Qualitative study of views of health professionals and patients on guided self management plans for asthma

Alan Jones, Roisin Pill, Stephanie Adams

Abstract

Objectives To explore the views held by general practitioners, practice nurses, and patients about the role of guided self management plans in asthma care.
Design Qualitative study using nine focus groups that each met on two occasions.
Setting South Wales.
Subjects 13 asthma nurses, 11 general practitioners (six with an interest in asthma), and 32 patients (13 adults compliant with treatment, 12 non-compliant adults, and seven teenagers).
Results Neither health professionals nor patients were enthusiastic about guided self management plans, and, although for different reasons, almost all participants were ambivalent about their usefulness or relevance. Most professionals opposed their use. Few patients reported sustained use, and most felt that plans were largely irrelevant to them. The attitudes associated with these views reflect the gulf between the professionals' concept of the "responsible asthma patient" and the patients' view.
Conclusions Attempts to introduce self guided management plans in primary care are unlikely to be successful. A more patient centred, patient negotiated plan is needed for asthma care in the community.

Introduction

Asthma has a considerable impact on domestic, school, and industrial life as well as primary care workload. This, taken together with the innate variability of the disease, makes it seem logical to involve patients in managing their own care. However, attempts to implement self management have met with varied success, and the evidence is inconclusive, particularly in primary care, where asthma patients receive most care.

Self management plans are currently advocated in most international guidelines on managing asthma.[1 2] The use of such plans reflects expert opinion that the way forward is to form an ongoing partnership with patients[3] that enables a "treatment strategy in which patients are taught to act appropriately when the first signs of asthma exacerbation appear."[4]

Many, often innovative, plans have evolved, including written patient education programmes, video assisted material, credit cards, audiocassettes, and computer assisted material. A systematic review of these self management education programmes showed some improvements in health outcomes.[5] Of the 27 trials scrutinised, only six were conducted in primary care and several noted poor attendance by patients.[6–8] None sought the views of patients or the health professionals who would implement the plans—that is, general practitioners and asthma nurses.

Levy and Hilton conclude that studies "have yet to produce incontrovertible evidence for the benefits of self-treatment plans."[9] Neville and Higgins conclude that education is useful only if it includes self management plans, written plans, and regular review and that delivering such plans to all asthmatic patients would be a daunting task.[10]

We report the results of a pilot study exploring the views of general practitioners, practice nurses, and patients on guided self management plans for asthma.

Participants and methods

We used focus groups because of the exploratory nature of the study. Focus groups were held separately with doctors, nurses, and patients to facilitate maximum freedom of expression by participants.[11]

We used purposive sampling (sampling designed to obtain rich detailed data) to ensure a wide range of experience and views in the groups. The professionals were selected from computerised practices in West Glamorgan that were approved for asthma surveillance. The area has two large district general hospitals. Each has a consultant respiratory physician and uses a respiratory liaison nurse and written guided self management plans.

Two groups of general practitioners were enlisted. The first comprised seven doctors known to have an interest in asthma care, and the other seven general practitioners offering normal pragmatic care. The nurses were all trained in managing asthma. We deliberately selected them from different practices from the general practitioners to maximise the number of practices included. The nurses were divided into two groups of six and seven.

Patient recruitment reflected our earlier work, which had shown that adherence to professionally prescribed regimens was associated with different beliefs and attitudes to the condition and coping strategies.[12] The patients were predominantly working and middle class and reflected the socioeconomic profile of the area. The four adult patient groups were recruited from the practices of participating general practition-

Editorial by Thoonen and van Weel

Department of General Practice, University of Wales College of Medicine, Health Centre, Llanedeyrn, Cardiff CF26 9PN
Alan Jones *senior lecturer*
Roisin Pill *professor of research*
School of Social Sciences and International Development, University of Swansea, Swansea SA2 8PP
Stephanie Adams *senior tutor*
Correspondence to: A Jones, Princess St Surgery, Gorseinon, Swansea SA4 2US research@gors.freeserve.co.uk

BMJ 2000;321:1507–10

Patient vignettes

Case 1—John was diagnosed as having asthma. He was prescribed reliever (salbutamol) and preventer (beclometasone) drugs. John said the doctor had told him that he had "slight" or "bronchial asthma," which John did not think was the same as "proper asthma." He told only close family that he had chest trouble and used an inhaler. John did not use his preventive medication or attend an asthma clinic as his asthma "came and went" and was not "real asthma."

Case 2—Sue was upset when she had asthma diagnosed. She was prescribed reliever (salbutamol) and preventer (beclometasone) drugs. She took both drugs as prescribed. She did not mind who knew that she had asthma or that she used inhalers. After a time she was not upset by her diagnosis. She said: "Asthma is just a small part of me and of my life. I keep it under control myself. I don't need an asthma clinic."

Case 3—Joe had asthma diagnosed and was prescribed reliever (salbutamol) and preventer (beclometasone) drugs. Initially Joe took his preventive drug as he thought that it was an antibiotic course that you took on diagnosis. He then used his preventive drug along with the salbutamol only when having breathing difficulties. Joe told people outside work that he had chest troubles and used an inhaler but did not tell anyone at work. Joe did not think an asthma clinic necessary for his "sort of asthma."

ers and stratified by sex and the ratio of reliever to preventer drugs prescribed in the previous 12 months. Patients were assessed as compliant (defined as those taking optimal (medically approved) doses of both reliever and preventer drugs) or non-compliant (those taking more than optimal amounts of reliever drug only despite having being advised to take preventer drugs in the past year). We had four adult focus groups (compliant men (seven), compliant women (six), non-compliant men (six) , and non-compliant women (six)) plus a group of seven teenagers (aged 12-17) recruited from the local comprehensive school with staff cooperation and parental permission. Ethical approval was granted by Iechyd Morgannwg Health Authority.

The groups met in convenient venues such as schools for the teenagers and surgeries, pubs, and the local community hospital for the adults, and the average length of a group meeting was 50-60 minutes. Fieldwork was carried out in 1997-8 by an experienced qualitative researcher (SA) accompanied by a secretarial assistant. The groups met twice at five to eight month intervals. All discussions were tape recorded, with permission, and transcribed in full for analysis. In the first round, participants were given a brief explanation of the format of the meeting and an additional explanation of guided self management plans consistent with the British Thoracic Society guidelines. This encompassed the concept of collective responsibility and partnership between the patient, the health professional, and the patient's family that allows the patient to keep well and adjust treatment according to a treatment plan developed by the clinician.[3] Three patient vignettes, based on a typology developed in our earlier qualitative research, were presented on cards to stimulate comment and encourage the members to talk (box). In the second round the patient groups were given feedback about the views of professionals and professional groups were given feedback on patients' views to see if it affected their opinions and to clarify and explore barrier themes. The bulk of the analysis was carried out by SA, with transcripts read and themes debated by RP. All three authors discussed interpretation.

Nurses' views

Nurse W: They do have a place but you have to give them to motivated patients—with instructions there to make sure they will seek medical advice if the condition is deteriorating . . . And not give it to people who would take it too far and leave it too long before seeking help.

Nurse X: Well they say, "The nurse has given me this so I should be able to manage myself." Your concern is then whether they will try to manage too long before coming back, and then they reach a crisis.

Nurse Y: You can't cover every eventuality on a plan either—you can't account for every symptom so some of them would say, "Well, I haven't got that or the peak flow hasn't quite got to that stage so I'd better wait until it gets there."

Moderator: You're making them sound quite dangerous.

Nurse X: They can be, especially for very intelligent people—they are the worst.

Results

Health professionals and patients were aware of guided self management plans. However, general practitioners and nurses made little use of them, and their experience was limited to the plans given out by the hospitals or, in the case of some nurses, by drug companies. Although all patients agreed that guided self management plans may be of use to other people with asthma, only one was currently using a plan and only five claimed to have done so in the past.

Nurses

The nurses' views were remarkably consistent and remained largely unchanged after feedback. The recurrent comments were the importance of patient education and the need for ongoing monitoring. These tasks were best achieved by the patient attending an asthma clinic, where nurses had the expertise and the time (unlike doctors) to explain the condition and the treatment.

All claimed to give some kind of written self management plan—" just a few pointers," " two or three instructions"—but only to patients who had accepted and understood their condition and were using drugs correctly. Such plans were not seen as appropriate for patients with newly diagnosed asthma or for patients who might be taking their drugs as prescribed but were not receiving regular checks. Patients were "all different" and needed different approaches. Patients were "not the best judges of their own health" and "could be overconfident" and "cocky." The concern was expressed that patients would rely on a guided self management plan and not return for regular review (box). Such failure would "increase the likelihood of falling into bad habits" since neither their inhaler techniques nor their use of drugs would be monitored. This was seen as particularly dangerous if the patient had misunderstood the plan initially. In this sense nurses thought that guided self management plans could militate against optimal health and treatment.

There was general agreement that each plan had to be "individually constructed" and "regularly reviewed" and that plans were suitable only for patients with well controlled asthma who had enough intelligence or commonsense not to rely on the plan to the letter. Strong disapproval was voiced about the standard

plans issued by the hospital clinics and their possible dangers.

General practitioners

Both groups of doctors were equally unenthusiastic about standardised plans and the relevance of plans generally for their patients (box). They were more likely to disparage their patients' capacity for self management, citing their inability to "take on board more than a very small amount of information at a time." Like the nurses, they stressed the need for continuing education and dialogue and debated their role with non-compliant patients. Patients' had "the right to choose their own treatment," they were "autonomous" and had to "be responsible for their condition." It was even proposed that it was inappropriate for the doctor to try strategies to encourage compliance (this was delegated to the nurses).

They shared the nurses' worry about "blind obedience" and argued that the plans could be interpreted by the patients as dismissive: "You have asthma—here's your plan." Others felt that the plans "encouraged dependency." All tended to agree that the plans were difficult to achieve in everyday practice given the constraints of time and tended to militate against a meaningful doctor-patient relationship. In contrast to the consensus displayed by the nurses, their discussions were marked by greater ambivalence and pragmatism. Feedback of patients' views did not substantially alter the key themes.

Patients

All but one of the patients agreed that self management plans might be of use to other patients but, for differing reasons, were not relevant for them. Only five of the 35 patients reported recording and monitoring their asthma for the nurses, and all of them had let this lapse as "too bothersome" or an "unnecessary complication." Most saw the role of nurses as providing access to crisis care in place of seeing the doctor.

All the adults felt that they were already self managing competently and were behaving responsibly by not bothering the doctor or nurse unless necessary. For them self management meant taking drugs as they saw fit, avoiding "triggers" that brought on asthma, and requesting medical assistance only when this self care failed (box). Emphasis was placed on "knowing your own body best," what drugs worked for them, and therefore what to "reorder."

Non-compliant patients felt plans could be useful for people with "more serious" or "proper" asthma, whereas compliant patients felt they were "pointless for them personally" or "they already had a full understanding of the issues."

The teenagers showed the same ambivalence about the chronic nature of the condition and the need to take drugs as prescribed. Again there was minimal or no reported use of clinics. Although most participants claimed they would try plans if offered, they were convinced that they would probably quickly lose them and, at best, follow them for a limited time.

Feedback of the health professionals' views did not substantially modify the key themes identified in the first round in any of the groups.

General practitioners' views

Dr A: But my experience is that they've got to be in words of one syllable and fit on one side of A4, preferably on one side of A5. And if they don't then they are not worth having. And I don't think you can do a useful plan that encompasses all the concerns we've mentioned in that way.

Dr B: They should be short and sharp. But how can they be effective then?

Dr C: I think they should fit on a credit card [laughter].

Dr B: Yes. That's a realistic approach to self management plans. Because if you've got more than three or four key points I think that apart from the most diligent and meticulous patient—who is probably complying anyway—then you are not going to achieve anything.

Dr D: Hospitals have a self management plan telling patients about techniques and another one telling them that if your peak flow drops increase this and that and it just confuses patients. They don't understand it. And all patients get the same plan.

Dr A: Yes. You can't do that. It's ridiculous.

Dr B: Every patient is different and needs different advice. And only educated patients can deal with the information they are given anyway. Some of my patients have shown me these plans and I've told them to put them in the bin.

Discussion

The professionals and patients in this study were unenthusiastic about guided self management plans. Almost all participants were at best ambivalent about their potential usefulness and relevance, although the reasons for their ambivalence varied greatly. Attitudes in general are rooted in the professionals' experiences of dealing with patients in the context of everyday general practice and the patients' experiences of coping with asthma at work, home, and social events. A fundamental mismatch is apparent between the views of professionals and patients on what is a responsible asthma patient and what patients should be doing to control their symptoms.

We found that many patients with mild to moderate asthma do not regard it as a chronic disease that needs regular monitoring and therapeutic adjustments. Indeed, they prefer to manage it as an intermittent acute disorder, and they are uncomfortable with a guided self management plan that reinforces asthma as a chronic, ongoing disease needing monitoring and managing. These findings confirm our earlier work on attitudes of asthma patients.[12]

Patients' views

Moderator: Where do you think self management plans fit into this or don't they?

Patient J: We are self managing to a certain extent, where they give us the medication to take—so we are self managing ourselves, aren't we—we're not going to the doctors or the nurses or anybody to fuss around them to show us how to take it. They explain to you how to take it—you're on your own then. Can you imagine flying to Spain? You can't phone the doctor then and say your chest is bloody tight—you've got to deal with it.

Patient K: Why do I want something written down? You know … your chest tells you.

Patient J: No, you don't need it written down. What you need is being kept up to date with any advances or new treatment.

Patient F: It would take a bit of convincing for me.

Patient H: At the end of the day it all boils down to ourselves—and knowing what to do.

What is already known on this topic

Guided self management plans for adults with asthma are widely advocated and seem to have some health benefits

Attempts to implement this approach have met with varied success and do not incorporate patients' views

What this study adds

Neither health professionals nor patients were enthusiastic about guided self management plans

A fundamental mismatch exists between the views of professionals and patients on what is a responsible asthma patient

Guided self management plans for adults with mild to moderate asthma are unlikely to be accepted or sustained in primary care

The attitudes of the professionals were more unexpected. Guided self management plans were seen as a low priority, and most patients were managed by monitoring or policing. Education appeared to mean, at the most basic level, ensuring that the correct drug was taken at the right time in the most effective way.

Our findings suggest that attempts to introduce guided self management plans in primary care are unlikely to be successful. If guided self management is to work, new plans that are more patient centred need to be developed in place of those based on the medical model. Nurses need to be not only helped and supported by general practitioners but trained in techniques that enable changes in patient behaviour.[13] In addition, we need to identify which patients need or are likely to accept guided self management.

We thank the general practitioners, asthma nurses, and patients who volunteered to take part in this study.

Contributors: AJ was instrumental in coordinating the study and formulated the idea. RP designed the method and advised on the interpretation of the data. SA undertook the interviews and the analysis in collaboration with RP. AJ and RP were responsible for the initial drafting of the paper, but all three authors contributed to the final version. AJ will act as guarantor for this paper. Barbara Jones organised the focus groups and transcribed the tapes for SA.

Funding: This study was supported by a grant from the Wales Office of Research and Development (C96/2/008)

Competing interests: None declared.

1 British Thoracic Society. Guidelines for the management of asthma: a summary. *BMJ* 1993;306:776-82.
2 Haughney J. Guidelines on the management of asthma—the global initiative. *Airways* 1997;4:2-4.
3 Partridge MR. Patients' self-assessment and treatment strategies for acute asthma. *Research and Clinical Forums* 1990;15:65-73.
4 Lahdensuo A. Guided self management of asthma—how to do it. *BMJ* 1999;319:759-60.
5 Gibson PG, Coughlan J, Wilson AJ, Abramson M, Bauman A, Hensley MJ, et al. Self-management education and regular practitioner review for adults with asthma. In: Cochrane Collaboration. *Cochrane Library*. Issue 2. Oxford: Update Software, 2000.
6 Ayres JG, Campbell LM, Follows RMA. A controlled assessment of an asthma self-management plan involving a budesonide dose regime. *Eur Respir J* 1996;9:886-92.
7 Jones KP, Mullee MA, Middleton M, Chapman E, Holgate ST. Peak flow based asthma self-management: a randomised controlled study in general practice. *Thorax* 1995;50:851-7.
8 Yoon R, McKenzie DK, Bauman A, Miles DA. Controlled trial evaluation of an asthma education programme for adults. *Thorax* 1993;48:1110-6.
9 Levy M, Hilton S. *Education and self-management, in asthma in practice*. 4th ed. London: Royal College of General Practitioners, 1999:63-9.
10 Neville RG, Higgins BG. Issues at the interface between primary and secondary care in the management of common respiratory disease. *Thorax* 1999;54:813-7.
11 Guba EG, Lincoln YS. *Fourth generation evaluation*. Newbury Park, CA: Sage, 1989.
12 Adams S, Pill R, Jones A. Medication, chronic illness and identity: the perspective of people with asthma. *Soc Sci Med* 1997;45:189-201.
13 Rollnick S, Kinnersley P, Stott N. Methods of helping patients with behaviour change. *BMJ* 1993;307:188-90.

(Accepted 24 July 2000)

My most unfortunate mistake

Always double check

The staff in the accident and emergency department had asked for a medical opinion on the first patient of the evening. Recently arrived from west Africa, the unfortunate young man was struggling to describe his numerous symptoms to his family in French, who were then translating his problems into English. I knew that this was not going to be straightforward.

Raised voices and increasingly frustrated gestures between the patient and his bewildered uncle and mother indicated that there were other issues at stake besides his fever, lethargy, and joint pains. After exhaustive questioning, I thought that a recent onset of dysuria was, perhaps, relevant in the aetiology of his problems. Although he emphatically denied any recent sexual contact, I wondered if this was more to do with the presence of his family members. Unfortunately, as it was late in the evening, there were no other translators available.

Sitting in front of the results computer later in the evening, I typed in my enigmatic patient's name and duly noted the normality of the tests that I had requested. As I pondered the differential diagnoses, I scrolled idly back through the results file, looking for any previous investigations. And there it was. Two days ago a urethral swab was sent from the genitourinary medicine department taken from my patient. I clicked on the relevant line to view the result—culture had grown *Neisseria gonorrhoeae*.

I returned to the cubicle and asked the patient's mother to wait outside. Through his uncle I asked the patient why he had been to the clinic two days before. He started to get angry, insisting that he had been nowhere near the clinic and that he could not have a sexually transmitted disease. He and his uncle exchanged words, and his uncle then asked if we could speak alone.

Out in the corridor the uncle explained that it was actually *he* who had attended the clinic earlier in the week and that he was currently taking antibiotics for gonorrhoea. He and the patient shared the same, albeit unusual, name and it was actually his result that I had seen and mistakenly ascribed to his nephew.

Having diagnostic information available without a patient's consent carries with it a degree of responsibility to check the accuracy and relevance of the information. Something I shall endeavour to do in future.

Lloyd Bradley *senior house officer in medicine, London*

We welcome articles of up to 600 words on topics such as *A memorable patient, A paper that changed my practice, My most unfortunate mistake*, or any other piece conveying instruction, pathos, or humour. If possible the article should be supplied on a disk. Permission is needed from the patient or a relative if an identifiable patient is referred to. We also welcome contributions for "Endpieces," consisting of quotations of up to 80 words (but most are considerably shorter) from any source, ancient or modern, which have appealed to the reader.