup> The vast majority of patients also adhered to their therapy regimens as strictly as, or even more than before the lockdown occurred, indicating good self-management of COPD.<sup>29</sup> This careful behaviour expressed by patients could be linked to fears regarding poor health outcomes such as death if they were to be infected with COVID-19.<sup>2</sup> Access to medication did not appear as a major concern in the reports included in this review despite some patients expressing feelings of being forgotten by the health system.<sup>2</sup>

A majority of the included studies were published in 2020 and reflect experiences during the early stages of the COVID-19 pandemic, prior to the development of vaccines to protect against COVID-19. Hence, non-pharmacological interventions were the primary protective measures and the patient experience may be reflective of this situation at the time the studies were conducted. As vaccination rates have increased and better protective measures and antivirals have been introduced throughout 2021 and 2022, the patient experience may differ.

There are a number of strengths and limitations to the use of rapid review methodology. This approach allowed

the authors to investigate the experience of care for those with COPD with urgency as required of the topic, and use of systematic search methods guided by a subject librarian, and undertaking quality appraisal of included studies added to the methodological rigour of this paper. The review was limited by the inclusion of moderate-quality papers; however, this was anticipated given the need for researchers to collect and report data quickly, and this limitation was taken into account in the weighting applied to different findings in the synthesis and interpretation. There is a need for future research to more thoroughly investigate key patient issues highlighted in this review and their impact on self-management and health outcomes.

## CONCLUSIONS

The quality and experience of care for patients with COPD was impacted through the COVID-19 pandemic. Innovations and adoption of technologies such as telehealth and telerehabilitation were well received and mitigated the potential implications of severe disruption to care access to some extent. Patients feared feeling forgotten and experienced isolation and anxiety; however, telerehabilitation and exercise through modalities such as Zoom classes help support social connection and physical activity. These innovations are likely to be useful to be offered to patients on an ongoing basis, and education and standardised protocols around their use will benefit healthcare providers and patients alike.

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