RESEARCH ARTICLES

Understanding COPD Emergency Department presentations: using thematic analysis to explore the voices of patients, nurses, and doctors on the lived experience of managing COPD

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ABSTRACT

Aim: To describe for areas of improvement in the management of COPD and reduction in emergency department presentations in Queensland.

Background: If current trends in the management of COPD do not change, the predicted 4.5 million Australians diagnosed with COPD by 2050 will place significant burdens on already over-utilised frontline ED services. Separately COPD is more costly per case than cardiovascular disease and is a more common presentation to Emergency Departments in any year than most types of cancer, road traffic accidents and heart disease.

Study Design and Methods: This study used a qualitative thematic analysis methodology in which field convergent interviews were employed to generate data. Sixteen staff and nine patients across three major Southern Queensland Health acute care facilities participated in the study. The authors analysed interview data using qualitative thematic analysis.

Results: This research has revealed several noteworthy concepts worthy of further exploration. Thematic analysis from both staff and patient interviews identified the following issues:

1. Nurse case management, 2. Integrated communication of patient assessment and history data, 3. Failure in COPD management, and 4. Knowledge utilisation among ED clinicians. Inherent among these key concepts is a primary goal of coordinated congruent COPD management that optimise a patient's functional status and quality of life, improving symptoms management, and avoiding recurrent exacerbations.

Discussion: These insights into the experience of patients and hospital staff into the management of COPD provides valuable insight into current and desired practices that can help to minimise presentations to Emergency Departments. The findings of the research provide insights and future direction for improvements by addressing the inconsistency in disease management. The need for more accessible and consistent patient management and a more congruent centralised patient support framework was also identified.

Conclusion: There is indication of support stemming from the voices of patients and hospital staff around the need for COPD case management to become the dominant method of care. Future research should consider the cost benefit and patient outcomes of the implementation of such a role and the avoidance of ED presentations.

Implications for research, policy, and practice: The findings of this research imply a need to streamline the patient support and disease management discharged planning process by ensuring one health professional maintains ongoing education, support, and assessment to the patient. Future research needs to better ascertain the positive economic benefits to healthcare organisations by employing Case Managers for patients with COPD.

What is already known about the topic?

- Case management roles can be effective in reducing ED usage for adults with chronic illnesses.
- The World Health Organization (WHO) has called for planned ongoing assessment, care and support coordinated by a proactive investment in real time solutions that address the increasing burden of this disease on the healthcare sector.
- The WHO has endorsed targeted patient support strategies that coordinate care over time, addressing the physical and mental health needs of people with chronic illness.

What this paper adds:

- Findings from this research show that discharged planning support practices with Southern Queensland Healthcare Organisations require review and ongoing evaluation.
- This may include, streamlining the patient support and disease management discharged planning; or designated case management or integration of systems to prevent ED presentations.
- This research adds to the voices of patients and staff that confirm published research recommendations.

Keywords: Chronic Obstructive Pulmonary Disease, Emergency Department, Discharge Planning

BACKGROUND

Chronic Obstructive Pulmonary Disease (COPD) contributes to high levels of morbidity and mortality nationally and internationally. The lung disease is ranked as the fourth leading cause of death globally and the leading cause of health burden in Australia within an ageing population.[1-3] COPD is characterised by progressive and irreversible airway obstruction. Over 2.1 million Australians have COPD. Of these over 1.2 million people will have a sufficiently progressed stage of COPD that it is already affecting activities of daily living.[3,4] There are four stages (I to IV) of COPD based on FeV1 spirometry results which rank the condition in terms of severity, with IV being the most severe.[5,6] Approximately 876,000 Australians have Stage I COPD,[7] many of whom will progress to develop more severe COPD if left unrecognised and untreated. Lack of utilisation of spirometry being gold standard to confirm diagnosis has led to underdiagnosis and presence of other comorbidities has led to misdiagnosis.[8-10] Fifty seven percent of those with COPD are women. Among people with COPD, 47% are of working age (15-64 years) and 62% are over 60 years. Underdiagnosis, misdiagnosis and comorbidities are a major issue with COPD. Symptoms for another condition, such as Chronic Heart Failure is one of the factors associated with misdiagnosis.[7,10] Medication compliance has also been recognised as a key contributor to Emergency Department (ED) presentations.[11] If current trends do not change, the predicted 4.5 million Australians diagnosed with COPD by 2050 will place significant burdens on already over-utilised frontline ED services, particularly when considering an ageing population and comorbidity with other conditions.[12] Separately COPD is more costly per case than cardiovascular disease and is a more common presentation to Emergency Departments in any year than most types of cancer, road traffic accidents and heart disease.[7,12,13] A recent Australian study found that the average

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daily cost of a COPD admission was A$8,297.[12] The World Health Organization has documented over 251 million cases of COPD internationally in 2016 and approximated COPD contributed to 5% of all global deaths.[11] In Australia, one in seven people aged 40 years and over have some form of COPD and the rate of hospitalisation for COPD among those aged 55 and over was 1,052 per 100,000 in 2015.[14] The Australian Institute of Health and Welfare indicate that poorly managed COPD is one of the top two causes of avoidable hospital presentations and is increasing.[1] International evidence surrounding chronic disease presentations has revealed that moving from reactive management to proactive management with improved communication demonstrated an increase in complex specialist nursing interventions and led to a decrease in emergency presentations and bed use at local hospitals.[3,7,15-17] A systematic review conducted in 2016 confirmed from several empirical studies that case management roles can be effective in reducing ED usage for adults with chronic illnesses.[18] The WHO has called for planned ongoing assessment, care and support coordinated by a proactive investment in real time solutions that address the increasing burden of this disease on the healthcare sector. WHO has endorsed targeted patient support strategies that coordinates care over time, addressing the physical and mental health needs of people with chronic illness.[19] A scoping review by Moloney et al. (2019) confirmed that future research should target ED avoidance with a stronger emphasis on coordinated community management.[20]

PURPOSE OR AIMS

This project entailed qualitative interviews with 12 staff and nine patients across three major Queensland Health (QH) sites, both metropolitan and regional. This study explored the perspectives of key healthcare stakeholders related to the reasons for COPD ED presentations. It asked these key stakeholders to offer insight into potential barriers and inefficiencies related to ED presentations, whilst highlighting some targeted ED avoidance recommendations.

STUDY DESIGN AND METHODS

Thematic analysis was chosen to facilitate an understanding of the clinical experience of key stakeholders in order to appreciate hidden details behind COPD presentations to an ED, and the adaptation of meaning of managing COPD for the participants. Numerous studies focusing patient experiences of living with COPD have been guided by a qualitative thematic analysis design.[21-23] Ethical approval was obtained from the Human Research Ethics Committee of the Queensland Health service where participants were working or were admitted (HREC/17/QGC/249). Informed written consent was obtained prior to participation, and participants were advised of their right to withdraw without penalty or prejudice at any time. Participants were recruited from three nominated sites in South Queensland via purposive sampling. Participants included nine registered nurses, two respiratory physicians, five emergency department clinicians and nine patients with COPD. Upon presentation to ED, patient sample participants were invited by health staff to be interviewed by members of the research team. Similarly, staff working in the ED were invited to be interviewed by one of the members of the research team. Data was collected by a registered health professional (i.e., Nurse or Psychologist) with prior experience in COPD education and management, and with the research methodology. Using the technique of in-depth interviewing, the participant's lived experience, opinions, attitudes, ideas, and self-realisation were gathered. In-depth interviewing enabled deeper questioning by progressing a cyclical process through continuous analysis.[24,25] Interview prompts such as "tell me about your interpretation of current COPD management within the healthcare sector" were asked. Digital recordings from interviews were transcribed in a de-identified and precise manner. Copies of transcripts were verified with 50% of participants prior to analysis as supported in interviewing methods.[26] Written transcripts were dissected using line-by-line coding and consequential theme categorisation leading to the identification of core concepts.[27,28] In undertaking thematic analysis the researcher became familiar with the data, began to generate codes, undertook extensive searching for themes, revised emerging themes thereby further defining the themes, and writing up the major themes for presentation.[29]

STUDY DESIGN AND METHODS

The notes were collated and analysed using principles of thematic analysis outlined by Braun and Clark.[23] This analysis required re-reading through the transcripts independently and multiple times to identify common themes. Findings were synthesised into dominant themes following researcher discussions with the team. An additional reviewer then reviewed the themes and only minor adjustments were made ensuring rigorous and accurate interpretation of the data.

The principal researcher (CM) is a clinical nurse with 27 years of experience working with patients exhibiting COPD. He also has a lived experience of a respiratory condition and is aware of the importance of a comprehensive management plan.

Each of the interviewers used a template of general interview questions. For staff questions included "What generally happens when a patient presented with an AECOPD", "what members of the multidisciplinary team are involved", "how is the GP involved" "does the patient leave with a COPD management plan". Patient interviews reflected the staff interview with questions such as "What happens when you present with an acute exacerbation of COPD", "what members of the multidisciplinary team are involved", "do you have a GP and are they involved", "have you been discharge with a management plan".

RESULTS

This research has revealed several noteworthy concepts worthy of further exploration. Thematic analysis from both staff and patient interviews identified the following issues: 1) Nurse case management, 2) Integrated communication of patient assessment and history data, 3) Failure in COPD management, and 4) Knowledge utilisation among ED clinicians. Inherent among these key concepts is a primary goal of coordinated congruent COPD management that optimise a patient's functional status and quality of life, improving symptoms management, and avoiding recurrent exacerbations.

LACK OF EFFECTIVE CASE MANAGEMENT

There was a strong consensus among patients and staff around the concept of lack of effective case management and fragmentation of care. Participants felt that the introduction of a nurse case manager might help patients avoid regular presentations, allow for alerts and warnings about adverse circumstances to patients (e.g., smoke from bush fires), and generally give more continuity and consistency in patient management. The strength of this concept is that it was mentioned by both staff and patients.

As one of the participating emergency nurses (Staff 1) expressed:

> *"So, I think from an ED management perspective it might be inefficient for an ED nurse to be only doing COPD, but it would make sense for a respiratory nurse or a case manager to assess COPD and be based in the ED. I think that would definitely help a lot of patients, definitely help the hospital, and in some respects may even assist in hospital avoidance".*

Staff member [1] further elaborated on the concept of Nurse Case Management saying:

> *"If, for example, people that live near this hospital, if there's planned burning, then if they have forewarning then they can take appropriate steps to reduce the risk of admissions. So those kinds of things would be helpful but would need a special team whose primary focus is COPD, and possibly asthma. There would need to have the ability to give out patients' certain instruments or devices for patients to be able to log on to their database and update symptoms, etc., and to have some person that they can contact and get feedback on as to what the next step there should be. So, it may be go to your GP* [General Practitioner], *take steroids and antibiotics, stay at home, or come into ED."*

In addition, one of the ED doctors (Staff 2) stated:

> *"I'd take a load of the layers out. I'd take a huge amount of the layers out, I would give the patient one case manager, and that same case manager every time, who is responsible for all that patient's referrals."*

Another participating nurse (Staff 3) suggested:

> *"One person who then liaises with the patient's GP, and who that patient calls, only one of them, that is the person who you* [The patient ring]*."*

One of the patients with COPD astutely expressed they would have liked:

> *"One person or single point of contact to coordinate my care."*

LACK OF INTEGRATED COMMUNICATION PROCESS

Both patients and staff thought that the communication process required some improvement. This communication related to discharge planning and patient follow-up requirements. Patients particularly wanted the communication to be more centralised with less stakeholders involved thereby making it more streamlined and simpler. They also wanted more timely communication to their GP. Staff also alluded to a need for centralised and consistent forms of communication, e.g., electronic over paper-based patient information.

As one example patient (6) alluded to a lack of communication to his GP stating:

> *"So, if you go and see your GP, a week later thinking he or she would have all the paperwork…but he sits there looking at me and says, I knew you were in the hospital because your wife left a message – I told her to do so. He said but I haven't got the report."*

Patient (3) alludes to confusing communication explaining:

> *"Actually, there's so many doctors and so many people that I've talked to about the airways about the lung, it's confusing. They all seem to come in at once and all the information gets all muddled up, up there."*

One of the Registered Nurses (RN; Staff 7) referred to the breakdown of patient information flow into the ED outlining:

> *"They were using paper records when we were using electronic, but that's all fixed. GP-wise - yeah, that's the obvious thing. We don't have access to their stuff. They do have access now, more often, to our stuff, so if it's important, in the right area. Yeah, we do spend a lot of time trying to get on to GPs, practice nurses, can you send us these?"*

Further to this theme another RN detailed:

> *"I think some of the other assessments that do get done in ED that I read are the - they call them the [arch] nurses, the ones that assess how they are at home and I see those in ED. It's hard for me just to guess what they do there because often it's not recorded in our medical records, which is tricky."*

One of the ED physicians (Staff 12) posited a solution by saying:

> *"They have their own system, and they will write things on paper which may be scanned in later. So, I'm looking at a patient that's in ED and I'll be reading what's written and I can only read what I can see, I can't see the piece of paper that they're writing on down there. I think that will change with* [IEMAR] *which starts on 1 April. So, they won't have a paper-based, where they write their vital signs, where they write what is happening with the patient, it will be all on* [IEMAR]*."*

PRACTICE GAP IN COPD MANAGEMENT

Self-management failures alluded to either patients recognising their own failures in seeking treatment early or actual patient risk situations that warrant improved preventative measures. Some patients were able to recognise a lack of recognition of early cues within their own condition, but only after reflection and hospital admission. Other patients attributed their re-exacerbation related to early discharge home, feeling they did not think they were ready. Other themes included lack of awareness as to the benefits of oxygen therapy, or in one case the availability of portable oxygen to allow timely transport and assessment by a GP.

Failures from a professional staff perspective were noted to be three main issues worth documenting for future consideration. The first related to the conditioned use of high flow oxygen therapy on CO_2 retainers by paramedics who respond to emergency call outs. The second related to the use of Non-Invasive Ventilation, with one ED physician feeling un-monitored NIV may contribute to increased length of stay upon hospital admission. Thirdly, health professional called for more supportive intervention, including psychological support for emergent anxiety and depression post discharge.

Patient (1) reflected on his own lack of response to a build-up of excess fluid saying:

> *"As I said, it was a slip up. I overlooked that build up. I went three kilos up in two days and stayed there for another day and I just didn't do anything about it, and it's my fault."*

Patient (3) referred to their one stubborn behaviour expressing:

> "*Now I know because the second time when I had the attack, I was gasping too but I still wouldn't ring the ambulance or get my sister to ring the ambos."*

One of the patients (Patient 4) referred to the quick turnaround from hospital as a contributing factor to a representation:

> *"Well, I've been in three times recently. I had one doctor that I saw the morning after I came into emergency and I was in one of the wards just near emergency, the holding ward type thing; and she sent me home and I knew I was crook; and I collapsed and came back. I think they do it to clear beds. Create more beds, that was my feeling, But I don't truly know that."*

One patient (Patient 4) through misguided interpretation of the effectiveness of oxygen therapy outlined:

> "*No. I've been asked* [about oxygen] *- I was virtually in hospital, it was considered in my case because I felt - I don't want to get on oxygen because to me it's the last thing; it's the start of the end. I've had a couple of friends go that way."*

Further related to the theme of oxygen one patient (Patient 7) outlined:

> *"No. I don't have portable oxygen. So, I've got to go without oxygen and get in the car. I've got to go there; I've got to get from the car to the surgery. I've got to sit in the surgery, walk to his office, walk back and then go out and get in the car and come home again. It's a drama."*

Two core issues were revealed from staff as risk management considerations for patients. One ED physician, Staff member (4) gave an example:

> *"Again, I'm talking about the small percentage of people who require Non-Invasive Ventilation. They're the high acuity patients. The problem with them is that if they're not managed initially, it adds another few days to their recovery in the long-term. Then there is the small chance that they may not actually improve because they have become so acidotic, so once their pH drops below seven, it's very hard to recover from that."*

Another respiratory physician gave a prime example of policy non-adherence which had contributed to admissions and patient complications on a number of occasions. Staff member (5) stated:

> *"It may not necessarily be an ED issue, but occasionally we have patients who have called the ambulance and said they're being short of breath, or the GP has done that, and the first thing that happens as soon as the ambulance staff sees the patient is well, this patient's hypoxic, and let's wack him on high flow oxygen and high Fio2. Once that happens, invariably by the time they've come into ED and resus, they're in dire straits or they're quite acidotic because they've gone into CO_2 retention."*

Patient (5) gave detail about their anxiety and depression demonstrating a failure of support mechanisms after discharge. Patient (5) states.

> *"Shortness of breath and that sort of thing. Yeah, and I just get other things, I can't even think at the moment. I get a lot of anxiety. I also have really bad depression, I'm on three Luvox at the moment. It's been useless, there's been no support during discharge. There's been no phone calls."*

The statement that there is no support during discharge is reinforced by a couple of the physicians interviewed in this study, staff (13) and (14)

Staff member (13) outlines:

> *"Because they (the COPD patient) need social support. Psychological support because this disease can lead towards levels of depression and anxiety".*

Staff member (14) says the lack of support as a causal factor for presentation outlining:

> *"They probably don't need to come in but because there isn't very good support for them or education for them that they end up being admitted when they probably don't need to."*

LACK OF KNOWLEDGE UTILISATION

Staff and/or patient knowledge (or lack thereof) was referred to in several instances as an influence to understanding COPD, cue recognition, continuity of care, and standard treatment. Examples included a lack of understanding around primary care or the palliative care requirements for COPD, the value of ED assessment information in ward care, continuity of care, and adherence to COPD evidence-based guidelines.

One of the ED physicians exclaimed that many people don't associate COPD with death:

> *"I always find it rather surprising that patients with, say, end-stage lung cancer, their family members acknowledge that their conditions have gotten worse, and death is an expected outcome, not so with COPD. I think it's a condition that people think they will just live with and die of something else, but very few people seem to believe that they will actually die because of COPD."*

One RN (Staff 3) mentioned the value that ED assessment can have for ongoing ward care:

> *"Some of their knowledge can be very insightful where they've picked up on things which may be missed on the ward. So, for example, carer stress would be one, which would sort of leave, it may have settled down by the time the person's come up to the ward, but it'd be quite obvious in ED."*

One of the ED Nurse Consultants (Staff 11) offered insight into continuity of care and the limitations of not having baseline knowledge:

> *"That's what should happen, whatever doctor or nurse or team who are looking after them will have to do their own assessment together and feel for the patient. But basically, if the patient is known to a particular service and team, you want to get them back to that service and team when they come in, because they're the best people that know of them. If someone who only sees them episodically is well how does this compare to your baseline? I don't know your baseline."*

An ED physician (Staff 4) outlined that most of the courses of action taken for a patient are done so without reference to the guidelines.

> *"Guidelines we don't refer to them often, they haven't changed for many years now, and it's usually standardised, you know, antibiotics if they've got a few infective type symptoms on them, otherwise its steroids and bronchodilators. That gets most people out of trouble, and a lot of patients are familiar with this regiment of treatment as well."*

DISCUSSION (INCLUDING LIMITATIONS)

This study confirms our findings from the scoping review by our COPD research team that future research should target ED avoidance with a stronger emphasis on coordinated community management preferably through nurse case management.9,20 COPD accounted for 12.2% of readmission within 90 days and 23.7% of readmission within 365 days from three major public hospitals in Tasmania.30 This study confirmed interventions to improve primary care access will reduce COPD related readmissions to ED.30 International evidence surrounding chronic disease presentations has revealed that moving from reactive management to proactive management demonstrated an increase in complex specialist nursing interventions and led to a decrease in emergency presentations and bed use at local hospitals.7,16 A systematic review conducted in 2016 confirms from several empirical studies that Nurse Case Managers can be effective in reducing ED usage for adults with chronic illnesses.18 The WHO has called for planned ongoing assessment, care and support coordinated by a practitioner case manager. WHO endorses a case manager following care over time to address both the physical and the mental health needs of people with complex multiple conditions or complicated circumstances.19 What this research was unable to confirm was the mix of resources within the participating health services that may already partially contribute to this type of role. COPD patient cases where nurses case managed and made monthly telephone calls and quarterly home visits to reinforce self-management education had an overall reduction in the number of urgent outpatient physician visits.31 Nurse case management have also proven to elicit prodromal symptoms in COPD patients which prevented acute exacerbations.32

Lari, Attaran, Tohidi,3 provided good evidence surrounding the need for regular communication of COPD Assessment. The authors recommend a COPD Assessment Test which is a simple and valid tool for evaluating patient symptoms on an ongoing basis. These authors believe these types of tools may improve patient–physician communication during routine clinical visits and would aid in assessing functional status and response to treatment.3 A broader problem though is embedding and encouraging compliance with the regular application of such tools and the sharing of information at an inter-professional level, as the success of good self-management is believed to be reliant on the accompanying ongoing communication with healthcare personnel.17 Dissler et.al., 2014 study summarised from 22 qualitative studies COPD patients require better understanding of condition on how to manage breathlessness, fatigue, frailty, anxiety, social isolation, and functional psychological status.33 Case management nurses are best positioned to work with carers along with patients to achieve optimal function and wellbeing as a team between patients, carers, primary healthcare professionals.34 Case managers also possess the ability to prompt primary care practitioners to

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utilise local support system especially with multimorbid patients and educate using flowcharts, action plan, holistic consultation through nurse led clinics.35

A lack of compliance with COPD guidelines does appear to be a catalyst for increasing the likelihood of harm with patients.15 Effective discharge planning coupled with good simple messaging to patients about their self-management appears to be the main recommendation that can potentially prevent relapse. Improving medication compliance through sound education, with a particular emphasis on inhaler techniques has been promoted as a means to decrease acute exacerbations.17 Fourteen Australian studies identified through a systematic review reported on COPD guideline nonadherence. COPD guideline indicators identified to be nonadherent with COPD guidelines over- or under-prescription of corticosteroids and antibiotics, and a lack of discharging patients with a smoking cessation plan or pulmonary rehabilitation.[8,35] Case managers frequently have the opportunity to review the discharge medication list and instructions after the physicians have completed them. Case managers have the capacity to double check patient data for accuracy and could ensure that transfer of necessary patient information accompanies the patient and is forwarded at an inter-professional level.[18,19] What this scoping research was unable to ascertain was a complete picture of associated deficits in patient assessment or care as a cause of ED presentations. Due to the nature of patient conditions, recruitment to this study was difficult with many potentially willing patients unable to participate.

Johnston and colleagues point to a lack of knowledge regarding pulmonary rehabilitation, and that building referral knowledge for pulmonary rehabilitation programs is a crucial step in achieving implementation of guideline recommendations in the care of people with COPD.[15] Utilising the knowledge of a broader inter-professional healthcare team not only assists the client, but also adds to the healthcare team's knowledge by informing them of a patient's strengths and weakness in everyday quality of life scenarios, including exercise.[15] What is clear from one staff statement, *"Guidelines we don't refer to them often, they haven't changed for many years now, and it's usually standardised"*, is that there is likely to be elements of evidence-based guidelines that are not being adhered to.[4] What is known from research investigating barriers to evidence utilisation is that evidence utilisation in healthcare can be difficult thereby interfering with knowledge generation, acceptance, and ultimately utilisation of the correct evidence.[28] Results from this study confirms findings from staff qualitative interviews from interdisciplinary emergency department staff on barriers of guideline adherence.[36] Prominent barriers reported to be interfering with guideline adherence included lack of knowledge, lack of professional role clarity, need for clinical behaviour regulation, Interference with memory, attention, and decision process, beliefs about departmental capabilities, environmental context, and resources.[36] Nurse case managers will be able to provide reported potential interventions from this study which included patient education, training (inhaler technique), providing time-efficient digitalised referrals to primary healthcare.[36] Lack of psychological interventions input to promote wellbeing in this patient cohort to mitigate anxiety, distress may also be provided by nurse case manager.[37]

IMPLICATIONS FOR PRACTICE AND/OR POLICY AND RESEARCH

Results stemming from this research initiative are timely. In order to reduce avoidable COPD emergency presentations the promotion of early intervention initiatives is required, through innovative and targeted ED and hospital avoidance strategies that offer alternative and regular COPD assessment points, ongoing support and monitoring, and earlier detection of deterioration, e.g. Nurse Case Managers.[7,18,19] Findings stemming from patient and staff voices herein indicate that healthcare services need to invest in resources that offer consistent and long-term continuity of care and support for COPD patients in order to minimise unnecessary presentations to the ED. These voices call for research that can demonstrate how cost effective a Case Management role for patients with COPD can be when implemented to complement and enhance existing inter-professional care structures. Future research not only needs to consider the cost benefits of such roles, but also the long-term impact roles like these have on mitigating risks to patients, improving inter-professional communication of patient data and disease progression, and improve compliance with COPD evidence-based guidelines.[3,7,16,18]

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