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Listening to the unmet needs of Europeans with COPD

Chronic obstructive pulmonary disease (COPD) is a significant cause of morbidity and mortality in Europe [1, 2], which has a major resource impact on both primary and secondary healthcare [3].

COPD has a huge impact on people with the condition, causing a gradual decline in functional ability and greater dependence upon health and social care support with both ageing and disease progression [4]. Patients with COPD are also likely to suffer with significant co-morbidities that further impair their quality of life and independent living [5].

Evidence is growing from audits in individual countries that COPD patient care varies widely between different hospitals and across Europe and is frequently not consistent with published guidelines [6–8]. There are many different service models and it remains unknown which deliver the best results for patients. In all likelihood, the care given to COPD patients can be improved if there is better understanding of care and service organisation factors in European hospitals that promote better outcomes.

The recent European Respiratory Society (ERS) European COPD audit, conducted in 2010–2011, provides data on quality of care from over 400 hospitals in 13 countries [9]. This study confirmed that the quality of patient care varies not just between European countries in different health systems, but that there is even greater variability between hospitals within individual countries [10].

Discharge from hospital is a key moment for patients, and data on medications, oxygen and rehabilitation relating to discharge were collected in the audit. The scope of the audit did not, however, include out-of-hospital care or specifically the views and experiences of hospital care of COPD patients themselves. Therefore, an event was designed to address this deficiency with the following aims:

1. To better understand the patient experience of COPD care in order to educate clinicians so they may provide more patient-centred care.
2. To inform the design and content of information provision for COPD patients discharged from hospital.
3. To use this information to develop a patient experience measure that could be incorporated into future European audits of COPD care.

The ERS and European Lung Foundation (ELF), together with the Austrian Lungeneunion, the largest respiratory patient organisation in Austria, used the opportunity of the ERS Annual Congress 2012 in Vienna to obtain qualitative input and feedback from COPD patients and their carers.

The session presented a unique opportunity to engage patients and their carers in facilitated discussions about the way they feel about their COPD care and what needs are currently unmet. Results from the first

Statement of Interest

S. Hartl is on advisory boards for GlaxoSmithKline, Almirall, Boehringer Ingelheim, and has received research grants from GlaxoSmithKline, Chiesi, Boehringer Ingelheim, AstraZeneca and Novartis. C.M. Roberts has received payment for lectures including service on speakers bureaus from GlaxoSmithKline, Almirall and Boehringer Ingelheim. P. Powell is an employee of the ERS.



HERMES syllabus link: modules F.1, F.4, I.4

ERS COPD audit were presented at the outset of the meeting, to provide context, and they were also used to develop four questions to discuss with the participants. The discussion questions were approved by the ELF Patient Advisory Committee, a network of respiratory patient organisations from across Europe.

Methods

The session was held on Wednesday September 5, 2012, in the Marriot Messe Wien hotel at the time of the ERS congress.

The meeting was organised as roundtable discussions with small input groups of 10 patients, each debating the same questions about their COPD. For each group there was a facilitator and a note taker, both of whom were doctors or representatives of ELF or Austrian Lungenunion. One of the tables was English speaking to accommodate patients and representatives from patient organisations from across Europe who were able to converse in English. The remaining tables were German speaking and all participants came from Vienna or the surrounding area.

The facilitators, note takers and patients/patient organisation representatives at each table remained at that table throughout the session, whilst the Chairs of the session (the lead of the COPD audit and the Chair of ELF) moved around the room to enable them to listen in to discussions.

After an introduction about the COPD audit, a series of four questions were posed to the room and 30 minutes of discussion was allowed for each question. After 20 minutes, the tables were advised to summarise their major inputs to short concentrated messages reflecting the consensus statement of each table. The results of all working groups were merged into one document for a plenary presentation and final discussion by the Chairs of the session during the breaks and ongoing discussions.

Discussion at the tables arising from the questions was mostly participant led, but the facilitators were provided with prompt questions to encourage discussion or maintain focus on the question and appropriate related topics.

Facilitators were asked to:

- ensure that each member of the table had the opportunity to contribute to the discussion
- ensure that each member's opinion was respected and listened to without interruption by others
- manage the group dynamic so that not only dominant voices were heard
- encourage quieter members to express their opinions

The note takers kept a record of discussion topics, key points, messages and any appropriate "sound bites". These notes were clearly summarised on flip charts and presented back to the Chairs of the session.

The four questions that were asked in the session were:

1. How informed are you about your condition?
2. What does COPD mean for you?
3. What are the most important things that you can do for your COPD?
4. How does COPD affect your daily life?

Results

There was a total of 75 participants (49% male) with an average age of 68 years (range 52–87). The average length of time that they had lived with their condition was 15 years. All participants were asked to rate the severity of their COPD on a scale from 1 to 5, where 5 was the most severe and 1 was mild. The average score from the group was 3.3 (range 2–5).

The answers and responses to each of the questions posed are summarised below:

How informed are you about your condition?

Well informed

This group of COPD patients and carers were generally well informed about their condition. The majority of the participants said they knew a lot about their disease. However, there were concerns expressed about the quality of the information provided to them. They stated that pieces of information were missing or lacking, including:

- advice on staying active
- guidance about what their stage of COPD really means
- information about limitations that COPD brings

- details about medication and side-effects
- guidance about self-managing exacerbations

Staged information

The participants of the session felt that information was often provided only once; however, the need for information was continuous and should be staged. They felt that it was not enough to be educated about COPD just at the point of diagnosis, but rather they wished to be given information at key points throughout the course of their disease: at the point of diagnosis; at follow-up appointments; and after an exacerbation. In addition, they found that advice about how to manage their COPD in the workplace was lacking.

Information provider

The group thought that their doctor should be the primary provider of information about their condition. However, issues included:

- healthcare providers not having enough time for meaningful discussion due to time-limited consultation slots
- different doctors giving contradictory or contrasting advice, resulting in confusion and worry for the patient

Patients felt that other sources of information were also key to understanding their COPD including:

- patient organisations
- the internet
- strong networks of other patients, family and friends

Action plan

The group felt that, when diagnosed, they should be provided with an action plan that would plan for the course of the disease, *i.e.* what to do when, who to get in contact, actions and essentials for different stages, and considerations in daily life.

Recommendation

Information provided to patients about their condition should be tailored to an

individual's circumstances and should be re-provided at each relevant opportunity. All patients should be provided with a personalised care plan relevant to their stage of COPD.

What does COPD mean for you?

Limitation

The main theme from the group was the restriction and limitation they felt that COPD put on their life: the overwhelming feeling of life getting slower. It was felt that this affected both daily life and quality of life. The restriction and slowing that was described had an impact not only on the person with COPD but also on their social life, family life and friends. It was felt that the changes brought by COPD created fear and anxiety affecting aspects such as travel and work, and even fear of how to cope with general life in the home and in the local community. The group felt that often the outcome for people living with COPD is isolation.

Lung function test

Many of the participants knew what a lung function test was and knew their forced expiratory volume in 1 s result. Some 50% of participants knew what their COPD stage was. However, the results and the outcomes meant little to many and often they had to request the results and an explanation from the doctor. Rather, the group wanted to know what the results meant for the future and what their prognosis was. Members of the group felt that the progression of COPD was unclear and scary, and the time scales and the life span that they had ahead of them were not explained or made clear. One example of this was that the use of oxygen was considered to be indicative of imminent death.

Quality of life

The group felt that although a lung function test gave a clear result, it did not actually relate to a person's quality of life or physical capabilities. Two people with the same spirometry results could experience completely different levels of quality of life and it was felt that there was no way of assessing this.

Variation of condition

The group felt that a big advantage would be the ability to self-assess. Many felt that as their condition varied from day to day, they would benefit from some means of self-testing; a self-evaluation process which would allow them to judge their current condition and capabilities.

Many felt that they were constantly fighting and adapting to make the most of their lives.

Recommendation

People living with COPD need better ways of assessing their current condition and to be better informed about the likely progression of their disease and what that means to them and their quality of life.

What are the most important things that you can do for your COPD?*Individual approach*

The overwhelming feeling from the participants was that, with COPD, the onus is on the individual to find out things for themselves. People living with the condition must be prepared to learn what works for them as an individual with regards their disease and adapt their lifestyles accordingly.

There were several things that the group were clear would help anyone with COPD, including:

- stopping smoking and avoiding passive smoking
- taking part in pulmonary rehabilitation schemes
- ensuring good nutrition
- staying as active as possible in everyday life and getting outside whenever possible
- taking medication regimentally
- using breathing techniques
- being conscious of changes in climate and temperature

Multiple morbidities

Many members of the group emphasised the need for healthcare professionals to appreciate that they were living with multiple conditions and not just COPD; that treatment for COPD should be integrated with treatment for their other conditions (including

diabetes, heart disease, osteoporosis and depression). Many felt frustration about being treated by different specialists for different conditions and the lack of understanding from each professional that they had to manage several conditions and medications at the same time.

Stay who you are

The final point, which was made strongly, was the necessity not to let COPD change you as a person. There is a need to adapt and amend your life to deal with the disease but it shouldn't change your personality; someone who has been outgoing and confident should fight to stay that way. Self-esteem is key to ensuring that this does not happen.

Recommendation

COPD treatment needs to address the whole patient and their other illnesses or conditions. COPD patients should be treated as individuals and be viewed as a person wanting to be a fully functioning member of society.

How does COPD affect your daily life?*Public awareness*

The group were clear that COPD is still not well understood by the majority of the public and many healthcare professionals. This means that there is discrimination and social stigma attached to having the condition which needs to be addressed. They felt that many other conditions and diseases were better known and had more awareness surrounding them, resulting in greater support.

Practical problems

The areas felt to be lacking included difficulties in obtaining and managing with oxygen in daily life but particularly when travelling. The group felt they were lacking social support for the things that they are incapable of doing. There was also a general feeling that intimate issues, such as sexual relations, were not addressed and there was little discussion with friends and family, or healthcare professionals about how COPD affected their personal relationships.

With regards the provision of care, the patient participants felt that the following was lacking:

- Psychological support
- Advice on physical activity
- Information on nutrition
- Opportunities for rehabilitation
- Coaching for increasing motivation

In short, there was a desire to be looked at holistically and as a person rather than just as a disease. For that to happen it was proposed that better education should be provided for healthcare professionals about the broader needs of patients. It was proposed that for this to happen universal standards were needed for all healthcare professionals across service throughout Europe.

Recommendation

Awareness about COPD in the general population and amongst healthcare professionals needs to be improved. European standards and education are needed to ensure that healthcare professionals are providing consistent and clear messages

Discussion

This was a very positive and productive qualitative exercise that enabled the ERS COPD audit team and ELF to obtain feedback from a group of European COPD patients. The view of carers was not separately noted in this exercise and therefore it has not been possible to include their specific views.

It must be noted that the group of patients involved were well educated about their disease. They had an established relationship with the Austrian Lungenunion, their own patient organisation or ELF. This meant that the population was well informed, motivated and keen to learn more, and therefore not entirely representative of a general sample of COPD patients. However, their views do compare with other published studies.

In one study in the USA, 47 COPD patients were interviewed about their condition. Three main themes were identified: loss, fear and desire for improved care. Because of breathlessness and fatigue, as well as symptoms from conditions other than COPD, patients reported the loss of ability to

participate in pleasurable and necessary activities of daily living and the desire to recover at least some of their functioning. They expressed problems with social isolation and uncertainty about their prognosis, as well as the hope to improve. In addition, they talked about fearful experiences associated with uncontrolled breathlessness and a wish for greater understanding and knowledge about treatment [11].

Another qualitative study from the UK worked with two focus groups made up of 16 people with COPD who had completed a course of pulmonary rehabilitation. From these focus groups, five main themes emerged: value of pulmonary rehabilitation, ongoing exercise, professional support, peer social support and health status [12].

Conclusion

The key messages to take from this session, which have been seen and approved by the group, are:

1. Information provided to patients about their condition should be tailored to an individual's circumstances and should be re-provided at each relevant opportunity. All patients should be provided with a personalised care plan relevant to their stage of COPD.
2. People living with COPD need a better ways of assessing their current condition and to be better informed about the likely progression of their disease and what that means to them and their quality of life.
3. COPD treatment needs to address the whole patient and their other illnesses or conditions. COPD patients should be treated as individuals and be viewed as a person wanting to be a fully functioning member of society.
4. Awareness about COPD in the general population and amongst healthcare professionals needs to be improved. European standards and education are needed to ensure that healthcare professionals are providing consistent and clear messages.

The key outcomes listed above will be used in the ongoing COPD audit to feed into the development of care bundles for patients on admission to and discharge from hospital. The information was presented at the opening of

the European COPD Audit and British Thoracic Society Joint Seminar entitled “Improving Hospital Care of COPD Patients: Designing European COPD Care Bundles” on Thursday May 9, 2013, at The Royal College of Physicians in London.

ELF will continue to work to improve awareness of COPD in the general population. It will look to develop, along with the COPD audit, a series of patient factsheets that can be given at different stages of disease.

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