How patients manage asthma

JENNY M. HARDING, BA, MSc
Research Officer, Kentish Town Health Centre

MICHAEL MODELL, MRCP, FRCGP
General Practitioner, Kentish Town Health Centre. Senior Clinical Lecturer in General Practice, University College London

SUMMARY. In this paper we discuss how patients cope with asthma and suggest that individuals use medical advice selectively in a manner they consider appropriate to their personal and social circumstances. Use of medical services is influenced by patients' perception of the effectiveness of medical therapies, concern about the long-term use of drugs, access to alternative therapies, support and advice from others and the need to make particular sense of living with a chronic disease. Some people are reluctant to use medical services under any circumstances.

Introduction

CHRONIC illness often compels individuals to adjust their daily routines and, where possible, aspects of their environment. They draw on a variety of resources in addition to medical help, in order to cope.[1-3] Many use medical regimes selectively, not taking their drugs when well because of unease about possible side effects or a wish to ignore or forget their illness. The advice of the doctor is only one consideration for patients in the management of their illness and may not necessarily be the dominant aspect.

Method

This paper is based on the results of interviews with 92 patients (Table 1) conducted in 1982, a year after a team of eight general practitioners with a practice list of over 12 000 had introduced a plan of management for asthmatic patients. The practice disease register was used to identify 170 patients, aged between 5 and 55 years, who had either had one or more episodes of wheezing in the previous 12 months, or a diagnosis of asthma recorded by the general practitioner in the previous two years. These patients were invited for interview by the researcher. Of these, 115 patients were interviewed at the start of the study (25 patients had left the practice and 30 patients preferred not to take part). A year later 92 patients were interviewed again (at this stage, 19 patients had left the practice and four patients did not wish to continue). The management plan emphasized the importance of discussion and patient education in the consultation and the use of a relevant drug regime.[4] The interviews, which lasted on average an hour, included questions about the use of medical services, attitudes to asthma, the amount of disability and the severity of the disease.

Results

Patients' use of drugs and medical services

Of the 92 patients interviewed 80 patients used some kind of drug therapy. Bronchodilators alone were used by 33 patients for symptomatic relief. The remaining 47 patients in addition used drugs prophylactically and of these patients 41 were able to describe the correct use of these drugs (for example, how many times a day they should be taken, and that they should be taken even in the apparent absence of symptoms). However, 26 of the 47 patients who used prophylactic drugs had their own ideas about what was 'correct' for them. Many used these drugs for symptomatic relief. Examination of the records of the patients showed that these 26 patients had fewer repeat prescriptions of drugs for asthma and had peak expiratory flow rates closer to those expected for their age, sex and weight, than the other

Table 1. Practice population, prevalence of asthma and the study group.

	Age (years)		
	Under 15	15–55	Total
Males			
Patient population[a]	969	4304	5273
Registered as asthmatic[b]	42	61	103
Interviewed at beginning and end of study year	26	19	45
Females			
Patient population[a]	862	5223	6085
Registered as asthmatic[b]	36	86	122
Interviewed at beginning and end of study year	16	31	47

[a] Estimated in 1980. [b] There were a total of 225 on the disease register and of these 170 fulfilled the study criteria and were invited for interview.

Table 2. The age of patients and their use of prophylactic drugs for asthma, the requests for repeat prescriptions during the two year period (1981–82) and the peak expiratory flow rate of these patients at interview (1982).

	Those who report using their prophylactic drugs		
	as advised by their doctor	not as advised by their doctor	Total
Age (years)[a]			
<15	12	5	17
⩾15	9	21	30
Total	21	26	47
Number of repeat prescriptions[b]			
<5	3	16	
⩾5	16	7	
Peak expiratory flow rate[c]			
Within normal limits: <2 standard deviations from predicted mean	7	15	
⩾2 standard deviations from predicted mean	14	11	

[a] χ^2 = 7.23, 1 degree of freedom, P <0.01. [b] χ^2 = 12.15, 1 degree of freedom, P<0.001. Information not available for two patients who used their drugs as advised, and for three patients who used their drugs not as advised. [c] χ^2 = 2.65, 1 degree of freedom, P <0.25.

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21 patients (Table 2). Those who used their medicines as advised also tended to be younger (Table 2). All patients who were prescribed drugs were asked about their attitude to these drugs. It appeared that a deep seated distrust of long-term medication, based on fears of possible side effects and dependence, often resulted in experimentation with alternative therapies such as relaxation and breathing exercises. At the same time, these patients often found the short-term use of drugs to control acute episodes of illness acceptable. Patients rarely excluded medical help and drugs completely. Often these remained the ultimate remedy, and a source of reassurance and support — 'something to fall back on' was one mother's description of bronchodilators.

All 92 patients were asked when they would consider it necessary to consult a doctor about their asthma. Thirty-five patients stated that they would contact their general practitioner if they found that their symptoms were persisting or worsening and 20 patients stated that they would contact their doctor if their usual medicines were not working. Twenty-three patients emphasized their reluctance to contact their doctor and three patients were unsure of the circumstances under which they would feel it necessary to contact their general practitioner. Eleven patients considered circumstances when they would contact their doctor unlikely or unthinkable or could not imagine that there was anything more to be done by their doctor. One middle-aged man said that he doubted that doctors could assist since he already had 'all the drugs'. One young man said that he would only contact a doctor if he was 'very scared' that he might 'stop breathing altogether'. None of these 11 patients asked a doctor to visit them at home for asthma during the study year or the year after and seven of these patients made no visit to the surgery for asthma during this two year period. Six of these 11 patients had peak expiratory flow rates within normal limits at interview and for two patients the peak expiratory flow rates were only marginally reduced; seven were assessed as having mild asthma by their doctors. These 11 patients together with those who emphasized their reluctance to consult a doctor consulted less frequently for asthma than the rest of the group (Table 3).

The 80 patients using drug therapy were asked what they would do if their usual medication was having no effect. Three patients said that they would go straight to hospital, 46 said that they would contact their doctor immediately and 21 said that they would wait and see if their condition improved — perhaps trying relaxation and deep breathing — and if it did not then they would contact their doctor. There was little difference between those aged under 15 years and those aged 15 years or over. However, 10 patients (two children, eight adults) said that they did not consider it necessary to contact their doctor or take any particular action. Again they all believed in their own ability to cope, given the resources they had, or they did not believe their general practitioner had anything more to offer.

Table 3. Circumstances under which patients would feel it necessary to contact a doctor and the number of consultations.

	Never or reluctant	If symptoms worse than usual or medicines having no effect	Uncertain
Number of patients	34[a]	55	3
Number of consultations at surgery during the two year period			
0 or 1	23	29	
2 or more	7	26	

$\chi^2 = 4.70$, 1 degree of freedom, $P<0.05$. [a] Four patients have left the practice list.

Patients' interest in the cause of their asthma

Many patients felt that information about their asthma was essential to their ability to cope with it. In particular they wanted to identify a definite and acceptable cause of the disease. One middle-aged woman was sure that her asthma was directly linked to her current housing situation. She began to get wheezy when she moved into her present flat and she suggested that she would get better if she were rehoused.

Almost half of the patients (48 per cent) were dissatisfied with the explanation of asthma and its treatment provided by their doctor. Some felt that their general practitioner did not spend enough time explaining the disease, others, though dissatisfied, were aware that their doctor would be unable to answer the questions that they considered most important; for example why they got the disease and whether they will grow out of it.

Many patients, thinking that they did not know enough about asthma, merely inquired 'what more is there to say about it?' This did not imply a lack of curiosity, but rather an awareness that what seemed to them most puzzling was beyond the scope of medical explanation. Even when a full explanation was considered to have been offered, failure to identify a specific cause was often mentioned as an important omission. One middle-aged woman stated: 'I've never been told anything really — nothing has been explained. I don't think that there is anything to be told. They [the doctors] don't know . . . I would like to know what caused it and why I got it.'

Some patients had developed their own theories about asthma which fitted their experience. One young woman described her asthma as 'where the tension comes out'. Her eating, smoking and sleeping habits were part of the process by which tension was linked to asthma; each aggravated and promoted asthma but were also a direct response to tension. She would be free of asthma if she followed a vegetarian diet, slept well and stopped smoking. She could do this only if she were happy and took personal responsibility for her own happiness.

Many patients sought to discriminate between 'psychological' and 'physical', particularly 'allergic', causes of asthma. Some felt uncomfortable with the idea that their symptoms might have an emotional basis and tended to regard asthma as a direct response to tangible stimuli in the physical environment. Any other explanation might imply that their illness was not quite 'real' or was, at least in part, their fault. These patients found medical resources, diagnostic tests and treatment useful in maintaining images of themselves as people who were genuinely ill. One mother described how medical testing had been a important aid in coping with the asthma of her 11-year-old son; it provided an explanation in which she was not blamed. She worried that her son's illness might be the result of family tensions. Identification of particular allergens furnished an acceptable explanation which reaffirmed family cohesion and her competence as a mother.

Discussion

To what extent do patients manage their own chronic disease and how much do they depend on doctors?

Doctors are concerned with relieving symptoms and feel at ease manipulating drug regimes. They often have only a hazy notion of how asthma affects the lives of patients. The consultation is, after all, only a fraction of the daily life of the chronically sick person whose main concern is to live as normal a life as possible within the confines imposed by the disease and to maintain a valid image of themselves.[5] This may involve disregarding advice and treatment suggested by doctors. Regular inhala-

tions and swallowing of drugs several times a day may damage the image patients have of themselves, as basically healthy people. Children may be reluctant to be seen using inhalers in case they are considered 'odd' by their peers. With the present high unemployment many individuals may be afraid to stay at home, and may continue working while severely wheezy. People will also tend to disregard advice which they consider incorrect, and this study suggests that some of the patients prescribed prophylactic drugs did not need them.

Medical help, although vital in making or confirming the original diagnosis, and an important resource for controlling and explaining symptoms and subsequent disability may be only one of many strategies used to cope with disease.[6] Doctors are not the only source of information about disease; patients have access to a range of information about health and illness from friends, relatives and the media, and may be continually reassessing the consultation, the action of the doctor, and the prescribed medicines.[7] In this study patients demonstrated considerable independence from medical help in their use of prescribed drugs, their willingness to consult a doctor and their use of other sources of information and relief. Their perception of the effectiveness of medical therapies, concern about continually taking drugs, access to alternative therapies (where time and circumstances allow), support and advice from other lay people, may all significantly influence the pattern of use of medical services by asthmatic patients and their understanding and control of the disease. Clearly, resources are not equally available to all, and strategies for coping are influenced by factors such as age and socioeconomic position. Adults may feel that they can take their health in their own hands and question advice given more easily than children who are encouraged by their parents to comply with the advice of the doctor. Many patients were aware of the limits of medical knowledge, and although they understood that symptoms could only be suppressed and that the disease could not be cured, they hoped that their general practitioners would be available when needed and would work with them and their families to establish a way of living with the disease.

The reluctance of some patients to consult a doctor about their asthma under any circumstances is worrying. These patients did not reject medical help *per se* and did consult for other problems, but they did not see their asthma as requiring medical attention. While patients may be correct in assuming that their disease is mild at present, they are not necessarily protected against future crises. Asthma is still a real threat to life and should not be underestimated. In a paper from the British Thoracic Association describing the events which preceded the deaths of 90 patients from asthma, the authors considered that in 67 cases the patients or relatives failed 'to appreciate the suddenness with which deterioration can occur'; a third had had no asthma for periods of at least three months during the year before their death.[8]

How can doctor–patient contact be made more useful? Patients might keep diaries in which they record details of the frequency and severity of asthmatic symptoms. A description of the routine of a typical day may help the doctor understand the effects of the disease on the life and work of that individual and to formulate a relevant treatment plan. Successful management is possible with continuing support from the general practitioner and a two-way flow of information. This also applies to many other chronic diseases such as diabetes, rheumatoid arthritis and multiple sclerosis.

A valid plan of management for a chronic disease is not simply a set of rules, guidelines or standards decided by the doctor. Patients should actively participate in defining a plan, tailored to fit their priorities, and taking into account the real pressures experienced, and choices available in their lives.

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Address for correspondence

Dr M. Modell, General Practice Unit, School of Medicine, University College London, University Street, London WC1E 6JJ.

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