



Information needs in COPD patients: the Lung Information Needs Questionnaire

Good communication on the part of the health professional is essential to ensure that patients have the information they need about their treatment and lifestyle. The authors explain how they used patient focus groups to develop the Lung Information Needs Questionnaire to aid compliance in patients with chronic obstructive pulmonary disease.

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Sometimes researchers start investigating a particular problem, and then end up investigating something completely different. That is what happened to us. We set out to research non-compliance with healthcare recommendations in patients with chronic obstructive pulmonary disease (COPD). The reason for this research objective was that there is evidence that compliance is poor in many diseases, particularly asthma,¹ and although there was some evidence that compliance was better in COPD,² it was an under-investigated topic.

We conducted five focus groups with a total of 29 patients to investigate non-compliance. Non-compliance was defined very broadly to include not only taking of medicines, but also adherence to other lifestyle changes. These lifestyle changes include those that have been shown to be related to better long-term outcome, such as cessation of smoking and exercise,^{3,4} but we were also interested in other aspects of self-management of exacerbations, e.g. when to call an ambulance.

Is non-compliance a problem?

For patients to comply with medical instructions, they need to know those instructions. It became clear right from the first focus group that the problem was not one of non-compliance, but lack of information. Many patients simply did not know what to do, and in some cases were very confused about what they had been told.

We found, for example, that many patients were confused about the name of their disease, as different health professionals had told them different things. Many patients reported no help with smoking cessation, and some believed that smoking did them no harm. Knowledge about exercise was very poor, and even when patients had been told to exercise, many had not been told how much exercise to do, leading to erroneous beliefs. Finally, we found very little evidence of intentional non-compliance with medication. Patients did not report the anxieties about developing tolerance (or 'addiction' in patient terminology) to medications that characterises some asthmatic patients.

Lack of knowledge is often a result of two interacting factors: poor communication on the part of health professionals and patients forgetting.⁵ The fact that COPD patients report lack of knowledge may be a result of either of these factors, but whatever the cause, it is clearly a problem. Patients cannot self-manage effectively if they do not know what to do. We believed that this problem needed addressing and so we changed our research effort.

The concept of information need

We reasoned that the best way to help COPD patients was to develop an assessment tool to measure information needs. Information needs are defined either by the patients expressing a need for information, or by clinician judgement that lack of information of a particular kind will lead to suboptimal self-management. Information needs can be distinguished from knowledge. Patients may lack knowledge but be unconcerned about that lack, and clinicians may feel that it is unnecessary for patient self-management. For example, patients may lack



Figure 1. The Lung Information Needs Questionnaire.

1. Do you know the name of your lung disease?
 Yes
 No

2. Has a doctor or nurse told you how this disease affects your lungs?
 Yes
 No

3. Has a doctor or nurse told you what is likely to happen in the future?
 Yes
 No

4. Which of the following statements best describes what will happen to you over the next few years? (*Tick one only*)
 I will get worse
 Now that my disease is being treated, I will probably stay the same
 Now that my disease is being treated, I will probably get better
 I have no idea

5. Has a doctor or nurse explained the reason for taking your inhalers or medicines?
 Yes
 No

6. Do you try to take your inhalers or medicines exactly as you have been instructed by a doctor or nurse?
 Yes
 No

7. Are you satisfied with the information doctors and nurses have given you about your inhalers or medicines?
(Tick one only)
 I understand everything I need to know
 I understand what I have been told, but I would like to know more
 I am slightly confused about my medicines
 I am very confused about my medicines

8. What sentence best describes what you have been told to do if your breathing gets worse (e.g. take two puffs instead of one)?
(Tick one only)
 I have been told what to do and the doctor/nurse has given me written instructions
 I have been told, but it is not written on paper
 I haven't been told, but I know what to do
 I haven't been told and I don't know what to do

9. Have you been told when you should call an ambulance if your breathing worsens? (*Tick one only*)
 I have been told what to do and the doctor/nurse has given me written instructions
 I have been told, but it isn't written on paper
 I haven't been told, but I know what to do
 I haven't been told and I am uncertain when an ambulance should be called

10. What best describes you? (*Tick one only*)
 Never smoked (go to question 13)
 Used to smoke, but don't now (go to question 13)
 Still smoking (go to question 11)

11. Has a doctor or nurse advised you to give up smoking?
 Yes
 No

12. Has a doctor or nurse offered to help you to give up smoking (e.g. given you nicotine gum or patches or referral to a smoking cessation clinic)?
 Yes
 No

13. Have you been told by a doctor or nurse to try to do some physical activity (e.g. walking, brisk walking and other forms of exercise)?
 Yes
 No

14. Has a doctor or nurse told you *how much* physical activity (e.g. walking, brisk walking and other forms of exercise) you should do?
 Yes and I know what to do
 Yes, but I am unsure what to do
 Yes, but I am unable to do it
 No

15. How much physical activity do you do?
 I push myself as much as I can
 I make an effort
 As little as possible

16. What have doctors or nurses told you about your diet or eating?
(Please tick all that apply)
 Eat several small meals per day (e.g. "six small meals per day instead of three large ones")
 Lose or gain weight
 Eat healthy food
 Nothing

17. Have you any questions or comments about your lung disease? If so, write them in the space below.

18. Sex (*Tick one only*)
 Male
 Female

19. In which year were you born?
 19__



Patient perspective

knowledge about the details of lung physiology, but if they do not want to know about this, it could not be described as an information need.

One important reason for focussing on information need, rather than knowledge, is that the amount of knowledge a patient wants varies with the patient and the stage of the disease. Thus, from a patient perspective, there is no optimal level of knowledge. By contrast, information need is defined in terms of the patient's need for self-management, and is adjusted depending on the level of knowledge required by the patient.

Using patients to develop the LINQ

One of the known difficulties when health professionals communicate with patients is that they use a different style of language.⁵ However experienced the health professional, they do not use language in exactly the same way as the patient. We wanted to develop a questionnaire that reflected patients' use of language rather than our own, as a tool for better communication.

First, we developed an initial questionnaire on the basis of the first five focus groups, supplemented by expert clinician opinion. This questionnaire was then examined in a focus group of COPD patients. Patients completed the questionnaire and were then asked to comment on the questions on an item-by-item basis. These comments led to a modified questionnaire, which was then examined in a subsequent focus group. We carried out this process iteratively so that a total of five further focus groups (30 patients) were used to develop the questionnaire.

It is worth providing some informal comment about our experience of using patients to construct questionnaires. We

found that patients have a considerable degree of expertise in devising and disambiguating questions.

When managed in a group, they exhibit skill in understanding their own use of language, which is substantially underused in questionnaire construction. Patients commented not only on the wording of the questions, but also on the format of the response options.

They commented on the salience of types of information

to them, for example, saying that knowing the diagnosis and prognosis was highly important. It has been shown in previous research that patients remember the diagnosis and prognosis better than self-management.⁵ One interesting observation was that the term 'exercise' is confusing to patients, with many interpreting the word in a way that is similar to sport. We settled for using the term 'physical activity' as an alternative.

The end result of these focus groups was a questionnaire (subsequently slightly shortened) called the Lung Information Needs Questionnaire, or LINQ (Figure 1). This questionnaire is currently in the process of validation and is available at www.pms.ac.uk/linq. It is self-completed, taking 6 min on average. It has six domains: disease knowledge,

medicines knowledge, self-management, smoking, exercise and diet.

Scoring and interpreting the results

The scoring system for the questionnaire is based on the principle that a higher number indicates that the patient has greater information needs. The scoring principle is based on common sense. For example if a patient has never smoked or has stopped smoking, their information need regarding smoking-related issues is scored as 0. If they are still smoking, but have been offered advice about stopping, their information need is scored as 1 – on the basis that they may still benefit from further information about the need to stop smoking. If, however, the patient is still smoking but has not been offered advice or help about stopping, it is important for them to receive yet more information, and this is scored as 2.

Applications of the LINQ

The LINQ has been designed primarily to aid the clinical encounter and, when used for this purpose, the questionnaire should be given to patients to complete while they are in the waiting room.

The clinician then quickly glances through the patient's responses prior to seeing the patient. An alternative use of the questionnaire is to audit clinical care where, for example, the questionnaire is completed before and after patients attend rehabilitation.

Conclusions

Patients with COPD appear to have high information needs that compromise their self-management. Health professionals should check patients' understanding of key aspects of self-management and provide them with sufficient time to ask questions.

The LINQ provides a quick and comprehensive way of assessing patients' information needs, and may prove useful in assessing educational initiatives such as pulmonary rehabilitation. ■

Further reading and resources

- Sweeney KG, Edwards K, Stead J, Halpin D. A comparison of professionals' and patients' understanding of asthma: evidence of emerging dualities? *J Med Ethics: Med Humanities* 2001; **27**: 20-25.
- Further information on the LINQ, the questionnaire itself and detailed scoring instructions are available from www.pms.ac.uk/linq

References

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