Patients with chronic asthma found medicine information to be unclear or confusing, did not receive complete information on medicine use and side effects, and found leaflets to be unhelpful

Raynor DK, Savage I, Knapp P, *et al.* We are the experts: people with asthma talk about their medicine information needs. *Patient Educ Couns* 2004;**53**:167–74.

Q What are the medication related experiences and perceptions of patients with chronic asthma? What are their views on mandatory leaflets provided by drug manufacturers?

DESIGN

Qualitative study.

SETTING

6 community pharmacies in Leeds, UK.

PATIENTS

23 patients (age range 13–82 y, 52% women) with asthma (duration 3 to >40 y).

METHODS

Patients participated in 1 of four 90 minute focus groups. After describing their medication related experiences, patients were asked to comment on 5 leaflets about asthma medicine (reliever and preventer inhalers, generic and branded broad spectrum antibiotics, and a generic oral steroid). Audiotapes were transcribed verbatim, and themes and categories were generated.

MAIN FINDINGS

10 themes were identified. (1) *Information experiences.* Almost half of the patients felt that the information they received met their needs and helped them to feel in control of their symptoms. The remainder felt that the information given was unclear or confusing or that information was wanted but not given. Patients identified 5 information needs: name and purpose of treatment; when, how, and how long to take it; side effects and what to do about them; problems with other drugs; and how to tell if the medicine is not working. (2) Although most patients knew the *name and purpose of their medicine*, some were not told, or did not understand, what their medicines were. (3) *When and how to take it.* Most participants received good information on how to use inhalers from nurses. About 1/3 received no information from their healthcare provider on inhaler use when they were first diagnosed. During acute attacks, patients noted the differences between “ideal” inhaler techniques and what they actually did without previous guidance. (4) *Side effects and what to do about them.* Patients obtained information on short term side effects from self observation or family and friends but obtained information on long term side effects from magazines, books, manufacturers’ leaflets, and nurses and GPs. Most patients felt that information on side effects was not freely provided. (5) Information on *problems with other medicines* was obtained from community pharmacists, and experiences were mainly positive. Some tension existed between official advice on contraindications and patients’ experiences. (6) *Is this the right medicine for me?* Most patients knew about the many asthma medicines available but were unsure about their physicians’ awareness of new treatments. Many were unclear about how physicians decided to use a particular medicine and why a medicine was the right one for them. (7) *What people do to get information.* Primary care providers were patients’ main information source. Physicians provided information on initiating treatment; nurses provided more detailed and customised instructions on inhaler use and peak flow monitoring; and pharmacists provided information on medication interactions. (8) *The place of written*

For correspondence: Dr D K Raynor, Pharmacy Practice and Medicines Management Group, University of Leeds, Leeds, UK. d.k.raynor@leeds.ac.uk
Source of funding: no external funding.

information. Written information was rarely mentioned without prompting. Patients preferred one to one information giving because information could be individualised to their needs and abilities. Patients often threw away leaflets because they looked unimportant, there was too much to read, the appearance was boring with small type, and they thought that inhaler technique was not best learnt by reading about it. (9) Patients believed that they should be *involved in developing leaflets*. Some patients viewed personal experience as more important than manufacturers’ leaflets and believed that leaflets should be tested on patients. (10) *Manufacturers: trust and priorities.* Patients felt that the primary purpose of leaflets was to provide insurance for manufacturers against potential problems and to help sell products.

CONCLUSIONS

Patients’ unsatisfactory experiences with information about asthma medicine included unclear or confusing information and no individualised, personally relevant information. They preferred personal contacts rather than written sources. Most felt that nurses and physicians did not freely provide information on side effects, and they did not find manufacturers’ leaflets useful.

Commentary

Patient self management is integral to effective management of chronic illness. Self care decision making is a complex skill, which is often based on interpretation of personal experiences over time rather than standardised knowledge.¹ Healthcare providers have episodic and often time limited contact with patients. A common solution to such limitations is provision of standardised materials with general information about disease process and treatment.

Raynor *et al* examined patient experiences regarding asthma medicine information, including manufacturers’ leaflets on chronic asthma care. More than half of the patients felt that information in the leaflets was unclear, confusing, or lacking. 10 themes were identified related to understanding asthma medicine and its use. Patients expressed a preference for receiving one to one information that was individualised to their needs. 5 information needs about asthma medicine were identified, which provided a guide to support self care decision making.

The “Chronic Care Model”² emphasises the need for supporting self management abilities to create an “informed, activated patient” who is capable of participating in care decisions that will influence health outcomes. Standardised information alone is not adequate. Patients need individualised information and interactions to assist them with daily problem solving and decision making about their health. Educational materials that fail to address essential questions for decision making discourage patients and potentially promote feelings of patient inadequacy. Use of such materials might also create a distance between patients and providers if their provision gives the impression that the provider believes these materials to be adequate for self care.

Margaret Thorman Hartig, RN, PhD, APRN, BC
University of Tennessee Health Science Center, College of Nursing
Memphis, Tennessee, USA

1 Thorne S, Paterson B, Russell C. The structure of everyday self-care decision making in chronic illness. *Qual Health Res* 2003;**13**:1337–52.

2 Wagner EH. Chronic care model. Accessed 04 October 2004. <http://www.improvingchroniccare.org/change/model/components.html>