Self management beliefs

Attitudes and behaviour of adults with severe life threatening asthma requiring an admission to hospital

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BACKGROUND
Adults who have had an admission for severe life threatening asthma are at high risk of future attacks or death. Optimal self management is the key to reducing this risk but relies on people recognising the severity of symptoms and engaging in specific health care behaviour.

METHODS
We used a focus group to examine self management beliefs, attitudes and behaviours in five adults admitted to hospital for asthma.

RESULTS
There were a number of themes. Patients delayed seeking medical attention until asthma symptoms were severe despite ownership of a peak expiratory flow meter, written plan, or experience of previous attack.

DISCUSSION
Insight into the significance of the severity of symptoms and need to change self management behaviour in response to symptoms is key to reducing the risk of future attacks. The general practitioner has a key role in determining and addressing self management behaviour and attitudes that place patients at risk.

In severe life threatening asthma attacks, consciousness is disturbed or appreciable hypercapnia recorded.[1] In Australia, patients who have experienced severe life threatening asthma represent a relatively small subgroup (5–6%) of those with asthma. However, they are grossly over represented in the morbidity and mortality data and consume 40% of the total medical costs for adult asthma in Australia.[2]

Specific characteristics associated with the risk of severe life threatening asthma[3–5] are similar to those who have died from asthma.[1,3] They include: a previous hospital admission for asthma, moderate to severe asthma, inadequate management of asthma,[1,3,6,7] and behavioural factors including denial, stigma and anxiety; all of which can be compounded by poor socioeconomic status[8] and psychiatric illness.[9] The presence of any behavioural factor and its interference with asthma self management is highly significant, putting adult asthmatics at risk of severe life threatening asthma irrespective of asthma severity or adequacy of physician management.[10]

As part of a larger study of severe life threatening asthma, we undertook a qualitative study to examine the notion that adults with severe life threatening asthma would report delay in seeking treatment, and downplay the seriousness of their asthma symptoms.[3,11]

Methods

All subjects gave written consent to take part in this study. Ethics approval was provided by La Trobe University Faculty of Health Sciences and Melbourne Health Directorate Human Ethics Committees.

We recruited people aged between 18 and 55 years who had been admitted to one of two Melbourne (Victoria) metropolitan teaching hospitals with a primary diagnosis of asthma (International Disease Codes 10, J45.0, J45.1, J45.8, J45.9, J46.0) from May 2001 to September 2003. We excluded those over 55 years, as the diagnosis of asthma is less certain at this age because of confusion with those of other respiratory and cardiac conditions. Other exclusions were: 'brittle asthma', any additional chronic respiratory condition, any other unstable medical condition, a cognitive or intellectual disability, history of psychiatric illness, or did not speak or read English.

Participants were sent a letter of invitation to take part in a focus group discussion about their admission to hospital for asthma. Seven participants were invited to take part in the focus group that was facilitated by one of the research group and took 2 hours. The discussion was taped, transcribed, rendered anonymous (names quoted have been changed) and analysed. Two members of the research group independently read and reread the transcripts, identified the emergent themes and grouped these with verbatim extracts. We repeated this with refinements until a final list of central themes was agreed between the research group.

This analysis and a copy of the transcript were sent to each participant to establish the validity of their perception of the discussion and to provide further comment, although none took up the option.

Results

Of the seven participants invited to take part, five attended (two men and three women aged 20–42 years) who had been admitted to hospital 1–5 times in the previous 28 months.

Reasons for worsening asthma

All participants could identify a factor they felt was responsible for the worsening of asthma symptoms and ensuing attack:

Andrew: 'A big night drinking the night before'

Grace: 'All the stress'

John: 'Because of the cold [acute respiratory infection], it made it worse'

Ann: 'I caught a cold and... the cold just kept incubating'

Netta: 'A cold and it just gets worse and worse and I just can't control it'.

In all but one of the last admissions, there had been a gradual onset of severe symptoms over periods of up to 4 days. In the case where a sudden onset was reported ('... woke up one morning just could not breathe, no warning, none whatsoever, woke up and whack'), the participant then reported taking '24 hours to go to hospital' (Andrew).

Possession and use of a peak expiratory flow meter and written action plan

Three participants (Andrew, Netta and Grace) had peak flow meters and action plans before their last admission. One participant, Ann, had been given a written plan but not a peak expiratory flow meter following the last hospital admission and stated:

'After my attack my doctor gave me an action plan, that was great'.

John (who has had asthma since childhood) had neither a peak expiratory flow meter nor a written plan. Those with plans and peak expiratory flow meters before the attack did not volunteer their use in guiding appropriate management initially as asthma symptoms worsened, but later used them to determine the endpoint of self management (ie. the point at which an ambulance should be called or they should attend an emergency department). They often delayed seeking help at peak flow levels well below those suggested in their written plans.

Netta: 'I usually call the ambulance around about the time where if I'm like, less than 100. I'm supposed to call the ambulance at 250'

Grace: 'The only way I'll go is when my peak flow is below 100. I know that I'm meant to go when it's 200'

Andrew: 'I couldn't shift the flow meter, I thought this is a bit worrying, if I can't move that then it's time to go to hospital'. He stated earlier that: 'if I drop anything below 300 I have to call an ambulance straight away'.

Reasons for delays in seeking medical attention

All participants commented on factors that had led to delays in their seeking medical attention when asthma symptoms first worsened, and instead waiting until symptoms were severe. Several reasons were given.

Dislike of hospitals

Grace: 'I'll always hang off because I hate going in hospitals'.

Desire to self manage

Andrew: 'Yeah, trying to get it to calm down with my own medication'

Grace: 'I just hang off until I can see my doctor but if it's really bad I'll just start a pump until I've seen the doctor'

Netta: 'Peak flows and controlling it with Ventolin and I do diaphragmatic breathing, I do relaxation techniques'.

Not wanting to call an ambulance

Ann: 'Ringing an ambulance for yourself, I don't know, it's awkward'

Andrew: 'You don't feel sick enough if you ring one yourself'

Grace: 'I've got to crawl to the phone before I call an ambulance'.

Uncertainty of severity of attack

Ann: 'I wasn't sure if I was having an asthma attack because I haven't had one in ages'

John: 'I think because I've had it like that but not as bad, when I was younger'.

Lack of recognition of cues that asthma was worsening or severe

Ann: 'I was on the Ventolin nebuliser every half an hour'

Andrew: 'I was on the pump nearly every hour'.

Evaluating when to call an ambulance or attend an emergency department

In all cases, participants delayed seeking medical attention until respiratory symptoms had worsened to a severe level, and for some when respiratory arrest was imminent:

Ann: 'When my sister noticed that my lips were turning blue'

Andrew: 'I couldn't shift the peak flow meter and I thought, this is a bit worrying'

Grace: 'The last one I think it was because I wasn't walking, I was crawling'

Netta: 'I call the ambulance at about 100 and that's when my lips are blue and it takes 15 minutes for the ambulance to get there and quite often by that time I'm in near respiratory arrest... but I've always arrested on the way to the hospital rather than the hospital'

John: 'I couldn't walk or anything and I had to stay hunched otherwise my chest wouldn't open'.

Experience on presentation to hospital

All participants had a hospital that they considered as 'their' hospital and in the instances when they had been admitted, all agreed that they were dealt with quickly and effectively:

Netta: 'You really get the royal treatment, everything is just done for you, no waiting and no mucking around'

Grace: 'You don't have to keep going over the same information... it's just streamlined... they don't muck around'

Ann: 'They know that it's asthma and they can deal with it straight away'.

Asthma self management behaviour following discharge from hospital

Participants fell into one of three postattack behaviour groups. First was a group who did not see a need or were unwilling to alter their asthma self management behaviour to improve asthma control and decrease the chance of further attack:

Netta: 'I've had seven hospital admissions in the past 2 years... I've been airlifted, I've arrested a few times'.

She admitted to waiting until her 'lips are turning blue' before calling an ambulance despite knowing it was a '40 minute trip' to the hospital. She went on to state that she has 'an asthma condition that I handle and I deal with' and that she 'didn't live her life like she might die'

Andrew: 'In the past 3 years I have been in intensive care four times and tubed three of them', yet stated the last attack 'took him 24 hours to get to a hospital' during which time he remained at work and 'on the pump nearly every hour... and I don't tell them, just go to the hospital, get well, come home, nobody at work knows half the time'. Following the attack, Andrew 'always upset my doctors something shocking, I come out of hospital and go straight back to work... if I'm fit enough to be out of there I'm fit enough to be back at work'.

Despite having the highest admission rate in the study period, with eight admissions between them, both seemed confident that they controlled the asthma and appeared unaware of its potentially fatal nature:

Andrew: 'I'm going to have it for the rest of my life so it is not going to win, I will win'.

Second was a group who changed their subsequent behaviour to both long term asthma self management and future response to severe attack:

Ann: 'You tip toe for a while. I tip toed. [But] I do a lot of things different now than I did 6 months ago... I'm over that, just call an ambulance and I've done that you know, ambulance care... I know I can't go without Seretide'.

In this case, the near miss experience of this severe asthma attack acted as a pivotal episode and the 'catalyst in initiating behavioural change'.[11] It has been suggested that those participants with a strong cognitive/affective response to asthma attack and little confidence about future asthma control can be more motivated to improve self care.[12]

Ann admitted to feeling 'scared... really terrified... I'm only 22, I'm not going to die' and recognised that her asthma was 'something you can't really compete with because it will win if you push it, it will just take over'.

Subsequently, she had no delusions that her asthma was unaffected by her 'lifestyle' and made important changes in her asthma self management behaviour. The changes required significant effort on her part such as setting money aside regularly in order that she could afford her asthma medications and general practitioner consultations and avoiding cigarettes, smoky music venues, and marijuana, which she described as being a major part of the band culture to which she belonged. Consequently her asthma control had improved, demonstrated by her medication use.

Ann: 'You know, I haven't touched my Ventolin since my attack which was a few months ago'.

The third group consisted of John and Grace, who made no comment about the effect that hospital admission had had on their asthma self management or the need to change asthma self management behaviour.

Attitudes about asthma medication

All participants placed a great deal of importance on having reliever medication readily at hand, perhaps indicating an over reliance on it:

Ann: 'When I've got it [Ventolin] in my bag, I don't even think about it and I don't even worry. But when I walk out without it, like, the hills seem a lot more of a struggle'

John: 'When you actually think, you know, I've forgotten my puffer, you can feel your chest like, you can just feel it, everything's harder'.

Over reliance sometimes led to misuse of medication:

Netta: 'I go through one [Ventolin puffer] every 2–3 days, at the most it might last me 4–5 days'

Andrew: 'I go through about one [Ventolin puffer] a week'

John: 'It's like I'm addicted to it [asthma pump] and I can't leave anywhere without it'.

Unlike reliever medication, participants were less willing to take oral steroids because of weight gain experienced in the past:

Grace: 'Oh yeah, I avoid it like anything, I don't want to take that stuff... when my doctor puts me on it I try to get off it as soon as I can'

Andrew: 'Before I was diagnosed with asthma I was 53 kg, now I weigh 104'

Ann: 'They said I could take it for 3 weeks, but after 3 days I said yes, well, I'm okay, going to avoid it'.

The cost of asthma medication was seen as important:

Andrew: 'My medication costs me over 160 bucks a month... it's a great tablet, Singulair, but it's dear'

Netta: 'I'm on a health care card and I still go over the safety net'

Ann: 'I was short of money... so I went without Seretide for a week and that was a big mistake because I ended up going back in [to hospital]'.

Importance of GP in asthma self management

The GP had an important role to play in managing their asthma. They had 'doctor shopped' (Ann) to find a doctor who knew them, and that they trusted. Having a 'backup' was not uncommon:

Grace: 'I've a couple of doctors I stick to'

Netta: 'You call a doctor you can trust, you might have your back up you know, your second choice, but you call a doctor you can trust'

Andrew: 'If you know that they [GP] are there with you every step of the way, and you can trust them too, to ring up and say I'm not feeling well'.

Again, the cost of GP consultations was seen as important:

Ann: 'Visiting my GP just getting a real assessment... it would help me yeah, just to listen to my breathing and pick up when I was getting a cold' and that her inability to do so before her attack was *'a financial thing'.*

Discussion

Despite the diversity of patients studied, it is nonetheless a very small group and this is a limitation of the study. However, their attitudes and experiences were consistent with previous and larger studies[11,13] and cannot therefore be discounted. We also used

methods to enhance the method rigour (eg. the independent analysis of the transcripts by the second researcher),[14] participant validation of transcripts and analysis,[15] and the use of direct quotations.

The lack of written plans for some may have delayed care access because of uncertainty about the severity of the attack. The evidence based review of the Australian Six Step Asthma Management Plan[16] shows that an individualised written plan is an essential component of self management, reducing the likelihood of repeat hospital and emergency department admission and death from asthma.[5,17–19] Peak expiratory flow readings can be included to help guide patients to the appropriate action.[16] However, we found participants both with written plans and peak flow meters still delayed seeking treatment beyond their plan's action points. This has been reported before,[3,5,17,18,20–23] denial of or downplaying the importance or severity of attack being the principal mechanism.[9,11,24,25] Denial levels may even increase following severe attack[9] as we confirmed here. Denial may be the reason for the paradox between feeling the GP is important in asthma management but failing to arrange consultations as symptoms deteriorate.

Perhaps participants did not go to the GP earlier, or delayed going to hospital because they knew they would be dealt with immediately on presentation as an urgent case. Rather, embarrassment about calling an ambulance, not wanting to disrupt life and work, and a strong desire to self manage were foremost in their minds. In fact, it's possible that good emergency department care in the past may be associated with even more delay in the future.

General practitioners are ideally placed to ask patients about any emergency asthma admission which might result in a focus on relevant circumstances, behaviour and attitudes, and improvement in self management.

Conflict of interest: none declared.

Implications of this study for general practice

What we already know

- Previous hospital admissions are a reliable and easy way to identify patients at higher risk of poor self management practices, future admissions and death from asthma.

What this study shows

- Written plans may not be meaningful to the patient.
- GP consultation and medication costs to the patient may impact self management, review and adherence.
- Discussions about emergency hospital admission might provide valuable information about a patient's asthma self management and attitudes, and might be useful in initiating improvements.

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