

A qualitative study of action plans for asthma

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Abstract

Objectives To investigate the perspectives of patients with asthma on the use of an action plan and the implementation of this plan during an asthma attack that culminated in a visit to an emergency department.

Design Qualitative study.

Setting Tertiary teaching hospital, suburban hospital, and rural hospital.

Participants 62 patients aged 18 to 69 years who presented to an emergency department with asthma over a two month period.

Results 29 participants described having action plans given to them by their doctors. Most patients with action plans reinterpreted their plan from the perspective of their own experiences with asthma. 33 patients did not have an action plan, the most common reason being that they had not been given one by their doctor. Some occupational groups were significantly less likely to have been given an action plan by their doctor than others. Most patients with an action plan found them useful for management of their asthma.

Conclusions Action plans were viewed positively by patients. Participants modified their prescribed plan according to their experience of asthma. To facilitate the implementation of a prescribed action plan, doctors need to acknowledge and include the patient's personal experience of their disease.

Introduction

Action plans for asthma are a critical component of guidelines for asthma management promulgated in many nations.^{1,2} The plans comprise part of the recommendations for optimum care devised by the Global Initiative in Asthma.³ Meta-analysis of randomised, controlled trials shows that action plans have been associated with improved asthma outcomes when delivered in written form.⁴ Recent evidence from a case-control study of people who had died from asthma showed that the presence of an action plan was a major protective factor against death from asthma.⁵

The use of action plans in Australia is declining despite strong advocacy for their use and evidence of clinical benefit.⁶ Data from the United Kingdom show that they are unpopular with both patients and clinicians.⁷ Current strategies to improve patient care

rely on building partnerships between clinicians and patients to maximise adherence to a treatment plan.⁸ Given that action plans have been derived predominantly from a medical rather than from a patient perspective, we investigated patients' perspectives on the plans.⁹

Methods

Our study was designed to recruit patients with asthma not controlled by current treatment. To represent the range of asthma severity and geographical locations we recruited from a central city teaching hospital, a suburban hospital, and a rural hospital. All patients aged 18 to 70 who attended an emergency department for asthma over a defined two month period were sent a letter about the study. Patients who had not registered their unwillingness to participate were contacted by telephone, and an appointment was arranged for an interview. We made up to 10 attempts to contact each patient at different times of the day before we declared them uncontactable. Our study was approved by the ethics committee of each participating hospital, and we obtained written informed consent from each patient.

Interview

At the interview we collected information on personal details, respiratory health using a questionnaire adapted from the European Community Respiratory Health Survey, and knowledge of asthma with a questionnaire used to evaluate a self management programme for adults with asthma.^{10,11} We conducted a semistructured in-depth interview exploring the patient's asthma and the decision to present to an emergency department. Patients were asked whether they had an action plan prescribed by their doctor, and we explored the use of their plan. Transcripts of the interview were sent to the patients for confirmation of accuracy.

Personal details

Asthma severity as measured by the peak flow as a percentage of that predicted immediately on presentation to the emergency department was derived from the patient's medical record.² Occupation was classified according to the Australian Bureau of Statistics.¹² Occupations were assigned to the general categories of professional or managerial, blue collar worker, home duties (housewife), unemployed or retired, and clerical, service, or sales.

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Study recruitment of eligible patients with asthma within a defined two month period

Status	Men	Women	Total
Participant*	19	43	62
Non-participant†	6	7	13
Non-contactable	27	38	65
Refused	15	28	43
Died	1	0	1
Not asthma‡	3	8	11
Total	71	124	195

*Completed interview and questionnaire phases of study.

†Gave initial consent for interview but unable to agree on time.

‡Discharge diagnosis from emergency department not asthma and consequently patients excluded from study

Data analysis

We recorded and transcribed the interviews, and we examined the transcripts for emergent themes. We managed our database with the N4 and NVivo computer packages (Qualitative Solutions and Research International, Melbourne, 2000). We entered personal details and questionnaire data into the SPSS software package and N4 and NVivo to enable data triangulation between the qualitative and quantitative datasets.

The transcripts were initially read by the authors, and emergent themes were discussed. DG coded the transcripts. DG, RA, and JD independently examined the coded data for emergent themes and compared interpretations. This process allowed for the incorporation of deviant cases into the emerging thematic constructs. To enhance their face validity the final analytical concepts were presented to a consumer reference group including patients with asthma, nurses responsible for educating patients with asthma, and members of an asthma advocacy group.

Results

Patient group

We identified 184 eligible patients. Sixty two participants completed the interviews, 23 (37%) from a city hospital, 29 (47%) from a suburban hospital, and 10 (16%) from a rural hospital. The table lists all potential participants.

The participants consisted of 19 men and 43 women, mean age 39 years (range 18 to 69 years). Participants were predominantly of Australian, English, or Irish descent (44; 71%). Forty one (66%) participants had been admitted to hospital with asthma in the preceding year. Nearly all participants (61; 98%) had seen a doctor for asthma, 40 (64%) within the past month. Only 4 (6%) had not seen a doctor for asthma in the previous year. Asthma severity was assessed for all 62 participants: 30 had severe asthma, 20 moderate asthma, and 12 mild asthma. The patients' knowledge about asthma was satisfactory, with a mean (SD) score of 20.7 (4.6) out of a maximum possible score of 31.

Patients with action plans

Twenty nine participants had an action plan given to them by their doctor. Figure 1 outlines their use of such plans. Analysis showed several themes (box 1).

Action plans used but modified

The use of an action plan was underpinned by personal experiences and perceptions of asthma.

Participants who used their plan were likely to modify it on this basis.

"The red sticker, that's my danger sticker, and if its below that ... I have to go to hospital. But ... I find that that's just too low ... Like sometimes I can have asthma and not have the output, and sometimes I've got asthma and do have the output." (woman, 20s, home duties)

"Even though the [peak flow] got to 90 I said we'll wait. But ... I know that [if] the night falls I'm not going to cope if I'm 90." (man, 40s, manager and professional)

Not confident in using action plan

Some patients, although possessing a plan, did not express confidence in its use. In this group the action plan was provided after the index presentation, and the diagnosis of asthma was recent, although scores for knowledge of asthma did not differ from the other patients with action plans.

"No I haven't thought to use it [a peak flow meter] because it's probably a little bit of a problem with the perception. I still don't perceive myself as asthmatic." (woman, 50s, retired)

Action plan not used

Several patients had an action plan that they did not use owing to non-recognition of asthma symptoms. Lack of body awareness influenced confidence in interpreting the onset of an attack and hence in determining when to put the action plan into use.

"I had the flu a couple of days ago and I was getting 300 with my peak flow, and they said go to hospital if you're 350, and I didn't think it was necessary. I think it was just a lot of mucus coming up. So it wasn't relevant to me." (man, 18, student (clerical, sales, or service))

Patients without action plans

Thirty three patients did not have an action plan from their doctor (fig 2 and box 2).

Plan of action

Many of these patients had a "plan of action" for their asthma. Many of these plans were medically credible.

"I presume that if I have to take suddenly more than the regulation. I generally take two alright, but if I was to take a third sort of thing, I've got to get going, get the ambulance before I take 4 or 5 and its not working." (man, 60s, retired)

Other patients derived a plan independently from medical advice through personal understanding of body awareness or alternative remedies. One of these

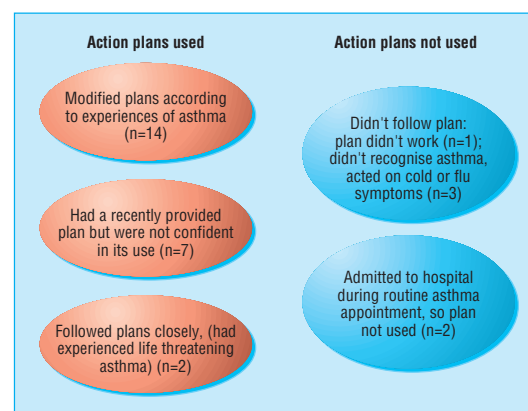


Fig 1 Patients with action plan for asthma

patients objected to a plan prescribed by his doctor and had formulated his own:

"I know when I've got my low point, I've got my medium point and I've got my major point ... It's something I know personally myself." (man, 50s, blue collar worker)

No plan of action

Several other patients thought that an action plan was not suitable for them because of lack of clarity about a diagnosis of asthma, such as an alternative diagnosis of emphysema.

"Well there's not a real lot of point. I've got ... a peak flow meter. But my peak flows are really pathetic anyway because of my emphysema. So you don't get a lot of difference, so there's not a lot of point." (woman, 40s, home duties)

Doctors not providing action plans

The most common reason for not having an action plan, offered by 15 patients, was that the doctor had not given them one. Correlation of occupational groups with provision of an action plan showed that plans were much more common among those engaged in home duties and clerical workers than other occupational groups.

Overall attitudes to action plans

Most patients with knowledge of action plans viewed them favourably. Most of the patients with an action plan prescribed by a doctor used it in the management of their asthma, and others had devised a plan of action. Other patients who did not have an action plan thought it would be useful if they did.

"But to tell me about an action plan would be good. To talk about alternatives, how it's going. Explain it to me." (woman, 19, clerical, sales, or service)

Discussion

The views of patients with asthma have not been widely heard in the development of guidelines for the management of asthma. We found that action plans for asthma were considered useful or desirable by many patients with the disease, and that even when patients denied the existence of an action plan, they often constructed their own plan of action. Patients who were confident in the use of their action plan reinterpreted even categorical statements such as peak flow readings

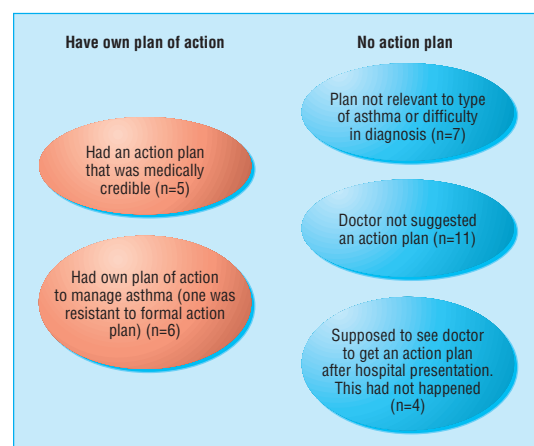


Fig 2 Patients without action plan for asthma

Box 1: Excerpts from interviews with patients with action plans

Modified plan according to asthma experiences

Interviewer: What about an asthma action plan? Have you ever had an asthma action plan? You said that you've been measuring the peak flow.
137: Yes, he's written one out for me ... but I sort of felt that what he put down was probably a bit drastic you know. Like I wouldn't have felt that if I blew 200 or 210 that I immediately get in the car and race to the hospital.

Interviewer: How low do you think it should be?

137: Well I don't know ... by the way I feel. If I was blowing 210 and I'm sitting here now and I'm breathing quite alright and I feel alright, I wouldn't as I said rush off to the hospital. If I was sort of going, you know, and having trouble breathing, well then I would. (woman, 50s, clerical, sales, or service)

Not confident managing asthma or use of plan

Interviewer: Even though you were given that sort of plan of action ... you felt a bit silly going into emergency.

48: Well that's right because the time that I was given that information it was when I was just unable to breathe I didn't even have a cough or anything. I didn't even realise that cough was associated with ... I didn't even think of it as being asthma. (man, 40s, blue collar worker)

Followed plan precisely

141: I do have a flow meter record ... the peak flow record is the best thing I've ever done I think. Because sometimes I look at it and oh I'm on a slide. I didn't realise it ... I've got to arrest it some way, and I'll increase my dosage, what have you. Sometimes you find you're on a slide that you can't improve. So I've been to the doctors and said quick ... I don't want to go into hospital, how can I stop it? (man, 60s, blue collar worker)

Plan useful

159: You've got to look at it on a day to day basis ... Using your peak flow meter obviously is one way to gauge. It's another tool that you've got to gauge your asthma and the extent it's at. (man, 20s, manager or professional)

9: It's kind of hard because I have asthma but I also have muscle spasms in my chest, which feels the same as asthma. Same tightness of chest and same pain in the chest. The only way I can tell the difference between the two is the peak flow. If my peak flow's normal I know it's a muscle spasm ... If it's asthma the peak flow drops. (man, 30s, blue collar worker)

Plan not used as it doesn't work

172: Now she told me what you were meant to do if you have a full on attack, which I didn't have any idea of what we were meant to be doing. But anyway, that was that. The plan was I was meant to be getting, using the preventer morning and night and not using the Ventolin during the day. I was meant to be getting to that stage. But we didn't ever get there but it didn't ever do enough. (woman, 40s, clerical, sales, or service)

Plan not used as didn't recognise asthma symptoms

Interviewer: And you were saying that this last time you were only blowing about 100 ... but you didn't ring the ambulance?

182: Oh, it sounds really weird, but it sneaks up on you. It does me. But it got worse. And I think oh no, I'm breathing alright ... I had pleurisy once and I thought I was getting something like that again. That sort of got a bit tight. But you get used to breathing shallower ... I was just, I don't know, doing less and less but not realising in a sense ... I was really tired ... You think you're going to get something, but I was waiting to get it. (woman, 50s, home duties)

from the perspective of their own experience of their illness. Moreover, interpretation of a plan from the perspective of experience of personal disease was vital to its implementation.

Our large qualitative study had a representative recruitment strategy. The patients were predominantly women. This reflects the imbalance between the sexes of presentation to emergency departments, where it has been shown that women predominate in a ratio of nearly 2:1.¹³ Our thematic analysis was conducted after the transcription of interviews, with contemporaneous analysis conducted by several researchers to enhance the validity of emergent themes. Criticisms of our study design are common to qualitative research and relate to the difficulties of generalising results from a specific

Box 2: Excerpts from interviews with patients without action plans

Had their own plan of action

190: Well I first go on the pump and if that doesn't work we ring the hospital, get information ... and if they say, well I go back on the pump. If that doesn't work we call an ambulance. (woman, 30s, home duties)

Medically credible plan

102: I feel like I can better judge it for myself anyway now. I wouldn't have said that prior to having gone to hospital for the first time. But you know I think that now I can judge it more quickly. I know what the patterns are. I've also sort of, I think there's been an opportunity for a pattern to develop on this prophylactic medicine having always taken that since March. So that if something, you know if I started getting attacks now and I had been taking that consistently, then I would be going back to the doctor fairly quickly and saying well, well actually that's not quite true. I'd probably say that I know I've cut down the medication down from what he originally put me on. So I would probably go back to what he initially put me on first. (man, 30s, manager or professional)

Action plan not useful—resistant?

123: Yes. I mean I have got the, what's the little tubey thing called that you measure?

Interviewer: The peak flow.

123: I've got that.

Interviewer: And do you use it?

123: I have yes. I've been, often if I'm feeling really quite ordinary with asthma. I don't use it because I worry. So I ignore it then and I just go off to the doctors and they then start to get panicky. I'd like to have written down what the optimum is when you use the peak flow meter. You know those sorts of things. Written nowhere. ... And that's annoying. So those are the sorts of things I'd like to know. So now I just sort of make a reasonable estimate (woman, 40s, clerical, sales, or service)

Doctor hasn't suggested a plan

138: Yes, I don't really know. I mean I sometimes think what would be my plan of attack and I think I've usually rang the doctor first.

Interviewer: And has he talked to you about what they might refer to as an asthma action plan or a plan of action what you might do?

138: No he hasn't actually ... You know I mean I've had discussions and I said I've been coming here long enough, you know me well enough, you tell me what's what and you know. And he's very good as a rule, but no we haven't discussed an action plan. (woman, 60s, retired)

Interviewer: Has your doctor talked to you about an asthma action plan?

173: No. The trouble is up in the valley you've got a constant flow of doctors that come and then they're gone again. You've got incoming new doctors all the time and up here you tend to, I don't know. You get a lot of good doctors that come from overseas and then they're up here for a while and then they're gone to Melbourne. You've got these, the flocks of doctors is never good up here. It's very hard to get ... There's no kind of like a family type atmosphere with doctors up here because they don't stay long enough. (woman 40s, unemployed)

population. We believe that our recruitment strategy addressed this issue and that the close similarities between Australian, British, and international guidelines for the management of asthma place our study in a broad context.

Several studies have explored by telephone survey the presence of action plans for asthma.^{6–14} Our results show that such studies would probably underestimate the number of patients with a medically credible plan of action for management of their asthma. In addition, such surveys provide little information on the use of these plans by their owners. Our study shows that not all patients with an action plan used it, and that scores for knowledge of asthma did not differ between those who had an action plan and those who were not confident to use it. This observation provides an explanation for previous findings that asthma education alone in the absence of an action plan and regular

medical review is insufficient to improve patient outcomes.¹⁵

The only previous qualitative study examining the use of action plans interviewed patients, general practitioners and practice nurses.⁷ In that study, neither clinicians nor patients were reported to consider action plans useful in most instances. A study by Jones et al utilised focus groups, a technique that is directed at analysis of group discussion and is well accepted for the conduct of qualitative studies.¹⁶ However, focus groups do not enable examination of sequenced accounts of a patient's experiences and perceptions. Our findings, based on the analysis of individual in-depth interviews, explored the details of the provision of action plans and the way in which they were understood and used by patients. Such data would not be obtainable from a focus group interview. The major differences between our results and those of Jones et al probably reflect these methodological differences.¹⁷ In addition, it is likely, given the clinicians' views of action plans reported by Jones et al, that the patients interviewed had not been provided with action plans and may have been reflecting their doctors' views on their utility.¹⁸ Overall, we agree with the conclusions of Jones et al, that for action plans to be utilised they must be negotiated with patients in partnership with clinicians. Our study indicates further how this may be approached.

In our study the most common reason for not having an action plan was simply that the patient had not been given one by his or her doctor. Some of these patients thought an action plan would be useful if they had one. That some occupational groups were less likely to have an action plan shows that doctors perceive barriers to the implementation of such a plan. Such perceptions may partly be determined by the social interaction occurring during the consultation. Better understanding of the influences on the prescription of action plans by doctors is clearly integral to increasing the ownership of plans by patients.

Intuitively, clinicians might expect action plans to be modified or adapted by patients, but our study is the

What is already known on this topic

Action plans for the self management of asthma are standard and have been shown to improve patient outcomes and to protect against death from asthma when provided in written form

Factors that enable patients with asthma to implement an action plan and their perspectives on the use of such plans have not been explored in an individual context

What this study adds

Most patients with action plans found them useful

Most patients modified their plans according to their perceptions of severity and likely disease outcome

Clinicians must engage with a patient's experience of asthma to facilitate the use of an action plan

first to show this. Prescribed action plans were interpreted and implemented by patients from the perspective of their experience of asthma. The importance of a partnership between doctor and patient has been emphasised in the construction of management plans for chronic illness.¹⁹ Paradoxically, provision of an action plan prescribed by a doctor is not, in itself, an act of partnership. We show that an iterative process encompassing experience of disease would enhance the use of an action plan. Indeed the modification of an action plan was integral to its ownership and use. Doctors should expect patients to modify their action plans and should inquire in ongoing consultations how this has been done.

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