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Do we need asthma clinics in primary care? Patients' views and perspectives

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Asthma is a common chronic condition which places a considerable burden on patients and NHS resources. The relatively high prevalence, together with its innate variability, makes the provision of care by primary teams an essential and recognized part of overall management which is now generally undertaken by enthusiastic asthma-trained nurses. Despite 10 years of such organized care, there is little evidence of its effectiveness, with few data available on who attends and for what reason. We do not know the views of those for whom the clinics were intended, namely the patients. Here we report the results from two qualitative studies, one using in-depth interviews with individual patients and the other using focus groups on a range of different patients. The first study involved 30 adult patients whose pattern of compliance with inhaled medication allowed categorization of individuals into 'compliers' and 'non-compliers'. The results of this study allowed a typology to be developed which categorized patients into 'distancers/deniers', 'accepters' and 'pragmatists'. The focus group involved 70 patients (35 patients on two occasions) from a mixture of practices, and varying age and socio-economic groups. Both studies yielded remarkably similar results, and they show that patients, for a variety of reasons, do not regard asthma clinics as being of relevance to them and generally do not attend. Using the typology that was developed, we present reasons for their non-attendance based on the recurring rich quotes from patients. It is clear from these results that if practices run endless clinics, patients will not attend for the reasons given. Further work involving both quantitative and qualitative techniques is needed to explore who attends asthma clinics and why. Patients' views should now be integrated into future service planning, and the current educational role of the asthma clinic should be replaced by one which more closely reflects patients' needs and expectations.

Key words: adults; asthma; clinics; patients; primary care; self-management

Introduction

Asthma places a considerable burden on patients as well as on the NHS. Its prevalence, coupled with the innate variability of the disease, makes the provision of care by primary care teams an essential and recognized part of overall asthma management. The new contract for GPs in 1990 that provided remuneration for asthma clinics (Griffiths, 1990) resulted in proactive care being offered to practice populations of asthma patients. However, the effectiveness of this system of care has received only limited evaluation by today's standards of rigorous evidence-based medicine. Although health authorities in the UK generally require audited data on asthma clinics, the focus is usually on structure and process, rather than on outcomes. In 1993 the National Asthma Task Force set out to establish a baseline of work under-

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taken in community asthma clinics, and called for further evaluation of the effectiveness of asthma clinics (Barnes and Partridge, 1994). However, there are still no published randomized controlled trials that directly address the issue of the effectiveness of asthma clinics in the UK. Moreover, since most practices now implement nurse-led asthma clinics, it has been argued that it may be impossible to undertake such a randomized controlled trial (Jones and Mullee, 1995).

Traditionally, asthma clinics have an educational role, which is highlighted in the training courses attended by the majority of asthma nurses. Whilst some examples of education processes in asthma have been evaluated and can show favourable outcomes (Keeley, 1993; Abdulwadud *et al.*, 1999), there are dangers in extrapolating because of 'enthusiast bias' (Neville *et al.*, 1996). Levy and Hilton (1999) point out that although patient education can be effective in reducing short-term and medium-term morbidity, this is only true for the interested minority who respond to invitations to participate. This view is further supported by the fact that several attempts to evaluate the effectiveness of educational programmes in asthma have described poor attendance by participants (i.e., patients) (Yoon *et al.*, 1991, 1993; Abdulwadud *et al.*, 1999).

What is certainly lacking in the literature are the views of those patients for whom asthma clinics were originally intended. This paper reports the comments of patients on primary care-led asthma clinics in the UK. in order to stimulate a debate about best care for patients and ensure that issues of resource effectiveness are addressed and integrated into service planning and practice.

Method

The data come from two studies undertaken in South Wales in order to explore asthma patients' perceptions of their illness and its management. Qualitative methods were used, as the objective was to explore and understand the patients' perspectives in their terms, rather than to test specific hypotheses (Britten and Fisher, 1993).

The first study (Adams *et al.*, 1997), which allowed the development of a typology and has been described elsewhere, involved one-to-one, taped, in-depth interviews by an experienced qualitative researcher (S.A.). These interviews were conducted at home with 30 adult asthmatic patients recruited from one practice of 10 000 patients in a mixed, predominantly urban area. The sample consisted of 16 men and 14 women, with ages ranging from 19 to 57 years. Patients were deliberately sampled according to their patterns of compliance with prescribed medication, using their ratio of inhaled reliever to prophylactic medication as a measure of good care (Shelley *et al.*, 1996), thus permitting a classification into 'compliers' (low reliever/preventer ratio) and 'noncompliers' (high reliever/preventer ratio). Further sampling within these two broad categories to generate patients of different age, gender and socio-economic background was undertaken by the researcher (S.A.) to ensure purposeful sampling without introducing any bias by selective sampling by the GPs or asthma nurses. The length of time since asthma diagnosis ranged from 2 to 27 years.

The second study used focus groups, again with purposeful sampling to ensure that the participants broadly mirrored the variety of primary care patients diagnosed as having asthma. Focus groups were considered to be appropriate in that they enable a specific set of issues relating to asthma management to be explored and contrasted (Morgan, 1992). Patients were approached by letter from the doctors of two contrasting types of practice, namely those in whom there was known to be an asthma 'expert' or enthusiast GP (three practices) and those from a further three practices that offered general pragmatic care. Every practice ran a nurse-led asthma clinic approved for asthma surveillance by the local health authority. 'Compliers' and 'noncompliers' were again recruited deliberately to provide a range of age, gender and socio-economic status, using the ratio of reliever to preventer medication. The patients were also stratified by age and sex so that the following groups were identified: male and female adult compliers; male and female adult noncompliers; two mixed teenage asthmatic groups. Small numbers of patients (5–8) were then invited to attend the focus groups moderated by the same researcher (S.A.). Vignettes describing patient attitudes and behaviour were used to stimulate discussion. The focus groups, which lasted 50–60 minutes on average, were arranged at nonpractice venues such as a local pub (for adult groups) or the meeting room of a local community hospital. Teenagers participated

in a focus group at local schools. All meetings were tape recorded with both ethical and educational approval, and were then transcribed and analysed.

A total of 35 patients were involved in the six focus groups, each on two separate occasions 8 months apart, thus enabling feedback from all groups to stimulate debate in the two interviews.

In both studies, the patients' views on asthma clinics were explored as part of the general discussion on management of the condition. The one-to-one interviews also collected information on patients' attitudes to asthma itself and medication use, whilst the focus group interviews examined patients' experiences of and attitudes towards guided self-management plans and asthma clinics. Although all of the practices involved ran asthma clinics, no information on whether the patients who were interviewed attended these clinics or not was available to the researcher (S.A.) prior to the two studies.

Analysis of both the one-to-one interviews and the focus groups was undertaken by S.A. with regular discussion and input from all three researchers. As both studies show a surprising but remarkably similar view of asthma clinics expressed by patients, we shall present the patients' views from the two separate studies together.

Results

The most striking findings from both studies, and the original stimulus for this paper, concerned the small number of patients who reported regular attendance at the clinic, or indeed *any* attendance. In the first one-to-one study, all but two of the 30 patients were aware that the practice ran an asthma clinic, all but three admitted to having been prescribed regular prophylactic medication, but only one of them had attended the asthma clinic. The same pattern was found in the focus groups. Of the 35 adults and teenagers, all were aware of the clinics, seven had attended at some stage, but only one was doing so regularly at the time of interview. Since we had found that the broad classification of patients' attitudes to asthma into 'distancers/deniers,' 'accepters' and 'pragmatists' described in the one-to-one study (Adams *et al.*, 1997) was confirmed by the discussions recorded in the focus groups, this typology is used to structure the presentation of the data on clinics.

Comments made by distancers/deniers

Patients in this category either denied that they had asthma at all, or felt that their condition was not 'real' or 'proper' asthma. They regarded their condition as acute attacks of 'chestiness', did not disclose it to others who would be 'shocked if they thought I had asthma even if I did', and were concerned to distance themselves from those they defined as 'wimps' and 'weak people who had "real" asthma.' With hindsight, their reactions to asthma clinics are predictable. Indeed, given their perception of the acute nature of their 'bad chests', many of them did not see the need for asthma clinics at all. For example, a typical comment was as follows: 'You don't need a clinic. It [slight asthma or a bad chest] is like having a bad knee. It's not an illness. It just affects you sometimes' (Interview 5).

Several other respondents who accepted that 'real' asthma could be serious for 'other' people did consider that there was a use for clinics, although not for themselves. For example, 'I've never bothered going, but it might help those with *real* asthma' (Interview 6) or 'Perhaps if you've got *proper* asthma then . . .perhaps people like *that* need it [clinic]' (Interview 8) and 'I think real bad asthmatics do use the clinic regularly' (Focus Group 6, respondent 1).

An additional argument that militated against the use of an asthma clinic was that when their 'slight' asthma/chest problems 'gave trouble' they were far too ill to attend. For example, 'If you are bad enough they'll bring the nebulizer out. You can't get to clinic for it' (Focus Group 4, respondent 2) or 'You wouldn't be able to get there [clinic] if you were in trouble. You call the doctor out' (Focus Group 6, respondent 3).

Whilst it became increasingly clear throughout the interviews and focus group meetings that 'chest troubles' for this category of patient caused considerable disruption to their lives, it was equally clear that they did not attribute this to 'asthma'. Why, therefore, should they attend an asthma clinic or should the interviewer/group moderator be bold enough (or foolish enough) to suggest it? None of these patients, quite logically given their beliefs, considered attendance necessary. As one respondent exclaimed, 'OK, I like a few drinks but I'm not an alcoholic, so I don't go to an Alcoholics

Anonymous clinic. I've got a bit of a cough but it doesn't mean I would go to an *asthma* clinic. I wouldn't belong there' (Interview 3). It was clear from these patients that if a practice ran two asthma clinics a day they would still not attend.

Comments made by accepters

This category had completely accepted the medical diagnosis and the necessity to take both types of medication. Asthma was now 'part of them' – an integral aspect of their identity – and they often held almost evangelical opinions about the need to take control and cope. Therefore a major characteristic of this category was a sense of pride in being able to manage their asthma themselves without bothering the doctor except in times of crisis. For example, 'I don't need the doctor as long as the medication is working' (Interview 10) and 'I'm keeping it under control. I rarely go to the doctor's. I just get repeat prescriptions' (Interview 26) or 'I don't need the doctor as long as the medication is working' (Interview 29) and 'I don't need any help with my asthma. I control it myself' (Interview 26).

All of the 'accepters' were aware of the availability of the asthma clinics, but few of them attended. With few exceptions, the small minority that did avail themselves of this service did so only when their self-management had failed them and they wished to see a doctor as soon as possible. For example, 'Often if you go to see the doctor you can't get an appointment quickly. The nurse can refer you' (Focus Group 1, respondent 4) and 'I see the nurse when I'm in trouble so she can refer me to the doctor' (Focus Group 3, respondent 6). The majority of these patients also agreed that their main point of contact with medical staff was when they called the doctor out because they were having a really bad attack. However, apart from such times of crisis there was no point in bothering the doctor or attending the asthma clinic, as they were 'in control themselves'. Consequently it was other asthmatics who did not cope well that needed asthma clinics. For example, 'I don't need it. I manage on my own. Perhaps it's useful for those people that can't manage' (Interview 24), or 'These people who don't understand their medication. They're the ones that need a clinic' (Focus Group 3, respondent 4) or 'I've heard they're very good there [clinic], but I can manage myself. I don't feel the need to use it' (Focus Group 1, respondent 5). Thus although their reasons for not attending were very different, the results were the same as for the deniers/distancers.

Comments made by pragmatists

All of these patients accepted that they did have asthma but their notions of the illness and use of medication were somewhat idiosyncratic. Their attitudes to asthma clinics also varied, although none of them, for differing reasons, had attended. For example, one patient who had accepted that asthma was a chronic condition made the following comment: 'No. I know there is one [clinic] but I've never bothered. What for? I'm happy just with scripts. It's not curable anyway, so what's the point?' (Interview 28). In contrast, another respondent who considered her asthma to be an acute condition suggested that asthma clinics were equally pointless: 'Well, it just comes and goes. I don't see why they have an asthma clinic anyway. It's daft! You don't see them having clinics for colds, do you?' (Focus Group 4, respondent 5).

A small minority of the patients did acknowledge that if one had 'the sort of asthma that kills' then an asthma clinic 'may be useful', but none of them considered that they suffered from this 'very serious' type of asthma. While the rationale underlying non-use of asthma clinics differed between these respondents, and differentiated this category from both the 'deniers' and the 'accepters', none of the patients could see the relevance of this service to them. They also shared the predominant overall view that medical care for asthma consisted of repeat prescriptions and crisis care (usually involving house calls from GPs) and that *their* asthma did not warrant attendance at an asthma clinic.

Discussion

The low reported rate of use of asthma clinics was a finding that was not anticipated, but which emerged from the respondents' own accounts in the first study, and was substantiated in the second study. The classification of patients into distancers/deniers, accepters or pragmatists that was adopted in the single practice study seems to have been vindicated by the results of the focus groups that drew on a number of practices and patients.

For quite different reasons, the three groups do

not regard attendance at practice-based asthma clinics as being of potential benefit to them. It is clear from this research that no matter how many asthma clinics health professionals run in a primary care setting, patients are unlikely to attend. This may partly explain the frustration that trained asthma nurses appear to feel at the reluctance of many patients to attend. It may also in part explain the relatively low attendance rates observed at many of the apparently well-organized and well-intentioned asthma education programmes reported throughout the UK and other parts of the world (Yoon *et al.*, 1991, 1993; Abdulwadud *et al.*, 1999).

The samples for the two studies were drawn from the same area, namely South Wales, but used different practices and patients who varied with regard to age, gender, socio-economic status and compliance patterns, thus giving a reasonable spread of respondents with potentially differing experiences of asthma clinics. The unexpected finding that the majority of patients in these studies were not regular attenders and had limited experience of asthma clinics means that we have been unable to comment on the views of the minority of patients who clearly do attend these clinics. The characteristics of attenders and their reasons for attending at present remains unknown, but may provide evidence that would support the continued use of such structured care.

The views that were expressed encompassed those of adults and teenagers. It is possible that the parents of children with asthma may have a different view of asthma clinics. However, it was not possible to examine this possibility within the constraints of the present study.

The qualitative methods that were used were designed to give greater in-depth understanding, and our work suggests the reasons why patients may not be attending compared to quantitative data on attendance rates. Qualitative data will always be subject to the question of generalizability, but in this instance we offer the concept of 'transferability' (Pope *et al.*, 2000). Those involved in asthma care must decide for themselves whether these results are sufficiently credible, and the circumstances sufficiently similar to the situation with which they are familiar to be applicable in a different environment.

A worrying trend from the patients' perspectives is the apparent misconception that 'their' asthma was not deemed to be the variety that 'kills'. This belief flies in the face of the recent National Asthma Campaign reports on asthma deaths in Wales (Burr *et al.*, 1999), in which patients' behaviour or circumstances contributed to 31 of the 92 deaths recorded in Wales in 1994 among patients under 65 years of age.

It is clear from this research that patients did not appreciate the educational role of the clinic, and did not regard it as relevant to people like themselves. Controlled studies of educational programmes presented via asthma clinics have shown that increasing patients' knowledge of their condition has only a limited effect on altering patient's behaviour or on reducing morbidity. Some studies have concluded that any positive results might owe more to the enthusiasm of participating GPs (Hoskins *et al.*, 1996), or to the selection of patients who benefit most from increased care, such as those with poorly controlled symptoms (Allen *et al.*, 1995; Bauman *et al.*, 1995). If the nurse-led clinic is to be the focus of our educational effort, as is the case in the UK, then perhaps now is the time to acknowledge that perhaps our efforts are conceived according to the medical model rather than the patients' model.

Given past form, traditional health educational programmes delivered via asthma clinics are likely to be of limited effectiveness, and we need to think of innovative ways of helping to change patient behaviour. We are learning about behaviour change in alcohol, drug addiction, smoking and diabetes (Rollnick *et al.*, 1993), and it is hoped that this research will help to stimulate debate about the process of behaviour change in patients with asthma, using principles of patient centredness and shared decision making. Patients usually welcome help or advice, but they resent dogma (Stott and Pill, 1990) or prescriptive professional approaches.

It appears that the asthma clinic in primary care has done little for those for whom it was intended. If the present system of structured care via nurse-led asthma clinics is not being used by the majority of patients, perhaps it is now time to integrate the patients' views into service planning, and to consider replacing the current educational role with an approach that more closely reflects patients' needs and expectations.

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