

ORIGINAL ARTICLE

Understanding reasons for asthma outpatient (non)-attendance and exploring the role of telephone and e-consulting in facilitating access to care: exploratory qualitative study

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Objective: To understand factors influencing patients' decisions to attend for outpatient follow up consultations for asthma and to explore patients' attitudes to telephone and email consultations in facilitating access to asthma care.

Design: Exploratory qualitative study using in depth interviews.

Setting: Hospital outpatient clinic in West London.

Participants: Nineteen patients with moderate to severe asthma (12 "attenders" and 7 "non-attenders").

Results: Patients' main reasons for attending were the wish to improve control over asthma symptoms and a concern not to jeopardise the valued relationship with their doctor. Memory lapses, poor health, and disillusionment with the structure of outpatient care were important factors implicated in non-attendance. The patients were generally sceptical about the suggestion that greater opportunity for telephone consulting might improve access to care. They expressed concerns about the difficulties in effectively communicating through non-face to face media and were worried that clinicians would not be in a position to perform an adequate physical examination over the telephone. Email and text messaging were viewed as potentially useful for sending appointment reminders and sharing clinical information but were not considered to be acceptable alternatives to the face to face clinic encounter.

Conclusions: Memory lapses, impaired mobility due to poor health, and frustration with outpatient clinic organisation resulting in long waiting times and discontinuity of care are factors that deter patients from attending for hospital asthma assessments. The idea of telephone review assessments was viewed with scepticism by most study subjects. Particular attention should be given to explaining to patients the benefits of telephone consultations, and to seeking their views as to whether they would like to try them out before replacing face to face consultations with them. Email and text messaging may have a role in issuing reminders about imminent appointments.

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Asthma affects over five million people in the UK.¹ Regular review coupled with self-management is a marker of quality care and has, when coupled with self-management plans, been shown to be effective in reducing asthma morbidity.² UK data, however, reveal that over one third of asthma patients do not attend their hospital outpatient appointments, with comparable non-attendance rates in other specialties.^{3–9} Despite such high rates¹⁰ and the associated costs to the National Health Service (current estimates are £400 million/year),¹¹ we know surprisingly little about why patients do not attend for scheduled outpatient follow up visits. There is a need to progress beyond simply blaming those who do not attend to think creatively about how access to care can be improved.

The experiences of primary care can offer some useful insights. Here the situation is even worse with up to two thirds of patients with asthma not attending for their annual assessment, perhaps because patients believe that their asthma is so mild that the relative inconvenience of attending outweighs the possible advantages of an asthma review.¹² Building on this understanding, it has been possible to achieve significant reductions in non-attendance rates—without compromising quality of care—by offering convenient telephone based asthma reviews, as shown in a recent primary care trial.¹³ Whether such an option would be acceptable to patients seen in a hospital setting, whose

asthma is potentially more severe, is unclear. The question is highly topical with current policy initiatives aiming to improve attendance primarily by increasing patients' choice of hospital and booked appointments.⁸

We sought to explore patients' reasons for attendance and non-attendance for asthma review appointments to determine the main factors that influenced their decision making. In view of a possible broader role for information technology innovations in facilitating care, we also investigated patients' views on the roles of telephone and email consulting in facilitating asthma outpatient care.^{14–16}

METHODS

Patients

The study sample comprised 50 patients with moderate to severe asthma (British Thoracic Society asthma guideline step ≥ 3) from the outpatient asthma clinic of a West London teaching hospital. They had either attended all follow up appointments in the previous 6 months ("attenders") or had missed one or two follow up consultations during this period ("non-attenders"). In the 6 months preceding the study the non-attendance rate for asthma outpatients in the clinic was 26%.

Through purposive sampling we aimed to recruit participants with a range of age, sex, and ethnic backgrounds. We stipulated that included patients must have had at least two

Box 1 Initial interview topic guide

Asthma management

(Prompts about self-management, treatment satisfaction, treatment plan, desire for change in treatment, health effects, how long at this clinic)

Follow up consultations and non-attendance

(Explore views about follow up, benefits and disadvantages, usefulness personally, reasons for appointments, seeing different doctors)

Does your hospital doctor ask you whether you want to come to the clinic again?

Why do you think your physician arranges follow up consultations?

Did you ever have to miss an appointment in the past?

(Prompt: What happened? What did you do when you realised? How was your asthma at that time?)

Patient-doctor relationship

How would you describe your relationship with your doctor/respiratory physician?

Who is responsible for your asthma care?

Do you feel you have some responsibility yourself in managing your own asthma?

Clinic

(Consider accessibility, appointment times, consequences of non-attendance, organisation of the clinic)

Suggestions for improvement of care

(Scope the role of telephone, email and text messages in communication with doctor/clinic)

previous visits to the clinic before missing an appointment in order to exclude those in whom referral related factors might influence non-attendance.¹⁷ Eligible patients were sent an invitation letter and non-responders were followed up with a telephone reminder (most provided their landline number at registration).

Data collection and analysis

Guided by individual patient preference, JB and HJ jointly conducted interviews either in patients' homes or in hospital. Our initial topic guide (this evolved during the course of the study), which was informed by a review of the literature, aimed to explore patients' views on the role of structured asthma care and factors that inhibited or facilitated attendance in the context of each participant's personal experiences (box 1). A non-judgemental stance was adopted throughout the interview in relation to non-attenders. We also explored participants' views on the possible roles of telephone and email consulting in delivering asthma care.

Interviews, which lasted 30–90 minutes, were audio-taped (in all but one case) and transcribed verbatim by the interviewers; the individual who preferred not to be audio-taped agreed to extensive note taking.

The process of data collection and analysis was intertwined and iterative. Each interview was examined line by line to identify main categories and concepts. Emerging ideas and themes were explored in subsequent interviews using the constant comparative method.¹⁸ Themes within and across patients' accounts were compared, and also with issues already highlighted in the literature.

JB and HJ analysed all interviews independently to maximise rigour, with other members of the team analysing a selection of interviews. Members of the team with significant qualitative expertise closely supervised the field-work through frequent discussions regarding data generation, analysis and interpretation, including comparisons of particular coding queries.¹⁹

We carefully considered the influence of the interviewers' social positioning in the analysis of the data. It was evident from reading the transcripts and the richness of the data that the participants felt comfortable expressing their opinions to two female medical students.

Members of the project team brought diverse angles on the data (including a Dutch perspective) on reasons for the non-attendance of the patients. There was an obvious danger that JB and HJ may have missed or misunderstood British English (or South Asian English) idioms or typical non-verbal reactions. We tackled this issue on several levels. Firstly, non-English members of the team had frequent discussions with other members of the team who viewed their findings through local English and British South Asian "prisms". Secondly, to minimise any differences between patients' reported behaviour and actual practice, we asked them to support their responses by examples of their experiences. Thirdly, by frequently seeking and verifying meanings by asking questions that made interviewers seem naïve, such questions in a very positive way "reduced" any barriers as they put the interviewer in the position of someone who "does not know" and needs explanation (help) and the patient in the position of a person who explains.

RESULTS

Twenty two of the 50 patients approached agreed to participate, 19 of whom were successfully interviewed (table 1). The three patients who did not attend arranged interviews were all from the sample of non-attenders. The remaining 28 either did not respond to our invitations (n = 26) or declined to participate (n = 2). The views of the attenders and non-attenders did not differ in systematic ways in terms of decisions to attend and the place of telephone or email consulting and are thus presented together.

Motives for attendance and non-attendance

Participants emphasised two main motives for attendance: the wish to monitor/improve disease control and a concern not to jeopardise what was seen as an important relationship with their doctor. Although patients felt a strong personal responsibility to attend arranged appointments, they were often frustrated and disillusioned with the structure and delivery of hospital outpatient asthma care, citing this as a key factor that discouraged their attendance.

Attendance

Participants found that asthma assessments offered the opportunity to better understand and control their asthma;

Table 1 Characteristics of patients

| Characteristic | |
|---------------------------|-------|
| Sex (M:F) | 9:10 |
| Age range (years) | 26–84 |
| Attendance | |
| Non-attenders | 7 |
| Attenders | 12 |
| Employment status | |
| Employed | 11 |
| Unemployed/retired | 8 |
| Ethnicity (self-declared) | |
| Afro-Caribbean | 1 |
| Ghanaian | 1 |
| Indian | 1 |
| Irish | 1 |
| Pakistani | 1 |
| Somalian | 1 |
| South African | 1 |
| White British | 12 |

discuss important recent personal developments; have relevant tests performed (for example, lung function tests); obtain prescribed treatment; and obtain reassurance. An additional important motivation for attending the follow up appointment was the desire to keep up to date with recent therapeutic advances.

"It is very important to come to the clinic. It helps me to understand my asthma better. And, I am very into the new drugs and, different things and, I hope that the clinic will keep me up to date". (P11, male, non-attender)

An open non-patronising relationship with clinicians encouraged patients to attend:

"... If you get on well with a doctor, and you understand him, then you are going to help yourself with your asthma. But if you do not like your doctor you don't want to come ... if you do not feel comfortable with him." (P3, female, non-attender).

P: You know, in a lot of cases you go [to see a doctor], and you are feeling really grotty, and they make you feel like, you've got no brains, basically. You go out, and you're just like, you know, you ain't feeling very positive about it, actually going to see the doctors ...

JB: So a good relationship and attitude will improve your willingness to go?

P: Yes, yes! (P16, female, attender)

It was suggested that doctors could encourage attendance by showing genuine interest, explicitly inviting patients to return and by highlighting to them the possible benefits of attendance. For example, five patients who had previously experienced a life threatening asthma exacerbation explained that they would never again fail to attend because they now understood the need to maintain optimal control. Arguing on moral grounds, some attenders were, however, of the opinion that non-attendance was unfair towards other patients:

"Because they have given up their time for me and somebody else could have had that appointment and have been helped in that time". (P15, male, attender)

Non-attendance

We identified three main explanations for missing appointments: memory lapses, patients' health status (feeling "so well" or "too ill") to attend, and disillusionment with hospital outpatient care.

Memory lapses were related to patients forgetting the appointment and/or mistaking the appointment time, and it was suggested that a reminder letter sent to patients shortly before the scheduled appointment could help to overcome this problem. Some patients appeared not to fully understand how structured asthma care is organised and deliberately chose to miss their appointment because they felt "so well" at the time of the scheduled appointment (had no asthma complaints); conversely, others did not attend because they were "too ill" (not being able to leave the house on their own).

"... I think a couple of times I missed an appointment and I was not able to ring and cancel because I was too ill." (P17, female, non-attender)

Disillusionment with hospital outpatient care was another important theme contributing to patients deciding not to attend. Many attenders and non-attenders expressed concern that waiting times in the clinic were too long and that clinics were poorly organised:

"... the waiting time is tremendous, it is too much. When you go and see the doctor, usually it is a whole day's job, basically ... and that is, that is every visit, every visit is like that. For all my appointments, I don't remember in any of the appointments that I have seen the doctor at the allocated time. No, every ... has been an hour, two hours late. It is ... there are ... some issues, which are medical, and issues that are purely management issues, some issues that are customer satisfaction issues." (P7, male, non-attender)

Dissatisfaction was exacerbated by concerns about the poor design of waiting areas, which were believed to compromise confidentiality and increase the risk of contracting infections from other patients. This sense of disrespect was compounded by the general disregard for patients as evidenced, for example, by the availability of out of date literature and weighing the patient in front of others:

"How do you feel about this clinic? Uh, it is ok, but it is a bit open. You know, where they take your weight and things like that. It is a bit embarrassing to do. Yes, in front of all the other ... People to ... yeah ... taking your shoes off and stand ... I mean, I am underweight, but other people are overweight." (P3, female, non-attender)

Patients disliked seeing different doctors and registrars on different visits, describing how this made it difficult to develop any meaningful relationship with their clinician:

P: I never see the same doctor twice ... it's silly you know. (P9, female, attender)

HJ: Well, in the beginning you told me that you do not see one doctor every time?

P: You see different doctors every time, yeah ... Every time a new doctor ... you never see the same doctor twice ... I don't like that ... every doctor has got different way of working ... you really feel quite odd, uhm, quite unable to talk to some of them.

HJ: Can you discuss all the things you worry about then if you see so many different doctors?

P: No, you can't ... you think, what is the point? It is awful. (P13, female, non-attender)

Concerns were expressed that doctors who are constantly changing feel less responsible towards individual patients and, furthermore, often do not have an opportunity to get to the bottom of things:

"... if you are visiting a new doctor, they don't have the responsibility of the patient as their, their own responsibility to manage that patient ... It is very similar to my banking profession. ... If you go and see a new bank manager every time, you have to tell him that you have an overdraft and details so on. So in that ... way you can't discuss your financial details ... The same situation is here with the doctors. You can't discuss your physical situation ... You don't come to the fine details basically, you know, cannot go from, one point to the other. And what happens is that you start and give him the full details and now the conversation cannot go into the next gear, the next level of detail. But if a doctor, you have seen him previously, he knows what your background is, you don't need to explain. He is automatically going into the next gear and see what is the current situation." (P7, male, non-attender)

Not all patients, however, saw a problem in changing doctors:

"I do not mind changing doctors at all. You know, if they do know what they have to do ..." (P11, male, non-attender)

The inability to schedule appointments at a convenient time was also seen as a barrier to attendance.

Making use of information communication technology in asthma care

Although all participants in our study had easy access to the telephone, most did not welcome the suggestion that telephone consultations could substitute for some face to face encounters. We observed in early interviews that patients had a very restrictive understanding as to what a telephone consultation might entail, and consequently received predominantly negative reactions when exploring the subject of telephone based care. In subsequent interviews we therefore provided more contextual information, emphasising that it would still be possible to arrange a face to face consultation for patients preferring or needing clinic based care. Having received such assurances, patients could see possible advantages of this mode of delivering care but, even

then, they still expressed a clear preference for face to face encounters.

The difficulties of effectively communicating by telephone were believed to be an important barrier to telephone based care, this being a particular concern in those with limited use of English. Patients saw face to face contact with a physician as easier and more suitable for discussing private issues. The role of non-verbal cues in facilitating communication was also highlighted:

"Something from the, you know, the body language, he can understand something from you to get the real thing. Like me, if you try to tell me something over the phone, maybe I couldn't understand. If I sit there, the doctor trying to talk to me, when he opens his mouth, I know the movement he is doing, then I can understand." (P2, female, non-attender)

Other voiced concerns centred on clinicians' inability to conduct a physical examination and/or investigations when consulting by telephone, these being indicative of broader anxieties about the possible incompleteness of telephone assessments.

Only a few patients favoured the possibility of substituting some face to face consultations with telephone reviews. Those who did saw possible benefits for better asthma management, citing increased convenience and efficiency because of minimising travel and waiting times:

"Anything that could stop wasting time, not just for the patient but for the people who structure the way things are working, yes, it would be very valuable." (P17, female, non-attender)

These participants were of the opinion that face to face consultations would still periodically be necessary with the option of readily switching from a telephone to face to face review if circumstances demanded this.

More than half of the participants had access to email and those who did welcomed the possibility of an email reminder about their next clinic appointment. However, patients held widely differing views about the role of email in relation to a possibly broader role for email consultations in delivering asthma care. Those who were positively inclined described relatively focused tasks including facilitating the asking of straightforward questions, the opportunity to send in and receive feedback on completed peak flow charts, and obtaining information on new therapeutic advances. However, most were sceptical about the role of email consulting in anything more than such circumscribed tasks.

During the discussions around the possibilities that information technologies might offer, three patients spontaneously raised the subject of text messaging, stating that it would be useful to receive a text message reminder about forthcoming appointments.

DISCUSSION

Evidence indicates that regular monitoring, coupled with self-management plans, not only improves asthma control and knowledge about treatment but can also provide reassurance. Our findings show that, on the whole, patients in this study valued the opportunity for follow up assessments, but that there are a number of factors which mitigate against attendance. For most, the role of telephone and email consultations in delivering asthma care is limited to ways of facilitating the face to face clinical encounter.

There is a large body of literature on access to health care that identifies numerous relevant factors. The complexity of the issue is reflected in the ongoing and widespread nature of the problem, in spite of the high attention that it receives. Our study focused on the patient perspective on the problem.

Previous studies have found that non-attendance relates to forgetfulness, family and work commitments, underestimation of disease severity, not feeling well enough to attend, and resolution of symptoms.^{3-9 12 20 21} In addition to these

factors, our findings suggest that disillusionment with the structure of outpatient care is a key explanatory factor. Participants also cited maintaining the patient-doctor relationship as an important motive for attendance, and this is in keeping with the findings of Ratcliffe *et al*²² that patients with asthma greatly value relational continuity of care (an ongoing therapeutic relationship between a patient and one or more providers²³).

We identified a number of factors that patients believe to have a negative impact on their decision to attend. Most important of these are long waiting times and discontinuity of care, these issues being construed as standing in the way of any ongoing therapeutic relationship. But these patient identified deficiencies are open to improvement, admittedly with some difficulty, after suitable adjustments in organisational procedures. These may include consultant based clinics or transfer of the patients from a junior doctor's list to the consultant's list after the junior doctor changes.

A key obstacle in the organisation of the clinic was the appointment system. Our participants suggested that the opportunity to choose between different consultation days and times might facilitate attendance—a central point of the UK government's choice agenda.⁸

Only a limited role was envisaged for telephone and email consultations. These participants expressed deeply felt concerns about clinicians' inability to perform a comprehensive examination and the lack of opportunity for face to face reassurance. This contrasts with findings from other studies and may reflect the fact that our sample comprised patients with moderate/severe disease who had relatively little experience of using telephone and email for consulting.^{13 14 16}

Limitations of study

There is an intrinsic difficulty in following up non-attenders, and this is reflected in the fact that we were only able to recruit 19 of the 50 patients in our original sampling frame. Our sample of participants may be seen as relatively small, but a number of valuable new themes were identified.²⁴ We were nevertheless surprised that certain other themes did not arise in the interviews including non-arrival or late arrival of appointment letter, or miscommunication with hospital appointments clerk that result in logging of cancelled appointments as non-attendance.

Other limitations of the present work include the fact that, although drawn from both primary and secondary care in different countries, all members of the team were from a clinical background which may have limited the insights gained. Further work may benefit from inclusion of

Key messages

- People's decision to attend for hospital asthma reviews often involves weighing the perceived benefits of attendance against the necessary investment of effort and time.
- Disillusionment with the structure of hospital outpatient care is an important factor influencing patients' decision not to attend for asthma reviews.
- There appears to be only a limited role for information technology in improving access to asthma care in this inner city multi-ethnic population.
- Most would, however, value receiving an email or text message reminder to attend their forthcoming clinic appointments and this may help to reduce non-attendance resulting from forgetfulness.

sociological and psychological perspectives. Related to this is the fact that the current study is primarily descriptive. We suggest that follow up studies should have a clearer and more explicit theoretical underpinning in relation to health beliefs, illness cognition, and consultation behaviour.²⁵

Given that this study was undertaken in one large inner city teaching hospital, relational continuity of care may be expected to be less than is achievable in a district general hospital.²³ The London population is highly mobile, both in terms of moving address and—for some ethnic groups such as South Asian and Caribbean—spending prolonged periods in their countries of origin, often regarded as second homes. From the authors' personal experience, this may also add to non-attendance. Further work in hospitals in geographically more discrete areas and with less ethnically diverse populations might yield different results.

Previous work has found that patients welcome the introduction of telephone reviews as a convenient alternative to regular follow ups, these having the potential to greatly reduce travel and waiting times.^{5 13 14} Wasson *et al*²⁶ have shown that people who have never experienced such a consultation will be more sceptical than those who have. Further qualitative work in a cohort of patients with more experience of telephone facilitated asthma outpatient care may therefore provide additional insights.

In conclusion, poor outpatient clinic organisation resulting in long waiting times and seeing different doctors at each visit is considered by patients to be a deterrent to attending for hospital asthma assessments. Such structural issues are construed by patients, in personal terms, as being disrespectful of a relationship that they believe to be important. Although potentially convenient, the idea of telephone review assessments was viewed with scepticism by most of our sample. Therefore, when these are being considered as a substitute for scheduled face to face encounters, particular attention needs to be given to explaining to the patients the logistics and potential benefits of such consultations. They need opportunities to experience this form of consulting before they can decide whether they wish to replace some of their face to face consultations with those undertaken by telephone. There is, however, a clear and potentially important role for email and text messaging in issuing reminders about imminent appointments.

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