Organising primary health care for people with asthma: the patient's perspective

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SUMMARY

Background. *The 1993 chronic disease management contract encourages United Kingdom general practices to implement a standardised package of care with an emphasis on regular visits to an asthma clinic.*

Aim. *To explore the views of people with asthma about the organisation of asthma care in general practice.*

Method. *Semi-structured interviews with 20 patients registered with one practice with a nurse-run asthma clinic. The sample was selected to provide people with a wide range of ages and disease severity, and included parents of children.*

Results. *The age range of the interviewees was five to 87 years (parents of children were interviewed) and half of the interviewees had attended the asthma clinic at some time. In describing how they managed their asthma, people identified their medical care alongside other important factors, such as avoiding smoking and pollution, and a decision to seek medical help was made in the context of all of life's other priorities. People expressed diverse views about the organisation of care, describing how their needs changed over time and how they balanced up several factors in deciding what was best for them. These factors were encompassed by four themes: the accessibility of care, severity of asthma and dealing with uncertainty, self-knowledge and self-management, and expert knowledge and therapeutic relationships. Interviewees were evenly split between wishing to be seen regularly in the clinic and wishing only to attend when needing help.*

Conclusion. *Patients required asthma services that allow individual choice and flexibility, and eight service objectives were identified that would cover most people's needs.*

Keywords: *asthma; interview survey; general practices; patients' attitudes.*

Introduction

THE provision of asthma care in United Kingdom general practice, as required by the 1993 chronic disease management contract,[1,2] has shifted practice away from individualised care towards a standardised package of care audited by health authorities using process criteria. The current organisation of asthma clinics, with its emphasis on regular routine visits, followed the pattern set by diabetic clinics in primary care. However, people with asthma differ in several respects from those with diabetes; for example, they often experience long periods of being asymptomatic and off treatment, or have periods of stability on regular medication. In addition, they experience symptoms that, once they are well informed, could theoretically enable many of them to monitor their own severity and medication needs. The requirement for routine medical monitoring may be in contradiction to the aim of enabling and encouraging patients to take control of their illness, and it may also be inefficient.

Studies suggest that up to one-third of people with asthma in the community have a high morbidity from their asthma.[3] Nurse-run asthma clinics are a common way for practices to tackle this problem, but evidence that they result in a greater reduction in morbidity than traditional care is conflicting.[3-6] Two randomised controlled trials of the introduction of peak-flow-based self-management plans have produced negative results,[7,8] as has a trial of morbidity information feedback.[9] The most promising development to date is the use of a simple asthma morbidity index within nurse-run clinics.[10,11]

In view of this conflicting evidence about medical outcomes, patients' perspectives would seem especially valuable. A questionnaire study showed people with asthma wanted more information and more participation in decision-making.[12] Recent qualitative research has investigated medication use and identity,[13,14] diagnosis and doctor–patient communication,[15] reasons for delay in seeking treatment for acute asthma,[16] and how people experience and adapt to asthma,[17,18] but none of these have focused on how patients think their asthma care should be organised.

We interviewed 20 people with asthma who were registered at a practice with a long-standing nurse-run asthma clinic in order to explore their views on the organisation of their asthma care.

Method

Setting and sample

The study took place in a practice of 6500 patients in Taunton, Somerset in 1998. A practice nurse with a Diploma in Asthma Care ran a weekly clinic at the practice for 10 years, and for several of these years, but not the previous one, people on the asthma register have received an annual invitation to attend. Patients are also free to attend any of the six doctors for asthma care. The practice is fully computerised and the asthma register includes all patients who have consulted with, or received a prescription for, asthma in the previous two years. This qualitative study was part of a wider study that involved sending a questionnaire to all 505 patients on the asthma register in monthly batches from an alphabetically arranged list. The interview sample was drawn from the 120 patients who had received the questionnaire by the start of the qualitative study. A research assistant, who was independent of the practice and had no professional or personal interest in asthma, was instructed to select, without input from any practice staff, one patient for a pilot interview and then a sample of 20 patients, in accordance with a sampling strategy to maximise variation of interviewees on the criteria of age, sex, prescribed medication, and whether or not they returned the questionnaire. The research assistant interviewed the patients at their chosen venue, which was usually their home.

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Interview technique and analysis

An interview schedule was piloted, revised, and then used as a guide to each interview with each question asked as written in the schedule unless it had already been covered by previous discussion. The schedule started with the question, 'How has asthma affected your life?', and then asked open questions about people's aims for and experience of asthma care, including their views on attending routinely or just when they wanted help, about preference for a doctor or an asthma-trained nurse, and about learning to manage their asthma themselves. The interviewer sought in-depth clarification and detail on these questions.

The interviews were audiotaped, transcribed by a secretary, and then listened to on at least one occasion by one of the authors (CP), who analysed the data. The analysis involved reading and rereading the transcripts and developing an inductive coding frame that could organise and account for all of the data. On two occasions during this process, a second researcher, NB, independently coded a total of four interviews, and categories were compared and revised. Once the coding frame was unambiguous, all the interview data were coded into these categories; the data in each category were summarised and the core category was described using themes. A matrix of the data for each individual interviewee was made and was used to look for patterns in the data and to check out emerging hypotheses, including a search for negative cases.

Results

Twenty-seven people were contacted for interview; 21 interviews of 20 to 45 minutes in length were completed and, because of one audiotape failure, 20 were analysed. The age range was from five years to 87 years (six children were aged under 16 years, eight aged 16 to 60 years, and six over 60 years). For the four young children, three mothers and one father were interviewed and the two young teenagers were interviewed jointly with their mothers. The interviews related to 11 women/girls and nine men/boys. Half of the interviewees had consulted about their asthma in the six months prior to interview, and all but three were being prescribed medication. Three interviewees had not returned the questionnaire.

The lived reality of asthma

In describing how they treated and managed their asthma, people identified many factors other than medical care that affected their asthma-related quality-of-life, and for some people these were very important. Cigarette smoke and traffic pollution were important triggers to many people, and they described the difficulties they had in avoiding traffic fumes and public places and friends' houses where smoking was permitted. A variety of other triggers were mentioned, including stressful situations, and parents of young children were also affected by difficulties in getting their child's medication given at school and the extra strain an ill child can put on family relationships.

A decision to attend for medical care was made in the context of all life's other priorities, and when and how to consult could depend on such things as work and child care commitments, transport and financial problems, and being housebound owing to other illness. Doctors were generally seen as more available than the asthma nurse, with choice of appointment times, easy telephone advice access, and having the ability to do home and out-of-hours visits, though a few people said they would have difficulty getting an appointment quickly. The asthma nurse was not known to some people, and the set clinic time was inconvenient to some; however, once people had got to know her, access appeared easier. (Examples of how accessibility affected views on asthma care are given in Box 1.)

Views on the organisation of care

A wide range of views were expressed, and people talked about both the present and the past and about how their requirements changed over time. Interviewees were evenly split between wishing to be seen regularly in the clinic and wishing only to attend when needing help. Only two were unable to give a preference. Some of the people who did not wish to attend regularly still valued the clinic as being a session that they could book in to or phone for advice. Several, but not all, of the people who were enthusiastic about managing their own asthma were also enthusiastic about regular attendance at the clinic, which gave them the confidence to take responsibility for their asthma the rest of the time. When asked whether they had a preference for a doctor or an asthma-trained nurse, the majority had no preference or did not know, but several people preferred to see a nurse and several were very satisfied with their doctor.

The majority of people were in favour of asthma care aiming to teach people to manage asthma for themselves, and many of these expressed enthusiastic support for the concept. Others were in favour but added certain conditions, especially those such as having been established on the correct medication and having access to advice and support when they needed it. Quite a few people were unsure about the concept or unable to comment on it, and two people spoke out against it as not being feasible or being inappropriate.

Factors affecting the views expressed

Many people gave complex reasons for their views on the organisation of care, and were balancing up several factors in thinking what was best for them at any one time. In addition to the issue of accessibility described above, there were three other themes.

Severity of asthma and dealing with uncertainty. The majority of people mentioned the severity of their asthma as influencing the

Accessibility

That's probably me mind [Laugh]. *As I say, it's easy, accessible because lots of the others aren't. I mean, I had a doctor in a practice, which is obviously very popular, and it's three to four weeks before you can get her. I mean, there's five other doctors; it doesn't mean you're not seen to, but; to see her, but I can always get to see the asthma nurse, R, whenever I'm … but her real clinic is Wednesday.* [70-year-old woman (4).]

Yeah, sometimes my wife teaches reading, so therefore I have no access to the car and there's no public transport after, I think, half-past five, and, if the asthma clinic is in the afternoons, I'm probably lucky, so its very difficult to get there because its only certain times. You can see a doctor … you know he can fit you in rather than you try to fit them in. [49-year-old man (45).]

Erm, some of it's the mechanics of getting there because I am a child minder and I've got young children. It's not always easy, you know, on a regular basis to, say, once a month or once every two months to go down for an appointment. [33-year-old woman (115).]

I happened to be going to see the doctor anyway, and because we're so far away, erm, I sort of killed two birds with one stone as it were. I should really have gone to R [the nurse] *but it would have meant a separate visit. That again, you see, is bad for somebody like me who's on a lower income and hasn't got transport; you're not going to make different excuses for different appointments, do you know what I mean?* [Mother of eight-year-old boy (15).]

Box 1. Examples of the theme 'Accessibility'.

type of care they needed. However, this was not always the expected association of people with few symptoms wanting little care and vice versa. More often the severity of their asthma was given as a reason but was hedged with uncertainty. The concept of their asthma being 'under control' dominated a few interviews, and a search for the word 'control' and its derivatives were found in half of the interviews, though it was never used by the interviewer. However, the use of the word 'control' by interviewees was not necessarily related to lack of symptoms, and the fact that their asthma was 'controlled' was often qualified with memories or fears of it getting worse or out of control and that this could happen suddenly. This appeared particularly frightening for parents of young children with asthma. Uncertainty was also expressed in relation to diagnosis and the future illness trajectory. Examples of the effect of uncertainty on people's views about asthma care are given in Box 2.

Self-knowledge and self-management. Three people expressed strongly-held views about knowing their own and their own children's signs and symptoms of asthma better than anyone else could. For two of these, this led to a desire to manage their own asthma, though they appreciated a regular review as a back-up. The third, a mother of two children with asthma, was much more ambivalent about her role, and had felt under-supported in the past. Several other people indicated that they wished to take the lead or be in control of how their asthma was managed, or that they monitored it carefully themselves with peak flow measurements, or that their main requirement was to be able to get an appointment when they needed it. In contrast, three people said that they left the treatment of their asthma in the hands of the doctor or nurse, or that they did what they were told. Examples of this theme are given in Box 3.

Severity of asthma and dealing with uncertainty

It seems to be under control, you know, he doesn't seem to get bad enough to have to, you know, see a doctor or anything… Yeah we see her [nurse] *once a year, don't we? And erm, you know, he just takes his medication, you know, when she sort of like tells him to and, you know, touch wood, he seems a lot better.* [Mother of 15-year-old boy (65).]

I don't know really because she's quite mild asthma, I don't really think there's any more they can do…
Interviewer: *Some people feel that one of the aims for modern asthma care is that people should learn to manage it themselves. How do you feel about that?*
No, I'd always want somebody to go to. I'm not very confident in, especially when it's asthma and it could get serious. I'd much rather have someone professional to turn to… I think, with her asthma at the moment, I'm happy to just go if she seems poorly with it, but, if she suffered with asthma more so, then I would definitely want the clinic I could go to regularly, to monitor…
Interviewer: *And so why, why would you like that?*
Because asthma worries me. It just, the thought of her suddenly not breathing, I find that quite worrying, and if I didn't have somewhere to go I think I would panic more. [Mother of six-year-old girl (84).]

Interviewer: *So do you prefer to attend the asthma clinic regularly, no matter how well you're feeling, or do you prefer to attend at the surgery when your asthma is making you feel unwell?*
Oh no, no. Erm, I must say sometimes I feel I'm such a borderline case that I'm wasting everybody's time, and then I think no, erm, there's obviously something not right and it ought to be monitored. [80-year-old woman (7).]

When the child's young and your child's having an attack, it's very frightening and it puts you on edge…
Interviewer: *So, would you prefer to attend an asthma clinic regularly no matter how well J is feeling, or do you prefer to attend only when he's sort of feeling unwell?*
Yeah. Not regularly, no, because he's, he is very well, so, but I mean, when, it's just somewhere to go when he's not well. Yes. Not all the time. I think we've got it under control, and most of the time we know how to cope with it, but it's just when he's poorly. [Father of a six-year-old boy (25).]

Box 2. Examples of the theme 'Severity of asthma and dealing with uncertainty'.

Previous experience of care: expert knowledge and therapeutic relationships. Just under one-half of the interviewees had seen the asthma nurse either once or twice or on a regular basis, a few others remembered receiving a previous invitation but had not attended, and a few did not know that the nurse was available. Nearly one-half of the interviewees were enthusiastic about the specialist knowledge and role they perceived the asthma-trained nurse having, including some that had not attended a clinic, and a few had experience of such nurses in other situations. Several interviewees ventured that they may know more about asthma than doctors who had so many other things to deal with, while others were looking for any 'professional' help. Several people had reservations about seeing the nurse, especially when the asthma was more severe. A number of people expressed concern about 'wasting the doctor's time', because doctors were busy or had more important things to deal with.

Although only a minority of people talked about their care in terms of specific relationships with the nurse or one of the doctors, this was a very important factor when it was expressed. The descriptions included the fact that particular individualised care had been taken, and sometimes suggested a more personal relationship, such as having a good rapport and feeling at ease or getting on with the personality of the professional involved. Examples of this theme are given in Box 4.

Discussion

The limitations of this study are that it was carried out in one practice, that the interviews were a one-off and relatively short, and that the researcher analysing the interviews, CP, is a general

Self-knowledge and self-management

Because somebody else can't possibly know how you're feeling. I think it's better just sorted, I mean, I do with, when I've taken HRT, I do that to, I use the patches, I do that to suit when I feel I need it — if I'm getting hot flushes I do it and then when they go off I stop it, and the doctor left me to sort of manage it myself really. Yes. Yes, there's no problem with that at all … because I think you can probably get, probably so used to dealing with yourself, you may not, you may, you know, I don't know, probably overlook things, you could become too familiar with it I suppose. I think yes, I think you should, sort of, I don't know, six-monthly or something like that, definitely go in and get checked. [53-year-old woman (29).]

…although I monitor myself very well, I mean, I've got a peak flow that I do daily, twice daily. [39-year-old woman (31).]

…but I think I leave it in their hands really. They know what's best for me. [71-year-old man (51).]

Interviewer: *What do you think you would do then if, if you, if you got, just got an invitation to attend the asthma clinic?*
Erm, I'd probably try, I'd need to know a bit more information about what we would deal with. [23-year-old woman (54).]

Oh yes, I mean, I'm in their hands. I do as I'm told! [Laugh.] No good going to them if you don't do what they recommend, is it? [80-year-old woman (7).]

Box 3. Examples of the theme 'Self-knowledge and self-management'.

Previous experience of care: expert knowledge and therapeutic relationships

If she was fine, I don't have a problem with seeing the asthma nurse, I mean, I don't, if she was fine, but if she was really poorly, then I would rather, prefer to see the doctor … I mean, I know the asthma nurse could do that as well, but, I don't know, there's something about a doctor [laugh], *there's something about a doctor that gives you the confidence to you know deal with the situation.* [Mother of a six-year-old girl (2).]

Interviewer: *Do you prefer to see the asthma-trained nurse for your asthma or see a doctor?*
Erm, the asthma-trained nurse I think, 'cos she actually specialises in it. It's rather like, erm, taking a TV down to a TV repair shop or getting your friend to fix it. Sort of. He might know about it, you know, fair enough, but he's not really expert on it. [30-year-old man (57).]

We don't really need to waste the doctor's time to say that, you know, I mean, the doctor's a busy man. [Father of a six-year-old girl (25).]

If there's nothing wrong, then, if suddenly all these people that have got asthma are going every six months or whatever, are we not time-wasting for the asthma nurse maybe, I don't know? Well, yeah, I mean, you don't make an appointment to see the doctor every six months if there's nothing wrong, do you? [32-year-old woman (87).]

Well, erm, I think I would be wasting the doctor's time because nurse A is trained and, possibly, if this is what she does most of, she is more knowledgeable than, well, no, I mustn't say that, must I? But I'm perfectly happy and I think it would just be a waste of everybody's time to go and see doctor. [80-year-old woman (7).]

Yeah and well, I like the whole, er, Dr X's whole manner. I mean, it gives you ease, he takes time to talk to you on any subject you want, but, at the same time, you know, he's also treating me as well. [49-year-old man (45).]

Box 4. Examples of the theme 'Previous experience of care: expert knowledge and therapeutic relationships'.

practitioner in the practice. The techniques used to minimise these limitations and increase the quality and rigour of the method were:

- using an independent researcher to select the sample according to an explicit sampling strategy and carry out the interviews;
- analysing the transcripts without identification of the name or medical records of the individuals;
- involving a social scientist experienced in qualitative research, NB, to independently code four interviews and to discuss analysis as it proceeded; and
- relating the findings to wider social theory concerning chronic disease.

The interviewees had a wide range of ages and asthma severity, and, although the study practice had run an asthma clinic for many years, some patients did not know about it, some chose to see the doctor instead, and some had also experienced care from other practices in the past. The findings are therefore likely to have general applicability.

People experienced their medical care as only one of many factors affecting their asthma, and the importance of smoking, pollution, low income, and school and workplace policies suggests that these public health issues are just as important as the organisation of care at surgery level.

People expressed diverse views concerning the organisation of asthma care in general practice and gave complex reasons for these views. There were no simple patterns in the data, for example, people with few symptoms did not require a particular type of care, and people who wanted to manage their own care varied in what type of back-up they required, but the results are easier to understand when they are viewed in the context of previous sociological work on chronic illness.

The people interviewed described their asthma as a 'lived-in illness' that they must adapt to and learn to live with,[19] and their requirements for care changed over time; i.e. had a temporal dimension. The reasons they gave for wanting a particular type of care at any one time illustrated how they needed a type of care that fitted with all their other ways of dealing with their asthma.

The themes that emerged span the adaptation processes of coping, strategy, and style as described by Bury.[20] The term 'coping' refers to the cognitive and emotional ways that people learn to live with and manage their illness, exemplified in this study by such mechanisms as establishing 'control', or 'doing what I am told', or being 'monitored', or describing their asthma as 'mild'. Strategy relates to the actions that people take, exemplified here by the avoidance of triggers, attending for regular checks, telephoning for advice when required, or using the repeat prescription service. Style is perhaps the most difficult to define but was very evident in the interviews, especially within discourses about self-knowledge and self-management and in views on expert knowledge.

The theme of uncertainty was underlying many of the views on the need for medical care, and it seems likely that asthma, with its uncertain diagnosis, its episodic and unpredictable course, and in its variable triggers, is especially productive of uncertainty. The interviewees' frequent use of the word 'control' may have been a reflection of teaching and leaflets on medication use, but, as it was often expressed in relation to the concept of uncertainty and to the fear of 'loss of control' and was used with various attributions, such as 'it is under control',' I can control it', 'he is under control', it may have many meanings. Certainly it may not always denote the meanings that most health professionals attach to it, such as a disappearance of symptoms, safety, and good prognosis. Further exploration of this possible miscommunication would be useful in both clinical and research situations.

For some people, a particular therapeutic relationship appeared of over-riding importance, and this may be similar to the mentoring relationship described by Snadden.[17] The common concern about wasting the doctor's time would suggest that some people would find it easier to develop a relationship with a nurse than a doctor, and the concept of a specialist nurse was embraced enthusiastically by many people.

These results suggest that, in order for asthma care to be useful to patients, it needs to provided in a way that allows individual choice and flexibility. The facilities that were valued by different individuals in this study (in no priority order except the first) include:

- To be able to consult 'a professional' quickly when the need arises, either by telephone or by attending.
- To be given regular support and monitoring.
- To receive accessible care from a health professional they have developed an ongoing relationship with.
- To have expert asthma care at home when housebound or when very ill.
- To be given time, explanation, and help in understanding the causes of their symptoms.
- To have a choice of appointment times to fit in with other commitments.
- To have their own self-knowledge about their, or their children's, bodies and their illness acknowledged.
- To have access to expert professional advice about medication.

These results may help to explain the inconsistencies of previous research, in that asthma clinics are not 'better' than traditional care, but rather that they can usefully extend the options available to people with asthma if they are offered as part of a service that is based on an individualised, patient-centred approach.

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