

Treatment Burden Discussion in Clinical Encounters: Priorities of COPD Patients, Carers and Physicians

Adem Sav ¹, Sarah T Thomas², Magnolia Cardona ^{3,4}, Zoe A Michaleff ^{4,5}, Claudia C Dobler^{3,4,6}

¹School of Public Health and Social Work, Faculty of Health, Queensland University of Technology, Brisbane, Queensland, Australia; ²Gold Coast University Hospital, Southport, Queensland, Australia; ³Evidence-Based Practice Professorial Unit, Gold Coast Hospital, Southport, Queensland, Australia; ⁴Institute for Evidence Based Healthcare, Bond University, Gold Coast, Queensland, Australia; ⁵Northern NSW Local Health District, Lismore, New South Wales, Australia; ⁶The George Institute for Global Health, University of New South Wales, Kensington, New South Wales, Australia

Correspondence: Adem Sav, School of Public Health and Social Work, Faculty of Health, Queensland University of Technology, Brisbane, Queensland, Australia, Tel +61 7 3138 5795, Email adem.sav@qut.edu.au

Purpose: Many people with chronic obstructive pulmonary disease (COPD) feel overburdened with the treatment and management of their illness. Although research has begun to shed light on how COPD patients experience treatment burden, most of what we know is limited to personal experiences of patients. The aim of this study is to identify and prioritise areas of treatment burden that should be discussed during the clinical encounter from the perspectives of COPD patients, carers, and respiratory physicians.

Patients and Methods: Data were collected from participants using the nominal group technique. Five nominal group sessions were conducted in total (n = 31); three sessions with patients (n = 18), one with carers (n = 7) and another with respiratory physicians (pulmonologists or chest physicians) (n = 6). Each session was recorded and analyzed using thematic analysis.

Results: Going beyond understanding patients' and carers' experiences of treatment burden, this study offers a practical viewpoint of what should be discussed in a clinical encounter. Each group of participants contextualized treatment burden issues for discussion from their own perspectives. There was strong agreement, however, across the groups that difficulties accessing healthcare, lack of education and information, and worry about COPD treatment and prognosis were the most important treatment burden priorities for discussion.

Conclusion: Understanding and creating opportunities to discuss these issues in a clinical encounter is important in not only reducing treatment burden but also improving health outcomes and quality of life for COPD patients and their carers.

Keywords: COPD, burden of treatment, treatment burden, nominal group technique

Introduction

Chronic obstructive pulmonary disease (COPD) is a progressive lung disease characterized by airflow obstruction and alveolar destruction.¹ It is one of the leading causes of death worldwide, causing 3.23 million deaths in 2019.² Although COPD is mainly driven by tobacco smoking, exposure to other environmental toxins are also risk factors.¹ The most recognized symptom of COPD is dyspnea or shortness of breath.³ Other non-specific symptoms frequently reported by patients include fatigue, sleep disturbance, stress, anxiety, and depression.^{3,4} People diagnosed with COPD, particularly the elderly, often have significant co-morbidities. Hence, many struggle to fully understand their illness and cope with their symptoms,⁵ leading to hospitalizations and high readmission rates.⁶ This carries significant health-care costs as well as financial and emotional burdens for patients and their families.⁷

COPD management is multi-faceted. This includes pharmacological treatments (eg, inhalers), pulmonary rehabilitation, and risk factor modification, specifically, assistance with smoking cessation.⁸ In more advanced stages, patients may require long-term oxygen therapy, non-invasive ventilation devices, and rarely, lung volume reduction surgeries or a lung transplant. There is evidence to suggest that many people with COPD feel overburdened with the treatment and management of their illness.^{1,4,9} Indeed, a study estimated that an individual with a combination of COPD, arthritis, heart disease or diabetes can

spend 50 hours per month on health-related activities, take 6–12 medication per day and see their doctor 2–6 times per month.¹⁰ Large time investments in treatment and the requirement of long-term self-management of the disease can lead to (overwhelming) treatment burden for patients.⁸

Treatment burden is defined as a patient's treatment workload. It can include learning about and implementing treatments, completing paperwork, arranging, and attending medical appointments/tests, experiencing side effects and financial costs of treatment.¹¹ This differs from disease burden, which encompasses the morbidity or mortality related to the disease.^{12,13} Treatment burden refers to the negative consequences of treatments that patients experience, including medications, therapies, and medical interventions.^{13,14} Of course, treatment burden is multiplied for patients with multiple chronic conditions.¹⁵

Given the highly burdensome nature of COPD management, there has recently been research published investigating the treatment burden experiences of patients with COPD and their family members.^{5,8,11,16,17} This body of literature demonstrates the substantial treatment burden that people with COPD experience, including changing daily routines,^{4,9} and health behaviors, difficulty attending medical appointments because of travel restrictions,^{5,16} attending specialist appointment because of financial costs,¹⁸ not being able to afford medications,¹⁸ inconsistent or contradictory information about COPD and treatment,⁵ experiencing treatment side-effects,¹⁹ the burden of transitions between health-care institutions, and lack of communication between health-care professionals.⁵ Further, Lippiett's (2019)⁵ systematic review highlights that frequent hospitalizations compound treatment burden, with hospital stays reported to be confusing, and disruptive.

Although research has begun to shed light on how COPD patients experience treatment burden, most of what we know is limited to personal experiences of individual patients. Perspectives of carers are largely missing, despite carers being acknowledged as a critical source of support for patients.²⁰ Finally, little is known about the perspectives of respiratory physicians (pulmonologists or chest physicians), who play a key role in the treatment and management of COPD. This study seeks to understand important areas of treatment burden from patients' and carers' experience, and respiratory physicians' perspective to identify what should be discussed during a clinical encounter. This may help empower patients and enable clinicians to tailor their care accounting for patient's personal values, preferences, and capacity to cope with their treatment workload. Using an innovative method of nominal group technique, the aim of this study was to identify and prioritise areas of treatment burden that should be discussed during the clinical encounter from a patient, carer and a respiratory physician perspective.

Materials and Methods

The nominal group technique was used as the primary research methodology in this study. Developed by Delbecq and Van de Ven as a qualitative research technique, the nominal group technique aims to identify strategic problems and develop appropriate and innovative solutions.²¹ The technique allows for many ideas to be developed, avoids "quick" decision-making, has a high degree of task completion, and anonymously measures the relative importance of the ideas that are developed.²² Although time consuming and regimented, the nominal group technique is particularly useful when investigating health-care problems and producing action-based solutions.²³ It has been used widely in chronic disease research, particularly around priorities for treatment outcomes,²⁴ unmet needs,²³ and patient-centred care.²⁵ Compared with traditional focus group interviews, nominal group technique provides the opportunity for all participants to express their ideas and democratically vote on their priorities rather than have discussions dominated by outspoken participants.²⁶ Informed consent, including publication of anonymised responses, was obtained from all participants prior to data collection, and Gold Coast Hospital and Health Service Human Research Ethics Committee provided approval for the study (LNR/2020/QGC/61202). The study also complied with the Declaration of Helsinki.

Participants

Purposeful sampling was used to recruit participants diagnosed with COPD for the study. Eligible participants were contacted from lists of outpatient clinics, entries in the electronic medical record, and direct referrals from respiratory physicians and nurses working at the Gold Coast University Hospital (GCUH). Unpaid carers, who provided care to people with COPD, were recruited in a similar way. Respiratory physicians practicing in different Australian hospitals were contacted in person or via email by one of the investigators.

After signing the study consent form, a research assistant collected data on COPD patients' characteristics: age, sex, marital status, number of people living in the same household, employment status, carer arrangements, type and year of diagnosis of chronic disease(s), number of medications (per day, per week, per month), estimated time spent on treatment work for disease management, including taking of medication, device maintenance, attending medical appointments, filling pharmacy scripts, monitoring health, diet, exercise and other activities (per day, per week, per month). Patients were also asked to rate on a four-point Likert-scale how burdened they currently felt about all the work they had to do for their healthcare: not at all burdened (0), somewhat burdened (1), significantly burdened (2), overwhelmingly burdened (3).

For carers, the following information was collected: age, sex, marital status, relationship to patient they care for, duration of carer's duties, estimated time spent on helping patient with treatment work for disease management, including preparing and administering medication, accompanying patient to medical appointments, going to pharmacy to fill patient's scripts (per day, per week, per month). For physicians, we collected information on speciality and location of practice.

Procedure

Nominal group technique sessions were conducted in person at the GCUH or online using a video conferencing platform. Sessions lasted between 2.5 and 3 hours (with a break), and participants attended one session. All the nominal group sessions were audio recorded, and the discussion following the ranking of treatment burden challenges was transcribed and de-identified. The sessions followed the below structure:

1. Introduction: The aim of the study and nominal group process was explained.
2. Silent generation of ideas: Participants were encouraged to record, in silence, as many ideas as possible to the following questions.
3. Patients: What issues related to the patients' burden of treatment do you think should be discussed between doctor and patient?
4. Carers: What issues related to the burden of treatment do you think should be discussed between the doctor, you as the carer and the person you are caring for?
5. Respiratory physicians: What issues related to patients' burden of treatment do you think should be discussed between doctor and patient/carer? Please think about the elements of treatment that are likely the most burdensome to your patients, and why you think it would be good to discuss these during a consultation.
6. Round Robin: Each idea was elicited in a round robin approach, meaning that everyone had an opportunity to contribute one idea at a time, until all ideas were exhausted. One researcher recorded the ideas verbatim on a screen visible to all participants. Some new ideas were also generated during this process.
7. Clarification: All participants were asked to clarify ambiguous ideas to ensure that the meaning was clearly understood by everyone. Similar ideas were then grouped together if there was consensus, and a code was allocated to each idea for ranking reasons.
8. Ranking: Participants selected their top five ideas, and then ranked them in order of priority, with five marks allocated to their top, and one mark to their lowest, priority. The top five ideas for the whole group were determined by adding up individual votes.
9. Discussion and solutions: The top five priorities and the potential solutions that could be implemented were discussed together as a group.

Analysis

Quantitative and qualitative data were generated by the nominal group technique sessions; (a) quantitative ranking of treatment burden priorities, (b) qualitative discussions of priorities and potential solutions. Data analysis followed the following process:

1. Individual group scoring/ranks was reviewed by the entire research team.
2. Where there are potential overlaps, similar priorities were grouped together under an "umbrella theme." For example, trouble with parking at the hospital and waiting times for specialist appointments were grouped under the

umbrella theme of “access to healthcare”. Umbrella themes were cross-checked by another research team member for validation.

3. The scores (votes on priorities) for each nominal group session were calculated according to the method based on McMillan et al.²⁷ Specifically:
4. The scores for all priorities combined under the same umbrella theme were added up from all three patient nominal group sessions, resulting in an aggregate score for each umbrella theme. For physicians and carers, scores for all priorities combined under the same umbrella theme were added up from the one session nominal group session.
5. Frequency of voting indicated how many times a particular theme was voted for or how popular the theme was.
6. Ranked priority was the overall priority score for each umbrella theme based on the aggregate scores. If there were equal aggregate scores, frequency of voting was used as secondary ranking criterion with more votes resulting in a higher ranking.

Results

Overall, five nominal group technique sessions were conducted (n = 31); three sessions with patients (n = 18), one with carers (n = 7) and another one with respiratory physicians (n = 6). The mean age of patients was 70.4 years (range = 59 to 82 years), including 13 females (72%), while the carers’ mean age was 70.1 years (range = 54 to 85) including five females (71%). Patients were on average taking 10 pills and/or inhalers per day (range = 3 to 20). In addition to COPD, recruited patients were diagnosed with other chronic conditions including anxiety, diabetes, heart failure, thyroid disease, and asthma. All patients were retired, some because they could no longer work due to their COPD. On a four-point Likert-scale of degrees of treatment burden, nine patients reported being significantly burdened and nine felt somewhat burdened.

For carers, most (n = 5) were spouses/partners of the care-recipient and three were still in paid employment. Some of the assistance provided by the carers included transport, medication management, diet, paperwork/administration, and financial management. Physicians were all specialists in respiratory medicine who worked in different hospitals and private practices in the state of New South Wales, Australia.

Thematic analyses of the nominal group transcripts generated nine umbrella themes. Table 1 lists and describes each of the nine umbrella themes. Top priorities for patients, carers, and the respiratory physicians are presented in Tables 2–4 respectively.

Table 1 Description of Umbrella Themes

Umbrella Theme*	Explanation
Accessing healthcare	Difficulties with accessing healthcare, such as waiting lists, length of travel, lack of appointments, etc.
Carer needs	Needs of carers, including being involved in treatment decision making, burden of caring, lifestyle adjustment because of caring, etc.
Disconnect and coordination of care	Disconnect between health professionals, lack of communication and follow-up issues
Education and information	Physician led education and information on COPD, treatment options, medications, etc.
Financial and cost burden	Financial cost of treatment and out of pocket expenses, such as cost of parking at hospital, private health insurance premiums, etc.
Individualized care/treatment	Holistic care and thinking about the patient as whole during treatment to suit patient preferences.
Medication related burden	Burden associated with medication use, including side effects and polypharmacy
Support with self-management	Helping to support the person self-manage their condition and treatment of COPD.
Worry about COPD treatment and prognosis	Worry by patients regarding adhering to COPD treatment and its prognosis.

Note: *Alphabetical order.

Education and Information

Across all three COPD patient groups, education and information emerged as the most important treatment burden theme to be discussed in clinical encounters (Table 2). Education and information emerged as the third most important priority for carers (Table 3) and fourth for respiratory physicians (Table 4). For patients, they needed information about and referral to services which provide support with symptom management and education about treatment options. Considered and personalized discussions between the patient and respiratory physician were deemed more important than generic written information:

I think it'd be ideal to have someone who can consult with you and give you a bit more information than just a pamphlet about what's available. (Patient)

Carers, on the other hand, preferred this information to be given in writing:

Maybe a folder that would at least help with the diet, with medications or allergy or things that reacts with other medications. That might be something that we can go back to ask the doctor. (Carer)

There were extensive discussions about health professionals (including respiratory physicians) being too busy and not spending enough time with patients to explain their symptoms and treatment options. Some participants reported that they found out about support services from friends and other people. Rather, they would have preferred this to be discussed during a consultation. When education about treatment and self-management were not offered to the satisfaction of patients, other channels and sources of support were utilized:

I'm lucky I've got a really close friend who's a really good physio ... and she showed me different breathing exercises to do. I mean that sort of education is really good. (Patient)

Patients also believed that health professionals should be empathic and patient when conveying this information. Patients felt the personal responsibility to invest time into learning about the condition, the management, and be ready to ask the relevant questions to their doctor:

I think also, you need to be prepared for when you go to the doctors to have your questions ready, written down. (Patient)

This was reiterated by respiratory physicians, who said that patients often do not voice their concerns nor indicate that they are depressed or anxious, which makes their job harder. They agreed that all health professionals needed to be good listeners and probe patients for further information:

I think you can jump in with a question and probe a little deeper, and if you've known the patient for a little while, you can read them, and even if you've met them for the first time, you can read body language and with symptom burden. (Physician)

Finally, all groups agreed that the information given by all health professionals, including the hospital paperwork, needed to be simple and easy to understand.

Regarding solutions, it was suggested that a checklist could be developed to assess patients' physical, psychological and social level of function as well identify their information and education needs specific to COPD, its progression and communication preferences. A need for a designated person with time and good interpersonal skills to 1) provide this holistic, personalized information, 2) help them navigate the system, and 3) identify suitable services was also discussed as a solution:

Someone within the practice who has the information to be able to guide you to different services. (Patient)

Carers agreed and extended this sentiment to also include the designated person having an advocacy role to support the patient and family through their COPD journey. Respiratory physicians acknowledged that multiple health-care professionals can provide COPD specific information and education for example respiratory nurses and pharmacists. The respiratory physicians emphasized the need for there to be more specialized nurses in community outreach positions.

Table 2 Priorities for COPD Patients (n = 3 Groups) 18 Participants

Umbrella Theme	Sum of Scores All Themes Group 1	Sum of Scores All Themes Group 2	Sum of Scores All Themes Group 3	Sum of Scores All Themes (for All Groups)*	Freq. of Voting (for All Themes)^	Ranked Priority (via Scores for Themes)
Education and information	30	10	16	56	9	1st
Accessing healthcare	25	10	16	51	5	2nd
Worry about COPD treatment and prognosis		39	11	50	5	3rd
Disconnect and coordination of care	12	14	8	34	5	4th
Medication related burden		17	9	26	3	5th
Financial and cost burden	5		12	17	3	
Individualized care/ treatment	17			17	2	
Carer needs			4	4	2	
Support with self-management	2			2	1	

Notes: *Sum of all participants scores from the three groups conducted. Participants scored the themes identified in their session on a scale of "1" to "5" with 5 being the highest priority (ie, what the most important burden of treatment was to them) to 1 being least important. ^Frequency of voting indicates how many times a particular theme was voted for. This was summed across the three sessions conducted.

Table 3 Priorities for Carers (n = 7 Participants)*

Umbrella Theme	Sum of Scores All Themes Carers [†]	Freq. of Voting (for All Themes) Carers [‡]	Ranked Priority (via Scores for Themes) Carers
Carer needs	56	4	1st
Worry about COPD treatment and prognosis	21	2	2nd
Education and information	20	1	3rd
Disconnect and coordination of care	8	1	4th

Notes: *Only four priorities emerged. [†]Sum of all participants scores. Participants scored the themes identified in their session on a scale of "1" to "5" with 5 being the highest priority (ie, what the most important burden of treatment was to them) to 1 being least important. [‡]Frequency of voting indicates how many times a particular theme was voted for in the one session conducted.

Table 4 Priorities for Respiratory Physicians (n = 6 Participants)

Umbrella Theme	Sum of Scores All Themes Respiratory Physicians ^{^^}	Freq. of Voting (for All Themes) Respiratory Physicians ^{**}	Ranked Priority (via Scores for Themes) Respiratory Physicians
Accessing healthcare	32	5	1st
Worry about COPD treatment and prognosis	27	5	2nd
Medication related burden	21	3	3rd
Education and information	3	2	4th
Individualized care/treatment	7	1	5th

Notes: ^{^^}Frequency of voting indicates how many times a particular theme was voted for in the one session conducted. ^{**}Sum of all participants scores. Participants scored the themes identified in their session on a scale of "1" to "5" with 5 being the highest priority (ie, what the most important burden of treatment was to them) to 1 being least important.

Abbreviations: COPD, chronic obstructive pulmonary disease; GCUH, Gold Coast University Hospital; COVID19, Coronavirus disease 2019.

Accessing Healthcare

Do you have to wait until you're so low that you go back to hospital?. (Patient)

As illustrated by the above quote, COPD patients perceived difficulties with accessing treatment as a source of treatment burden. Although it did not emerge as one of the top five priorities for carers, this was the second most important priority for patients and the most important priority for respiratory physicians for discussion during clinical encounters. Physicians also acknowledged the difficulties with accessing health services, particularly with long waiting times for specialist appointments and pulmonary rehabilitation:

I think access is an issue, probably the waiting list (Physician)

The travel difficulties that many patients experienced were also commented on by the physicians. Disappointment and frustration were clearly expressed by patients when talking about issues of healthcare access. There was acceptance that insufficient government funding contributed to burden associated with accessing healthcare.

... you've got to wait another two years, before you're eligible for it, because of the funding. Well two years down the track, Jesus, you wouldn't know where we were going to be. (Patient)

Despite not being a top five priority, accessing healthcare was nevertheless discussed in the carer group, particularly in the context of the Coronavirus disease 2019 (COVID19) pandemic. Carers' discussed how the COVID19 pandemic negatively affected the ability to access healthcare in a timely manner:

During the COVID when Brisbane was going through the lockdown, I was not allowed to go into the hospital. I had to sit outside the hospital in the rain for five hours. (Carer)

Beyond the straightforward solutions of providing patients with a choice of appointment timeframes, access to free or subsidized community transport, and the need for long-term pulmonary rehabilitation programs that are easily accessible, patients and physicians discussed alternative, virtual delivery models of care. Physicians posited a hybrid model of care for the delivery of pulmonary rehabilitation programs including online group-based, and one-on-one private sessions. It was commented that younger patients may appreciate the opportunity to exercise via online social media or communication platforms while older cohorts can continue with more traditional group based, face-to face programs and supplement with one-on-one sessions as required.

Worry About COPD Treatment and Prognosis

Worrying about COPD treatment and prognosis was burdensome, and patients wanted to share their experiences with physicians. This theme emerged as either second or third most important priority across all groups, although it was a higher priority for carers and physicians, compared to patients. Although, for one of the patient groups (see Table 2), it was the highest priority. Respiratory physicians discussed how people with COPD worried as they made significant lifestyle modifications, particularly in their home environment, but at times did not have the capacity or capability to undertake the work. There was also discussion on how some patients became further stressed and worried during treatment or medical tests:

It can feel quite stressful. You've got this person saying, keep going, keep going, keep going [lung function test], and that causes them anxiety. (Physician)

For patients, one aspect of this type of burden was worry about their condition worsening and requiring intubation, with one participant voicing concern and anxiety which resonated across the patient groups:

That's one of my biggest fears ... I'm scared to death of it [intubation]. (Patient)

Many expressed worries about their COPD worsening and end-of-life treatment options and wanted their respiratory physicians to discuss these issues with them openly and honestly. Currently, such discussions were mainly held with social workers and other allied health staff but, according to patients, should also be proactively broached by the treating physician. The importance of having conversations about advanced care directives and formally documenting them were also highlighted by carers. One carer discussed a personal family experience:

I just know that when my dad was in ICU [Intensive Care Unit] following heart surgery and he didn't come through. My mum was not listed as being allowed to speak on his behalf. I stood there in the ICU and said he has not signed a DNR [Do Not Resuscitate], you guys need to do everything you can. But there was nothing on paper. (Carer)

As a solution to minimise this type of burden, patients, carers and respiratory physicians all agreed that clear and empathetic communication about the condition, its prognosis, treatment plan, goals and outcomes were required. Patients wanted their GP or respiratory physician to initiate conversations about prognosis and the management of advanced symptoms, end-of-life care and resuscitation orders. Patients and carers both thought that it was important to be provided with information about their health and prognosis even if the news is not positive than affirmative action is taken in response.

If you are giving a nasty prognosis, follow up with would you like a referral to the social worker, the psychologist, the chaplain, someone who helps you process it?. (Patient)

Disconnect and Lack of Coordination of Care

COPD patients frequently discussed the difficulties they experienced when health-care services and providers were disconnected and offered little continuity and coordination of care. Patients ideally wanted consistent messaging,

information, and guidance about how to manage their COPD and continuity in the health-care professionals they consulted. When asked what they wanted to be a discussion point in a clinical encounter, one patient responded:

Better communication obviously between specialists, doctors, overall. (Patient)

There were considerable discussions around the lack of coordination of care between respiratory physicians working at the hospital and family physicians. According to one patient, it was mostly the hospital-based specialist physicians not sufficiently communicating with their family physician rather than the other way around:

As far as the COPD part goes, no they're in the dark. The hospital doesn't forward that stuff back to them automatically. (Patient)

One participant voiced her frustration on this issue:

If they've got it on a computer, all they've got to do is put in an email address, and press send. How hard can that be?. (Patient)

Another participant echoed this frustration, adding that the e-health system should have addressed this issue, only if physicians in her words, "learnt how to use it". Relocation of respiratory physicians or GPs (General Practitioners) was also a problem and contributed to potential disconnect between physicians and other health professionals. Despite not being happy with their care coordination, the patient groups did however acknowledge that physicians may not have the time to adequately communicate with the family physician:

I think the problem is, the specialists are so busy, they're not going to have a great deal of time to communicate very much with the GPs. (Patient)

For carers, there was also a sense of disconnect in communication between the respiratory physician and the nurse, with carers' expressing a desire for better communication and coordination between the two. In the respiratory physician group, although the importance of coordination between them and the family physician was discussed, this theme did not emerge in their top five priorities.

One solution for reducing the burden of disconnected care was having specialist referrals automated, which would overcome patients having to visit their GP for a new specialist referral. Further, if appointments and tests could be arranged to occur on the same day, it could save patients having to attend the hospital on multiple occasions:

I used to have an x-ray, blood test, scan, if necessary, all lined up, one after another, so I only had to make one visit to the hospital for one day. (Patient)

Medication Related Burden

Burdens related to medicine use were the fourth and third most important priority for patients and respiratory physicians, respectively (Tables 2 and 4). Although patients did acknowledge the burden of having to take multiple medications and experiencing side effects, most of the discussion on medications were around the correct use of medications and the need for regular medication reviews. Patients wanted their respiratory physicians to spend time discussing and reviewing their medications to ensure that they were being used correctly and still indicated:

Because I take that many tablets and puffers, that I'm sure it can't be doing my health any good long term. (Patient)

The importance of communication and continuity around medication prescription between the GP and the respiratory physician was also discussed:

... when they give you different medications, I don't know whether they actually look back on what they've already given you, or do they know what you've taken?. (Patient)

Respiratory physicians were also aware of the burden patients experienced because of medication use, with one physician pointing out his own personal experience:

To take medications every day is a burden. We all just write up prescriptions but from a personal point of view, I hate taking medicines every day and it's something hard to do. (Physician)

Although medication-related burden did not emerge as a top five priority for carers, there were discussions in the group around the ways carers' jobs could be made easier:

I guess every patient is different. They are on different treatment. They take different medications. So is there any like say they could give you a printout. (Carer)

Another carer added:

Maybe a folder that would at least help with the diet, with medications or allergy or things that reacts with other medications. (Carer)

Regular and routine review of medications was the main solution that was proposed by patients. GPs, respiratory physicians and pharmacists could all undertake a medication review. Again, there was acknowledgement that physicians may not have the time to adequately discuss and review medications during a short consultation. One participant suggested that community pharmacists could assist.

Patients and carers felt that there needed to be more responsibility taken by the person who is prescribing the medication to ensure all other medications are also necessary, check for interactions and communicate any changes in a timely manner to the patient's GP. Carers wished to be provided with a summary of the patient's medications, its indication, interactions and side-effects. From the perspective of respiratory physicians, solutions to minimize the burden of medications included tailoring prescriptions to a patient's specific needs and context:

The right device for the patient, but also communicating it back to the referring GP as to why that particular device and combination of medications was chosen. (Physician)

Carers' Needs

Issues associated with being a carer, such as their involvement in treatment decisions and the burdens caring for the care-recipient, were the highest priority for the carer group (Table 3). However, this theme did not emerge as a priority for physicians and emerged as a priority only during one of the three patient group sessions (not top five). Nevertheless, there was recognition in the patient and physician groups that carers should be involved in the care of the patient wherever possible. Regarding involvement in treatment, carers' believed that the physicians should consider patients' carers and other family members, and involve them in the care process:

I think it's not just looking at the patient as the patient but realising the patient has people around them. It's a holistic approach I suppose is required. (Carer)

One carer suggested that their involvement had increased treatment efficacy, especially when the patient was unable to fully participate in decision-making about treatments:

Because the doctor knows that he has memory issues and when doctors are asking him questions, his answers are not what doctors are expecting. So, my presence there is helpful to doctors. (Carer)

Although involvement of carers was discussed positively, carers did acknowledge potential privacy and confidentiality issues:

... sometimes the doctors are also very careful about the privacy issues. (Carer)

One carer, who was not invited into consultation by the care-recipient's physician suggested the following, when asked what she preferred to have happened:

The doctor to have said to him, is your partner with you or your wife with you and if so invite her in because she needs to be across what I'm saying. (Carer)

The burden and struggle of being a carer was also discussed in the carer group. One participant, who felt lonely and isolated in her caring role, commented:

I wasn't able to own up myself what I was going through or even tell anyone what I go through with my husband. (Carer)

Providing a space for carers could go to in the hospital to find solace, rest and re-energize (while the person they care for is hospitalized) was identified as a solution to reducing the burdens carers experience. The idea of a "chronic condition" support group was also favourably received by several members who had found attending the nominal group technique session cathartic. Carers, however, were not aware of any such support groups, nor did they know how they could find out if any existed.

Discussion

This study is one of the first to concurrently focus on treatment burden priorities and potential solutions among COPD patients, carers and respiratory physicians. For example, for patients, the most important priorities were receiving more education and information during the clinical encounter, difficulties they experienced with accessing healthcare and worry about COPD treatment and prognosis. In contrast, respiratory physicians believed burdens associated with accessing healthcare should be the first priority for treatment burden discussions between the physician and patient/carer, followed by education and information, and then discussions about worry. Carers were aligned with the priority to discuss worry about COPD treatment and prognosis, and the need for education and information emerging as the second and third priority, respectively. In contrast to patient and physician groups, carers' first priority was carers' needs.

The results indicated that the education and information needs of patients may not currently be fully fulfilled in a clinical encounter. There is evidence from other studies to suggest that many COPD patients struggle with managing their condition because they lack basic understanding of their illness and its treatment.^{18,28} For example, Bauer et al, in their qualitative study, found that patients voiced frustration with COPD-related information and support received during clinical encounters, particularly at the time of diagnosis.¹⁸ The need for education and information has been identified as a priority in many other chronic conditions, and patients' understanding of their illness(es) and treatments is an important determinant of engagement with health advice and treatment.²⁹ Perhaps, the desire for better education and information reflects COPD patients' need to feel in control of their condition and presents an opportunity to be heard in the context of all the worry they experience living with and treatment of COPD. We recommend that health professionals simplify treatments where possible, provide written and verbal explanations of treatment tasks to their patients, and make sure that patients have a basic understanding of their illness and its treatment.

Education and information emerged as the fourth most important priority for physicians. Although this may be construed as being less of an important priority for physicians than patients, the results must be interpreted in context. Only one session with physicians was conducted as opposed to three with patients and while this theme emerged as the most important priority for two of the patient groups, it was the fourth most important priority for the other. Either way, the need for education and information emerged as a top five priority for physicians and for patients signalling a common perception of its importance.

Furthermore, difficulties around access of healthcare have been described as a major source of burden for patients with COPD,¹⁶ and patients with chronic disease in general.^{13,30,31} Indeed, there are many documented examples of patient's having to wait months or travel long distances to seek specialist treatment.¹² The solution discussed by respiratory physicians regarding the hybrid model of care, specifically, the delivery of pulmonary rehabilitation programs for improving healthcare access, warrants further research attention. During the COVID-19 pandemic many patients were undertaking pulmonary rehabilitation online but future research is required to determine its effectiveness compared with the traditional model.

For the burden associated with worrying about COPD treatment and prognosis, there was mostly agreement across all participant groups. Physicians and carers ranked this as the second most important priority whereas the patients ranked it as the third most important priority for discussion in a clinical encounter, although this was ranked as the highest priority for one patient group (group 2). While the reasons for this could be complex, one possible explanation of this variation could be that two of the six patients in this group (group 2) were using continuous positive airway pressure treatment for an average of 7 hours each night, while this was 4.7 hours for group 1 and none for group 3. The burden associated with worrying about COPD treatment and prognosis is not surprising given COPD on its own is recognized as a "difficult" illness, with many people

experiencing high symptom burden, difficulties performing everyday tasks, social isolation and making lifestyle changes.^{3,18} There is also evidence to suggest that patients struggle to follow health professionals' treatment advice (eg, following diet advice and restrictions) and worry about their condition worsening.³² Clearly, treatment advice needs to be given in the context of specific circumstances and capacity of patients and carers to follow that advice.

Regarding disconnect and coordination of care, our results seem to confirm previous research that patients and carers find it difficult when there is a lack of teamwork and continuity of care between their health-care professionals.^{4,33} According to Haggerty et al's³⁴ seminal work on continuity of care, our results suggest that patients and carers preferred informational continuity, over management and relational continuity. That is, they wanted information on past events and personal circumstances around COPD and its treatment to be consistently used to inform current care and decisions. Haggerty et al³⁴ suggests that information can be disease- or person-focused but it is equally important that it reflects knowledge of patients' preferences, values, and context. However, in our study, the results indicated that patients and carers struggled with even the basic continuity around disease information and wanted their respiratory physicians to be aware of this.

Finally, although only one group was conducted with carers, our results confirm the widely reported frustration that unpaid carers experience. Research has frequently indicated that the burden a patient experiences is often inseparable from the carer's burden.^{20,35} It is also important to remember that many carers have chronic health conditions themselves, which means that they are faced with the overwhelming work of providing care for somebody else while at the same time managing their own health condition(s). Despite providing a valuable role in society, our findings confirm that carers' need may still not be sufficiently recognized and addressed by physicians and the broader health system. As discussed in the group, formal mechanisms of recognition, such as a carer card, could potentially minimize treatment burden and increase the quality of life of both the carer and the care-recipient. Other existing support strategies, such as accredited training, no interest loans for medical expenses, discount vouchers, etc. can also be more strongly advertised.

Limitations and Strengths

Although our findings offer a unique perspective into treatment burden of patients with COPD, they are based on a small group of participants. While we intended to recruit more participants from diverse backgrounds into each of the nominal group sessions, data collection was conducted during the COVID19 pandemic, and it was challenging to conduct group sessions with research participants in a health-care setting with changing regulations. The data reflect the opinions and experiences of a small group of mostly females, in one treatment centre and may therefore not be generalizable to other people and settings. Nevertheless, we believe that many of the raised issues are relevant to many patients with COPD, their carers and physicians, as they align with the findings in previous studies of patients with chronic diseases.

During the nominal group process, discussion among participants was limited, which may have inhibited the full expression and development of ideas. The decision to condense the priorities into umbrella themes, is a potential limitation of the nominal group technique. This may have also biased the results by potentially having different priorities contained under a particular theme. However, team discussions and consensus agreement during the development of the umbrella themes would minimize the risk of this bias.

The use of nominal group technique to elicit the priorities of participants is a key strength of our study. This data collection strategy made sure that the discussion was not dominated by one or two outspoken participants. Everyone's voice was heard, thereby empowering, and motivating them to discuss their experiences and expectations of what they wanted discussed in a clinical encounter. Finally, the nominal group technique allowed us to compare the priorities between three different types of participants (patients, carers and physicians) with their unique views and priorities regarding treatment burden.

Conclusion

This study provides an insight into the preferences of treatment burden topics that patients, carers and physicians wish to discuss in a clinical encounter. Challenges around accessing healthcare, the need for better education and information, and the worry caused by COPD treatment and prognosis, emerged as top priorities. Carers' needs were only identified as a priority by informal carers. Understanding and creating opportunities to discuss these issues in the clinical encounter is important to not only reduce treatment burden, but also improve health outcomes and quality of life for those living with and affected by COPD.

Acknowledgments

We would like to acknowledge Helen McEvoy with project management and Dr Bajee Krishna Sriram for assisting with recruitment. We would also like to thank all the participants for sharing their thoughts and priorities.

Funding

This study was funded by a grant from the Gold Coast Health Collaborative Research Grant Scheme (application ID RGS20190034). CCD had salary support (independent of the study) from the Australian National Health and Medical Research Council (NHMRC) (application ID APP1123733).

Disclosure

Adem Sav reports grants from Gold Coast Health Collaborative Research Grant Scheme, during the conduct of the study; and grants from the Gold Coast Health Collaborative Research Grant Scheme, outside the submitted work. Claudia C Dobler reports grants from Gold Coast Health and Australian National Health and Medical Research Council (NHMRC), during the conduct of the study. The authors report no other potential conflicts of interest in this work.

References

1. Dobler CC, Farah MH, Morrow AS, et al. Treatment of stable chronic obstructive pulmonary disease: protocol for a systematic review and evidence map. *BMJ Open*. 2019;9(5):e027935.
2. World Health Organization. Chronic obstructive pulmonary disease (COPD); 2021. Available from: [https://www.who.int/news-room/fact-sheets/detail/chronic-obstructive-pulmonary-disease-\(copd\)](https://www.who.int/news-room/fact-sheets/detail/chronic-obstructive-pulmonary-disease-(copd)). Accessed January 14, 2022.
3. Buttery SC, Zysman M, Vikjord SAA, Hopkinson NS, Jenkins C, Vanfleteren L. Contemporary perspectives in COPD: patient burden, the role of gender and trajectories of multimorbidity. *Respirology*. 2021;26(5):419–441.
4. Sigurgeirsdottir J, Halldorsdottir S, Arnardottir RH, Gudmundsson G, Bjornsson EH. COPD patients' experiences, self-reported needs, and needs-driven strategies to cope with self-management. *Int J Chron Obstruct Pulmon Dis*. 2019;14:1033–1043.
5. Lippiett KA, Richardson A, Myall M, Cummings A, May CR. 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(2):e020515.
6. Hakim MA, Garden FL, Jennings MD, Dobler CC. Performance of the LACE index to predict 30-day hospital readmissions in patients with chronic obstructive pulmonary disease. *Clin Epidemiol*. 2018;10:51–59.
7. Iheanacho I, Zhang S, King D, Rizzo M, Ismaila AS. Economic burden of Chronic Obstructive Pulmonary Disease (COPD): a systematic literature review. *Int J Chron Obstruct Pulmon Dis*. 2020;15:439–460.
8. Gu J, Yang C, Zhang K, Zhang Q. Mediating role of psychological capital in the relationship between social support and treatment burden among older patients with chronic obstructive pulmonary disease. *Geriatr Nurs (Minneapolis)*. 2021;42(5):1172–1177.
9. Gatti V, Banfi P, Centanni S, et al. Enlightening chronic obstructive pulmonary disease through patients' and caregivers' narratives. *Int J Chron Obstruct Pulmon Dis*. 2018;13:3095–3105.
10. Buffel du Vaure C, Ravaud P, Baron G, Barnes C, Gilberg S, Boutron I. Potential workload in applying clinical practice guidelines for patients with chronic conditions and multimorbidity: a systematic analysis. *BMJ Open*. 2016;6(3):e010119.
11. Dobler CC, Harb N, Maguire CA, Armour CL, Coleman C, Murad MH. Treatment burden should be included in clinical practice guidelines. *BMJ*. 2018;363:k4065.
12. Sav A, Kendall E, McMillan SS, et al. 'You say treatment, I say hard work': treatment burden among people with chronic illness and their carers in Australia. *Health Soc Care Community*. 2013;21(6):665–674.
13. Sav A, King MA, Whitty JA, et al. Burden of treatment for chronic illness: a concept analysis and review of the literature. *Health Expect*. 2015;18(3):312–324.
14. Eton DT, Yost KJ, Lai J-S, et al. Development and validation of the Patient Experience with Treatment and Self-management (PETS): a patient-reported measure of treatment burden. *Qual Life Res*. 2017;26(2):489–503.
15. Sav A, Salehi A, Mair FS, McMillan SS. Measuring the burden of treatment for chronic disease: implications of a scoping review of the literature. *BMC Med Res Methodol*. 2017;17(1):140.
16. Harb N, Foster JM, Dobler CC. Patient-perceived treatment burden of chronic obstructive pulmonary disease. *Int J Chron Obstruct Pulmon Dis*. 2017;12:1641.
17. Negewo NA, Gibson PG, Wark PA, Simpson JL, McDonald VM. Treatment burden, clinical outcomes, and comorbidities in COPD: an examination of the utility of medication regimen complexity index in COPD. *Int J Chron Obstruct Pulmon Dis*. 2017;12:2929.
18. Bauer WS, Schiffman RF. Factors influencing self-management of Chronic Obstructive Pulmonary Disease by community-dwelling adults. *West J Nurs Res*. 2020;42(6):423–430.
19. Bakthavatsalu B, Walshe C, Simpson J. A systematic review with thematic synthesis of the experience of hospitalization in people with advanced Chronic Obstructive Pulmonary Disease. *COPD*. 2021;18(5):576–584.
20. Denning J, Carter P, Galvin L, Pritchard L. How treatment burden affects the carer: the experiences of three individuals, a mother, a daughter and a husband. *Breathe*. 2021;17(1):200327.
21. Delbecq AL, Van de Ven AH, Gustafson DH. *Group Techniques for Program Planning: A Guide to Nominal Group and Delphi Processes*. Scott, Foresman; 1975.

22. Potter M, Gordon S, Hamer P. The nominal group technique: a useful consensus methodology in physiotherapy research. *NZ J Physiother.* 2004;32:126–130.
23. Drennan V, Walters K, Lenihan P, et al. Priorities in identifying unmet need in older people attending general practice: a nominal group technique study. *Fam Pract.* 2007;24(5):454–460.
24. Sanderson T, Hewlett S, Richards P, Morris M, Calnan M. Utilizing qualitative data from nominal groups: exploring the influences on treatment outcome prioritization with rheumatoid arthritis patients. *J Health Psychol.* 2012;17(1):132–142.
25. Ospina MB, Michas M, Deuchar L, et al. Development of a patient-centred, evidence-based and consensus-based discharge care bundle for patients with acute exacerbation of chronic obstructive pulmonary disease. *BMJ Open Respir Res.* 2018;5(1):e000265.
26. Sav A, McMillan SS, Kelly F, et al. The ideal healthcare: priorities of people with chronic conditions and their carers. *BMC Health Serv Res.* 2015;15(1):1–10.
27. McMillan SS, Kelly F, Sav A, et al. Using the nominal group technique: how to analyse across multiple groups. *Health Serv Outcomes Res Methodol.* 2014;14(3):92–108.
28. Kale MS, Federman AD, Krauskopf K, et al. The association of health literacy with illness and medication beliefs among patients with Chronic Obstructive Pulmonary Disease. *PLoS One.* 2015;10(4):e0123937.
29. Arat S, De Cock D, Moons P, Vandenberghe J, Westhovens R. Modifiable correlates of illness perceptions in adults with chronic somatic conditions: a systematic review. *Res Nurs Health.* 2018;41(2):173–184.
30. Morris JE, Roderick PJ, Harris S, et al. Treatment burden for patients with multimorbidity: cross-sectional study with exploration of a single-item measure. *Br J Gen Pract.* 2021;71(706):e381–e390.
31. Zucca A, Boyes A, Newling G, Hall A, Girgis A. Travelling all over the countryside: travel-related burden and financial difficulties reported by cancer patients in New South Wales and Victoria. *Aust J Rural Health.* 2011;19(6):298–305.
32. Russell S, Ogunbayo OJ, Newham JJ, et al. Qualitative systematic review of barriers and facilitators to self-management of chronic obstructive pulmonary disease: views of patients and healthcare professionals. *NPJ Prim Care Respir Med.* 2018;28(1):2.
33. Tavares N, Hunt KJ, Jarrett N, Wilkinson TM. The preferences of patients with chronic obstructive pulmonary disease are to discuss palliative care plans with familiar respiratory clinicians, but to delay conversations until their condition deteriorates: a study guided by interpretative phenomenological analysis. *Palliat Med.* 2020;34(10):1361–1373.
34. Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R. Continuity of care: a multidisciplinary review. *BMJ.* 2003;327(7425):1219–1221.
35. Hannan N, McMillan SS, Tiralongo E, Steel A. Treatment burden for pediatric eosinophilic esophagitis: a cross-sectional survey of carers. *J Pediatr Psychol.* 2020;46(1):100–111.

International Journal of Chronic Obstructive Pulmonary Disease

Dovepress

Publish your work in this journal

The International Journal of COPD is an international, peer-reviewed journal of therapeutics and pharmacology focusing on concise rapid reporting of clinical studies and reviews in COPD. Special focus is given to the pathophysiological processes underlying the disease, intervention programs, patient focused education, and self management protocols. This journal is indexed on PubMed Central, MedLine and CAS. The manuscript management system is completely online and includes a very quick and fair peer-review system, which is all easy to use. Visit <http://www.dovepress.com/testimonials.php> to read real quotes from published authors.

Submit your manuscript here: <https://www.dovepress.com/international-journal-of-chronic-obstructive-pulmonary-disease-journal>