Patients' views of the burden of asthma: a qualitative study

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ABSTRACT

Objectives: To explore the burden of asthma on the lives of people presenting to hospital emergency departments for asthma treatment.

Design: A qualitative study. Consenting individuals with asthma who presented to emergency departments were interviewed in-depth, and interviews were taped, transcribed and thematically analysed. Questionnaire data on medication use, respiratory health and asthma knowledge were also collected. Asthma severity was determined from the medical records.

Setting: A tertiary teaching hospital and a suburban hospital during March and April 2000, and a rural hospital during July and August 2000.

Participants: Sixty-two participants (19 male and 43 female), aged 18–70 years.

Results: The burden of asthma was broad, affecting social life, personal relationships, employment and finances. The cost of asthma medication was an issue for nearly two-thirds of participants. Individuals performed their own "cost–benefit analysis" for medication use, weighing up expense, perceived side effects and potential benefits. As a consequence, several participants chose to alter their medication dose, or not to take prescribed medications. For some participants, asthma directly contributed to diminished employment opportunities.

Conclusions: To achieve a therapeutic partnership, doctors need to be aware of the substantial social, personal and financial burden of asthma for their patients. They should also recognise that patients' perceptions of treatment cost may compromise treatment adherence.

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AUSTRALIA HAS ONE OF the highest national indices of asthma severity, and, paradoxically, one of the poorest rates of adherence with optimal medication regimens.[1] The establishment of asthma as the sixth National Health Priority Area in Australia recognises this sizeable disease burden.[2]

Optimal care for many chronic diseases is provided by clinicians in an environment of "therapeutic partnership".[3] Thus, an exploration of the breadth and nature of the burden of disease in patients' lives is of practical help to clinicians in understanding likely impediments to care. Such knowledge may be gained by qualitative research techniques.[4]

Our study, which was predominantly qualitative, aimed to understand the experiences of people with asthma and their families, and to explore how these experiences might influence asthma care in an Australian context.

METHODS

Recruitment of participants

We aimed to study people with asthma not controlled by their current therapy, and our sample was selected to represent a range of asthma severity and geographic locations. All patients aged 18–70 years who attended a public hospital emergency department for asthma (at a tertiary teaching hospital or a suburban hospital during March and April 2000, and a rural hospital in July and August 2000) were sent a letter about the study. They were then contacted by telephone to arrange an interview. Some were declared "uncontactable" after 10 attempts to call them at different times of the day were unsuccessful.

Ethical approval and consent

Our study was approved by the ethics committee of each hospital and written informed consent was obtained from each participant.

Interview

We collected demographic data, and participants completed a respiratory health questionnaire (adapted from the European Community Respiratory Health Survey)[5] and a validated asthma knowledge questionnaire.[6] We then conducted a semi-structured in-depth interview, exploring participants' history of asthma, previous health system experiences, medications, costs of treatment and the impact of asthma on their lives. Interview transcripts were returned to participants for confirmation of accuracy.

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1: Recruitment of eligible patients

Status	No. (%)
Participant	62 (32%)
Gave consent but not interviewed	13 (7%)
Not contactable	65 (33%)
Refused	43 (22%)
Died	1 (0.5%)
Discharge diagnosis not asthma	11 (6%)
Total	195

2: Participants' demographic characteristics (*n*=62)

Age (years)	
18–29	18 (29%)
30–39	11 (18%)
40–49	18 (29%)
50–59	9 (14%)
60–69	6 (10%)
Sex	
Female	43 (69%)
Male	19 (31%)
Ethnicity	
Anglo-Celtic	46 (74%)
Occupation	
Manager/professional	14 (23%)
Clerical/sales/service	24 (39%)
Blue collar	5 (8%)
Retired/unemployed	10 (16%)
Home duties	9 (14%)
Weekly income ($)*	
0–250	16 (26%)
251–499	15 (24%)
500–749	11 (18%)
750–999	2 (3%)
⩾1000	2 (3%)
Health Care Card	
Yes	25 (40%)
No	36 (58%)
Missing data	1 (2%)
Cost an issue†	
Health Care Card	15/25 (60%)
No Health Care Card	23/36 (64%)

*16 participants answered this question as "not applicable" or chose not to answer it.
†Data missing for one participant.

Asthma severity

We examined participants' medical records and used *Australian Asthma Management Guidelines* in determining chronic asthma severity, which is predominantly based on medication use prior to emergency presentation.[7]

Demographic data

Participants' occupation groups were assigned according to the general categories of the *Australian Standard Classification of Occupations* (professional/managerial, clerical/sales/service, blue collar, home duties, and retired/unemployed).[8]

Data analysis

Data analysis was performed as previously described.[9] We recorded and transcribed the interviews, and examined them for emergent themes. The computer packages N4 and NVivo[10] were used for data management, and we analysed demographic information and questionnaire data using the SPSS software package.[11]

Transcripts were initially read by all of us, and the broad emergent themes were discussed. One of us (D P G) performed the initial coding of the transcripts, but three of us (D P G, R A A and J A D) independently examined the coding and coded data for emergent themes, and then met to compare interpretations. We resolved disagreements by listening to the audiotape, and, after discussion, reached consensus. This process allowed for the incorporation of deviant cases into the emerging thematic constructs.

Two of us (D P G and M J A) performed the quantitative analysis. The analytical concepts were then presented to a reference group to confirm their face validity. The group included health professionals, asthma nurse educators and members of an asthma advocacy group.

RESULTS

Participants

Of the 184 eligible patients, 62 completed the interviews (Box 1): 23 (37%) from a tertiary teaching hospital, 29 (47%) from a suburban hospital and 10 (16%) from a rural hospital. The demographic characteristics of the participants are summarised in Box 2.

Participants' asthma history is given in Box 3. Nearly two-thirds of participants (40; 64%) had seen a doctor for asthma within 4 weeks of their presentation to the emergency department.

Qualitative findings

Cost of therapy

Thirty-nine participants (63%) stated that the cost of asthma treatment, including medication and health services, was of concern to them. This was irrespective of whether or not they had a Health Care Card. The prescribed asthma treatments for participants varied widely, and this had clear implications for their medication costs.

Effects of medication costs on therapy

The capacity to afford medication often determined treatment choices. In particular, 28 participants (70%) had comorbidities and required multiple medications. They had developed ways of managing costs, such as not buying medication ("It was an extra $30") or lowering doses to prolong medication use (Box 4). It was apparent that, for four men, decisions to reduce the use of preventive medication based on cost

3: Participants' asthma history

Severity of asthma	
Severe	32 (52%)
Moderate	14 (23%)
Mild	16 (26%)
Duration of asthma	
>10 years	52 (84%)
Admissions to hospital in past 12 months for asthma	
0	18 (29%)
1–2 times	36 (58%)
3–5 times	4 (6.5%)
>5 times	4 (6.5%)
Prescribed asthma medication	
Reliever	55 (89%)
Inhaled steroid	54 (87%)
Symptom controller	37 (60%)
Other asthma medications	26 (42%)
Oral corticosteroid	18 (29%)

were likely to have caused their hospital presentation.

Side effects of medication

Side effects of asthma medication were a concern for 45 participants (73%), and their perception of the risk of side effects influenced self-management decisions. Participants, particularly those who perceived their asthma to be mild or episodic, made their own judgement as to whether the side effects of medication were a greater risk than another asthma attack. This comment by a man in his 60s classified as a manager/professional with mild asthma is representative.

> I would take the medication if I knew what was in it, and I understood it, and I knew that it wasn't going to shorten my life by any more than say 10% or 20%, or something like that.

Side effects causing concern included tremor, mouth or throat soreness, hoarseness, change in skin or body appearance, osteoporosis (now or in the future), or other side effects less clearly related to the recognised pharmacological effects of steroids (Box 4).

Medical costs — decision to see a doctor

The decision to visit a doctor was influenced by costs, the necessity to take time off work, travel and waiting times, and the anticipated benefit. The cost of seeing a doctor was raised as an issue by 11 participants (18%), and several stated that they could not consult a doctor or specialist if they were not "bulk billed" (Box 5).

Personal costs — employment and financial

Fourteen participants (23%) stated that their employment had been affected by their asthma. Participants described losing their jobs, changing their jobs, or losing income as a consequence of asthma. In some, a cycle was identified of illness due to asthma, diminished work opportunities, and subsequent loss of income (Box 6).

Occupation and working days lost

Questionnaire responses indicated that most participants had lost days from work and other normal activities in the past 12 months because of asthma. Only 17 participants (27%) reported no days lost, while 11 (19%) reported more than a month lost because of asthma. Not surprisingly, time off work was related to asthma severity, with 63% of participants with severe asthma (19/30; data missing for two participants) losing more than a week from work or usual activities in the past year because of asthma, compared with none of the 15 participants with mild asthma. This difference was statistically significant (Fisher's exact test, $P = 0.001$).

Interviews indicated that participants managed their asthma and work in sev-

4: Excerpts from interview — financial and physical costs of therapy

Effects of medication costs on therapy

She said: 'Why do you think you didn't come good taking the medicine?'. I said: 'Oh, the puffer ran out and eventually I ran out of…[oral steroids] to swallow.'…And she said: 'Is there any reason?'… I said: 'Well, I'm not on the pension yet, and when I buy medicine it is very expensive, you know.' I think I bought some…and it came to about $75, $80.

Interviewer: *And how long would that last?*

About 2 weeks. …So that's why I didn't buy it (man, 60s, retired, chronic severe asthma)

When I ended up in Alfred … I had the green whizzer [controller] and I took that and I thought, oh, this is fantastic, this is great, and then it finished and I got a script and it was, like, $30 and it's a matter of, you know, I go, I don't need it at the moment, because $30, as well as the… [reliever] being, like, $15, it's all a big hit. So I'd just buy my…[reliever] and I avoid buying the other one (woman, 20s, professional/managerial, chronic mild asthma)

…see I got cut off my benefits and I couldn't afford medication, and that's when I rang them up and pretty much had an attack and no medication. They just thought it was [owing] to my neglect, but I just didn't have any money to buy anything… (man, 30s, unemployed, chronic moderate asthma)

It gets down to usage. …I have stretched my turbuhalers and puffers…

Interviewer: *When you say you've stretched your turbuhalers and puffers…*

I've felt alright so I haven't used it. …It holds on the bottom of the bottom and it doesn't really clear. But you know, where you haven't got money coming in, you've got to survive (man, 50s, professional/managerial, chronic severe asthma)

But I might say that, well, I've run out of Flixotide. I might say, in the last fortnight I've been without Flixotide.

Interviewer: *So you're not taking Flixotide at the moment.*

…(whispers) I can't afford it financially. It's another $23. You know. And I'm trying to compensate by using more Ventolin, more Atrovent, or something like that. So, this has an effect on me too. I've run out several times. But, generally, I've spoken to the doctor about it (man, 60s, blue collar, chronic severe asthma)

Side effects of medication

The [oral steroid]… Gradually, I lose the feeling in the top of the fingers … the deterioration of the hands … you can understand I'm rather reluctant to take much of it at home (man, 50s, blue collar, chronic severe asthma)

[She] had, I suppose, the body of a 35-, 40-year-old before she got this, and now she's got the body of her right age, 56-, 58-year-old. …It's [medication] put weight on her where she's never ever seen weight (partner of woman, 50s, retired, chronic severe asthma, who was present during interview)

My boyfriend said my boobs have shrunk [since taking preventive medication]. …But I have noticed as well. Like, dramatically (woman, 20s, clerical/sales/service, chronic moderate asthma)

Bad skin, rotten teeth, bad hair. Bad eyesight. Oh yeah. I've been on it [prednisolone] non-stop since I was 12 … wrecks everything. I mean I've got osteoporosis in my spine. Now I'm on calcium to counteract that… (woman, 30s, clerical/sales/service, chronic severe asthma)

Cost–benefit analysis — need versus risk

However, the medication that's currently available certainly to prevent it, being a pretty strong type cortisone, I end up with terrible thrush in the mouth. And I work on the principle that I have asthma so irregularly — although when I do get it, I really do get it — that I'd rather put up with that than put up with the thrush in the mouth (woman, 40s, clerical/sales/service, chronic severe asthma)

…I believed that I wasn't getting asthma … I wasn't having any asthma problems. I believed it was wasting my time to be taking the Becotide, and, because I had a bone density test done, and I was losing a bit of bone density on the lower back, I was quite concerned about that, and I read in this book that cortisone and steroids don't help the problem, and so I thought, okay, that's it, I don't need them. I'll go off them (woman, 50s, retired, chronic mild asthma)

5: Excerpts from interview — decision to see a doctor

[It's] $40. I got that on Medicare Card. They pay $22.50, so I've got to pay $18. When I had a Health Care Card, that was one less worry I didn't have to worry about. That was good.

Interviewer: *Does that influence how much you go to the doctor's?*

It does. If I can avoid going to the doctor's I will … But, yeah, it's not so much I'm slack or lazy. It's just, I think, down the track, oh, I'm going to have to pay that. That'll be another bill that I have to do. And I figure, well, that $18.50 will give me two … [relievers] in the long run. (woman, 20s, clerical/sales/service, chronic moderate asthma)

[The GP] bulk bills. Otherwise I couldn't afford to go. It's too expensive.

Interviewer: *What about the specialist then? Is the cost of going to the specialist a factor?*

At the hospital, I don't pay for it (woman, 40s, home duties, chronic severe asthma)

Interviewer: *So what if the specialist bulk billed? You talked about if you had to pay your $75 every time.*

Yeah, that's an excuse not to go. I don't have the money.

Interviewer: *But if they bulk billed?*

Well, then I've got no excuse.

Interviewer: *So would you go?*

Yeah (man, 60s, professional/managerial, chronic mild asthma)

6: Excerpts from interview — financial and employment costs

Time off work

…people think that if you employ an asthmatic you're going to have someone who's away sick all the time. …And I guess there's a certain amount of the public have a certain amount of baggage about asthma (woman, 30s, clerical/sales/service, chronic severe asthma)

Poverty trap

…I'm reluctant to take too much time off business. …every other job I've had to give away because of the asthma. …Financially, I've been knocked for six… (man, 60s, blue collar, chronic severe asthma)

I've always tried to choose employment that was fairly flexible. …if I had a choice between casual and permanent, I always choose casual. When they make the offer to me I will stay casual because that way I can take a day off and it wouldn't matter. I wouldn't worry about sick leave and things (woman, 30s, clerical/sales/service, chronic severe asthma)

Impact on home and family

I'd love to be able to walk … go on a holiday. If I go anywhere, I go out in the car, I've got to think … where's the hospital from there, where's the doctor from there … how far I'm going away. If I have an attack, okay, how long would it take me to get back. …have that all in sync before I drive off. …It's just been horrendous. …Like one time I had a really bad attack here. I ended up having four ambulance guys working on me to keep me alive and my kids witnessed it. …They never know when they go to school if I'm going to be here when they come home (woman, 40s, home duties, chronic severe asthma)

Dependence versus independence

…I don't want to call an ambulance for myself. My mum or whoever's around will say 'Look, I don't care what you say, I'm going to do it'. And I found that when you hear the ambulance coming it's sort of like, oh thank God, you feel a little bit better (woman, 30s, clerical/sales/service, chronic severe asthma)

eral ways. Some spoke of choosing flexible employment, such as casual work, so they would not be obligated to work when ill. Others described "trying to last", or "soldiering on" in spite of their asthma (Box 6).

Impact on daily life

Participants spoke of the emotions of fear and panic associated with experiencing an attack of asthma. The potential impact of an asthma attack influenced decisions about holiday destinations or where to dine out (Box 6). Several participants also spoke of how asthma had affected their emotional and physical relationships with their partners.

Impact on family and friends

Participants were acutely aware of the impact of their asthma on relationships. They recognised that during an attack of asthma, family members and even friends took on a caring role, which might result in their absence from school or work. They stated that "the scars and stress" for parents and siblings were often greater than their own. "…it's a lot harder for them … because they have to watch. …They are the ones who live on the bedside wondering if I'm going to survive".

Dependence versus independence

A common theme was the role change from wanting to be independent of help when well to needing assistance from family and friends during an attack. During severe exacerbations of asthma, several participants mentioned that they liked someone else, such as a family member, to make decisions for them about whether to attend hospital or to call an ambulance (Box 6).

DISCUSSION

We studied the perspectives of people attending an emergency department for asthma, and the impact of the illness on their lives. In this group, the impact of asthma on daily life was broad, affecting personal and family life, employment and finances. Some participants performed their own "cost–benefit analysis", weighing up expense, perceived side effects and potential benefits of their medications. As a consequence, a significant proportion chose to alter medication doses or not to take prescribed medications. Our study further suggests that, for some, asthma contributed to their low socioeconomic status through diminished employment opportunities. We also confirmed previous findings about autonomy and independence in relation to severe illness in patients with asthma.[12]

Compared with current estimates of 6% of patients with asthma in Australia having severe disease,[13] our study sample included a greater proportion of individuals with severe asthma. Our findings therefore apply particularly to those with severe asthma, a group which consumes the most resources for asthma care.[2]

Our results reflect the range of opinions and experiences of the participants; quantitative expression of our data would not accurately reflect prevalence.[14] However, the strength of the themes that emerged was partly indi-

cated by the number of participants stating such an opinion. Moreover, the breadth of our findings is underpinned by our comprehensive recruitment strategy, and our data collection and analysis conforms to best practice in qualitative research.[15]

Previous studies of the burden of asthma have relied on economic techniques to quantify costs.[16-18] A National Asthma Campaign Report[19] made extensive efforts to quantify both direct and indirect costs of asthma, with estimates ranging from $586 million to $718 million per year. However, such data do not reveal personal perspectives. A previous study estimating the impact of asthma on a broad range of life themes highlighted the economic effects of asthma.[20] Our study supports such findings, and further amplifies the mechanism of the economic disadvantage experienced by people with asthma resulting from reduced job opportunities.

Asthma treatments, particularly inhaled steroids, have been shown to be cost effective in moderate and severe asthma, when the costs of therapy are offset by a reduction in hospital costs.[21,22] Despite Australian Pharmaceutical Benefits Scheme subsidies, the cost of asthma medication was still reported to be a major issue by our participants, and is a likely important reason for poor medication adherence. To achieve optimal adherence, doctors need to ascertain their patients' perspective of the affordability and acceptability of medication. Our study further suggests that, in relation to total health expenditure for asthma, increasing copayments under the Pharmaceutical Benefits Scheme may be counterproductive — decreasing medication adherence and precipitating emergency presentations and hospital admissions.

Efforts to improve asthma care are unlikely to be successful if, from an individual perspective, the costs of therapy outweigh the known benefits of readily available treatments.[23] We urge doctors to explore and engage with patients' "real" burden of asthma to achieve a therapeutic partnership, and facilitate improvement in health outcomes of people with asthma.

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COMPETING INTERESTS

None identified.

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