Empowering people to self manage COPD with management plans and hand held records

People with long term conditions should be involved in developing self management tools. A trust consulted patients to meet their information needs

BACKGROUND

- Chronic obstructive pulmonary disease is a common chronic disorder.
- The condition results in frequent accident and emergency attendances and urgent hospital admissions (Wouters, 2003).
- Patients with long term conditions, such as COPD, should be empowered to self manage their disease (Department of Health, 2006).
- Patients need information, self monitoring devices, self care skills, education and training, and self care support networks.

This finding is supported by Boot et al (2005) who found, in a cross sectional study of 60 patients with COPD, that 30% did not know they had this condition, although 59% of their sample had been diagnosed for longer than 10 years.

USING FOCUS GROUPS

Hyland et al (2005) used focus groups to develop the Lung Information Needs Questionnaire. They found that patients were knowledgeable in devising and clarifying questions, and used language other people with COPD would understand. Patients need to be involved in the development of patient information resources (Wilcock and Grogan, 1998) so, after analysing the questionnaires, we arranged a focus group.

Six patients with COPD who attended the local British Lung Foundation Breathe Easy group were invited to attend. The optimum size of a focus group is 6–10 participants (Marshall and Rossman, 1999) as small groups are useful when in depth information is required or when respondents have a lot of involvement with the topic discussed (Greenbaum, 1998).

The group was held at the local hospital and facilitated by two respiratory nurse specialists.

Many of the knowledge gaps highlighted by this group had also been raised by patients who completed the questionnaires.
All participants in the focus group felt the most important information for inclusion in the hand held record related to managing deterioration, as they had received different advice from professionals in primary and acute care.

Participants also highlighted that they did not always understand their respiratory medication. They asked for their baseline medical information to be included, as each time they saw a new doctor they had to retell their “story”, often when they were unwell and acutely breathless.

Interestingly, the participants found the term “exercise” confusing, with many relating the word to sport, and suggested it should be replaced with “physical activity”. The group felt that smoking cessation advice was unnecessary, but this may be because all were ex-smokers.

The participants had very different expectations of the hand held record. One wanted a credit card sized management plan to carry around, in addition to the hand held record. Another wanted the record printed in several European languages so patients could have an appropriate translation to take on foreign holidays.

DEVELOPING THE RECORD

The steering group reviewed the findings from the questionnaires and focus group and developed the content, design and implementation plan of the hand held record.

Group members agreed with all the content apart from exacerbation management. One respiratory consultant felt including the descriptions “short of breath at rest” and “difficult to talk” with the recommendation to ring for an ambulance, would increase the number of unnecessary calls to emergency services. However, the respiratory nurse specialist leading the project felt it was better for patients to seek assistance at this stage, be assessed, and possibly sent home rather than waiting until they may need to be admitted with more severe symptoms. The group agreed to change the wording to “very short of breath” and “very difficult to talk”.

There was discussion around the use of the word “exacerbation”. Some of the group thought patients would not understand the term, and “flare up” or “attack” might be more appropriate. Partridge (2004) suggests that only 4% of patients with COPD use the word “exacerbation”, with the majority using “crisis”, “attack” and “chest infection”. Nordby (2006) discussed how medical terms have an important role in nurse-patient interaction, and suggested that terminology is introduced to patients with clear explanations. We therefore decided to use the word exacerbation accompanied by a brief explanation.

A draft version of the document was reviewed by the trust’s patient information and communication group who felt that the inserts had too many words per page, and not enough white space. The document was revised to make it easier to read and conform to trust policy. It was also sent to a board of professional readers who described the format as novel and saw it as a useful addition to the management of COPD.

One of the concerns raised by the steering group was whether healthcare professionals would view the hand held record as just another piece of paperwork. Inevitably it would take time to introduce patients to the record, complete the relevant personal data and investigations, and advise them on how to use it. However, we felt that in the long term the record could save health professionals time as relevant information would be available in one place. Many newly diagnosed patients know little about COPD and the document could be used as a teaching tool and provide signposting for additional information.

The final document contains an A5 sized envelope with information about what happens to the lungs in COPD and the importance of keeping physically active. It contains six inserts, listed in Box 2.

The plan continues to evolve and two further inserts are being developed: palliative care and telehealth.

IMPLEMENTATION

One of the main limitations of this project is that GPs and practice nurses were not invited to join the steering group, yet most patients with COPD are cared for in primary care.

The local primary care trust asked if the model could be adapted so that all four acute trusts within the PCT could use it. To facilitate this primary care nurses from each of the four areas joined the steering group and the plan was rolled out to more than 11,000 patients.

Launch meetings were held to inform all practitioners working with patients with COPD about the record, including GPs and practice nurses, hospital staff, paramedics, community matrons and staff working in GP out of hours centres, emergency departments, and local community hospital walk-in centres.

Patients are issued with the hand held records either during a hospital admission with an acute exacerbation of COPD, by the community nurses following a community managed exacerbation or at their regular clinic review. Patients who are confined to the house are seen by either a community matron or community respiratory nurse and given their plan.

PATIENT EDUCATION GROUPS

Education groups for patients and their carers run for 90 minutes over a period of four weeks and were organised in rural areas where patients have difficulty accessing healthcare services. The content of sessions is summarised in Box 3.

The education group was well evaluated by the patients and carers who attended the courses. Patients completed an evaluation form on week 4 of the course with the majority of attendees stating they felt they would be more able to manage their COPD, while all said they would be happy to recommend the course to others. All attendees completed a Bristol COPD Knowledge Questionnaire (White et al, 2006) at the beginning of the course and we intend to ask them to complete another six
months after the course to see how much knowledge they have retained. Carers were pleased they had been involved. They stated that they felt more empowered to help their partners, especially with exacerbation management.

**CONCLUSION**

Medical advances and an ageing population have combined to make long term conditions, such as COPD, one of the major challenges for healthcare systems, now and in the future (World Health Organization, 2002).

The aim of this initiative was to improve the patient experience by developing new ways of working. This was the first nurse led initiative within the local trust which had prospectively looked at patients’ knowledge gaps and information needs, prior to developing a new service. This initiative reflects the Department of Health emphasis on role development, new ways of working and greater patient and public involvement (DH, 2006; 2000; 1999).

Liberating the Talents (DH, 2002) identified COPD as one of the main areas where a specialist nurse can improve patient outcomes. The individualised approach adopted in this initiative demonstrates the valuable role of nurses in COPD disease management across acute and primary care.

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**Box 3. Content of Patient Education Groups**

- **Week 1:** Patients issued with hand held record and receive information about COPD
- **Week 2:** Information about inhalers and inhaler technique
- **Week 3:** Talk by the community physiotherapist on keeping active
- **Week 4:** Focuses on exacerbation management

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**References**

- Department of Health (1999) Making a Difference; Strengthening the Nursing, Midwifery and Health Visiting Contribution to Health and Healthcare. tinyurl.com/nursing-contribution