"Exasperations" of asthma: a qualitative study of patient language about worsening asthma

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ABSTRACT

Objectives: To identify expressions used by patients to describe worsening asthma; to examine the relevance of the word "exacerbation" to patients' experience; and to investigate whether their language is influenced by the severity of the episode and/or the target audience such as family members, friends and work colleagues.

Design and setting: Qualitative study carried out from 1 January to 30 December 2004 among community volunteers to a research institute. Semistructured face-to-face interviews were used to elicit descriptions of episodes of worsening asthma, and further questioning was used to examine language used with family, employer and doctor.

Participants: 25 people with asthma, aged 22–75 years.

Main outcome measure: Themes identified by open coding about patient language for worsening asthma.

Results: 12 participants were not familiar with "exacerbation" and only three would use it themselves. "Attack" was the only specific term spontaneously volunteered (20 participants), but it was used for anything from mild to life-threatening episodes. Patients often downplayed the severity of worsening asthma to their families. Different language was used with employers, sometimes to justify sick leave and sometimes because of fear of perceived discrimination. When communicating with clinicians about worsening asthma, patients used symptom descriptors rather than specific terms.

Conclusion: There are important differences in the language patients and clinicians use to describe worsening asthma, and the word "exacerbation" has poor utility for communication with patients.

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Effective communication between doctor and patient is integral to successful management of chronic disease.[1] Patients also need an appropriate illness vocabulary to allow them to communicate effectively with family and others. Asthma self-management education, which has been shown to be very effective in improving health outcomes,[2,3] includes the use of action plans to help patients to identify and manage episodes of worsening asthma.[4] To introduce and explain action plans, doctors need to have an effective vocabulary for discussing worsening asthma with patients. The medical word for "asthma which has worsened to the stage that it needs a change in treatment" is "exacerbation". However, this word is multisyllabic, difficult to pronounce, and sounds like medical jargon.

We set out to identify language which could be effective in communicating with patients about worsening asthma. The aim of our study was to determine the terms or phrases which are already used by patients to describe worsening of their asthma, and to assess whether their use varies according to the severity of the episode or the people with whom the patient is speaking.

METHODS

Purposive sampling was used to select adult participants with asthma from community volunteers for a concurrent study involving symptom questionnaires. The inclusion criteria for participants were: age 15–75 years; current non-smokers with ⩽ 10 pack-year smoking history; and currently using inhaled corticosteroids. The study was approved by the Central Sydney Area Health Service ethics committee. All participants gave written informed consent.

Participants were recruited through local and television advertisements between 1 January and 30 December 2004. They underwent a 30-minute semi-structured in-depth interview. Interviews were conducted by BGT and were transcribed verbatim. Participants were asked to describe two recent episodes of worsening asthma — one that they could self-manage and the other that required medical intervention. For each episode, participants were asked how they described the episode when talking to their family, friends, doctor or employer. To elicit specific terms rather than symptom descriptors, participants were asked about leaving a brief message, such as on an answering machine, about worsening asthma.

Analysis

After completing the first six interviews, SDV and HKR (respiratory physicians), BGT (psychologist), and RAA (sociologist) reviewed the transcripts, and the interview schedule was amended to enable further exploration of key areas. At completion of the study, these same four authors independently reviewed the transcripts. Emergent themes were discussed and explored using open coding,[5] with N4 Classic software (Qualitative Solutions and Research Pty Ltd, Melbourne, VIC). We stopped recruiting after 25 interviews when no new major themes emerged.

RESULTS

Twenty-five participants were interviewed, with an average interview length of 20–25 minutes. The Box shows patient details. All participants described episodes which were consistent with moderate to severe asthma exacerbations. Five participants had been admitted to hospital for asthma, 15 had attended emergency departments, 21 had one or more unscheduled doctor visits for asthma and one participant had collapsed from dyspnoea. There were no differences in language about worsening asthma between the 12 participants who completed high school or trade-level education and the 13 who completed university.

Participants' understanding and use of language

Twelve participants had never heard the term "exacerbation". Of the 13 who recalled hearing the term (eight only during the previous study), 11 had a general understanding of its meaning; three of these had completed a university degree. The remaining two proffered incorrect definitions. Most participants (18) thought that the term "exacerbation" would not be useful for them.

"Asthma exacerbation", it's a bit of a gobful, isn't it? (*man, 41*).

No. It's probably too . . . clunky (*woman, 35*)

The only specific term spontaneously volunteered for worsening asthma was "attack" (20 participants). However, participants attributed a wide range of severity to this word. Most (15) described an "attack" as requiring medical intervention.

When someone's had an asthma attack, they haven't been able to breathe. So they've needed medical attention or extra medicine (*woman, 22*).

So the asthma attack to me is when I need to see the doctor or go to the hospital (*man, 27*).

Eight participants reserved "attack" for life-threatening events, and did not consider episodes of moderate severity to be "attacks". None of these participants had another specific term for mild or moderate attacks, instead using symptom descriptors.

I wouldn't relate it to myself, because to me asthma attack sounds so severe that I've stopped breathing, and it's . . . really extreme (*woman, 33*).

I always feel funny calling it an asthma attack, because to me an asthma attack is a sudden and severe attack, like when you suddenly, you know, start wheezing uncontrollably and can't stop, and you sort of fall over and . . . need to rush to the hospital (*woman, 22*).

By contrast, seven participants used "attack" to describe mild symptoms such as exercise-induced asthma. This group was older (36–70 years) and over half had adult-onset asthma. Interestingly, all of these participants also used "attack" to describe serious episodes that required medical intervention.

Even though I could get attacks, they would be mild attacks playing soccer, and if I stopped for a little while, the breathing would get under control (*man, 75*).

Five participants emphasised that "attack" implied rapidly worsening asthma. Some contrasted this with "exacerbation", which they considered represented a more gradual onset.

An exacerbation, I think, would be something that's . . . come on gradually. I think it's more long-standing . . . but an attack, to me, would be something that came on very quickly. . . and probably disappears just as quickly (*woman, 52*).

To me it's sudden onset, like any attack is, you don't attack slowly, do you? (*man, 57*).

For episodes of worsening asthma that were self-managed, most participants (15) used symptom descriptors, such as "wheezy" or "breathless", rather than a specific term.

There's just tightness around the chest, and not being able to take deep breaths, just short and ineffective breaths (*man, 27*).

Some of the participants used colloquial or idiosyncratic terms, such as "funny chest" or "throat croaking", which were understood by close family or friends, but not by others. Three participants referred to their asthma having "flared up".

Communicating with family

About half the participants stated that they downplayed the severity of worsening asthma to their family in order to avoid creating alarm, especially with close relatives such as parents.

I think words like "asthma attack" are quite . . . harsh terms, aren't they? So they probably scare people. I certainly wouldn't use those terms with my family. . . "I'm a bit wheezy" or "I couldn't catch my breath". I think they're much kinder terms than "asthma attack" (*woman, 26*).

Usually I don't tell her [mum], because it worries her. So I try and downplay it to mum (*woman, 41*).

In some cases, episodes were downplayed with family in order to avoid criticism. One participant had often been criticised by her mother during childhood for over-using reliever medication.

My mother [said] that I would bring on an attack to get attention (*woman, 60*).

Communicating at work

Six participants would only tell their employer that their asthma was worse if they needed sick leave. In this situation, they would choose terms such as "attack", even if they would never use this word with family. These participants indicated that they perceived phrases like "worsening asthma" did not convey the severity of the episode sufficiently, and would not constitute grounds for sick leave.

["Attack"] . . . that's what I tend to describe it to people like at work . . . because that's more under-

Characteristics of the 25 participants

Participant characteristics	Finding
Female	14 (56%)
Mean age	42 years (range, 22–75 years)
Age at asthma onset:	
0–2 years	5 (20%)
3–12 years	10 (40%)
13–18 years	2 (8%)
> 18 years	8 (32%)
Used oral corticosteroids in past year	6 (24%)
Hospitalised in the past year	0
Current medication:	
Reliever as needed	25 (100%)
Inhaled corticosteroid	25 (100%)
Combination therapy	19 (76%)
Median inhaled corticosteroid dose	800 µg/day (IQR, 500–1000 µg/day)*
Highest level of education:	
High school	3 (12%)
Technical college/trade	9 (36%)
University	13 (52%)

IQR = Interquartile range. * Beclomethasone dipropionate equivalent. ◆

> standable, and that kind of is taken seriously, whereas saying you're wheezy, or your chest is tight, doesn't kind of have the same meaning, so it . . . sounds like you should be . . . managing it (*woman, 22*).

The terminology used in the workplace by two participants was influenced by a perceived risk of discrimination for having a chronic illness.

> I think there's probably this stigma attached with being asthmatic, so I think it's only recently I told [my employer] I was asthmatic, I just feel like . . . it's kind of [an] . . . unreliability, in an occupation, if you have something (*woman, 35*).

Two participants said that, for medical certificates, they asked the doctor to specify a self-limited illness such as respiratory tract infection, rather than asthma.

Communicating with the doctor

Most participants (16) did not perceive a need for specific terms to use when speaking to their doctors about worsening asthma. Instead, they described symptoms and their impact on daily activities, perceiving it as the doctor's role to label the episode. This included participants who had used "attack" in other contexts, such as with their employer. One participant used a colloquial family expression for what had clearly been a severe exacerbation, but the doctor did not understand it.

> I just told her [doctor] I've got a really bad funny chest. She did laugh at me (*woman, 33*).

Rapid communication

When participants were asked how they would leave an answering machine message about worsening asthma, seven used "attack". This was the only common term identified within this scenario. Most of these participants had previously described an attack as an episode that required medical intervention, although one participant did not previously use the term and another used "attack" for mild symptoms only. Participants who used the word "attack" in the context of rapid communication perceived that this word would have universal meaning, and would result in appropriate responses.

DISCUSSION

Our qualitative study provides insight into the terms and phrases that patients use to describe worsening asthma, and illustrates how social context influences their choice of language. We found no universally accepted terms or phrases for describing such episodes. In particular, the medical term "exacerbation" was not regarded by patients as being useful for communicating about worsening asthma.

Our study used well documented strategies for qualitative data collection and analysis.[6] We used purposive sampling to obtain a diverse range of participant ages, ages at asthma onset, educational backgrounds and asthma severity. All participants had previously had clinically important asthma exacerbations. One limitation was the high proportion of tertiary-educated participants. This partly reflects the volunteer base of our research institute. However, it does highlight the poor functionality of existing medical terminology for exacerbations, even in a population with good language skills.

To date, there have been no published studies exploring the use of the term "exacerbation" and its utility in communication for patients with asthma. In a recent study of 125 patients with chronic obstructive pulmonary disease (COPD), 74 patients had never heard of "exacerbation", and only two gave its correct meaning.[7] "Exacerbation" is widely used in medicine, but otherwise only in highly technical or scholarly contexts. Most of our participants perceived "exacerbation" to be a technical and user-unfriendly word. We have heard several patients substitute the word "exasperation", which, under the circumstances, is quite an appropriate malapropism. The same error was made by 11 patients in the COPD study.[7]

"Attack" is the most commonly-used word in asthma. While simple and evocative, it is clearly limited in its utility, as patients use it for a wide spectrum of episodes. This confirms the findings of another Australian study, which found that patients attached a wide range of meanings to "attack", from daily symptoms to extremely severe episodes.[8] The addition of appropriate adjectives to "attack" (eg, "mild", "severe") may help solve this problem. "Asthma flare-up" may be a useful alternative.

One of the striking findings was the extent to which social context influenced participants' choice of language. They commonly downplayed the severity of episodes to their family to avoid causing alarm or attracting criticism, or because of a desire to "tough it out".[9] Such behaviour may be hazardous, as it could cause delays in obtaining medical assistance.[9] In the workplace, many participants felt the need to use strong words such as "attack" to legitimise taking sick leave, even if they would not be prepared to use "attack" with friends and family. By contrast, some participants concealed their asthma from their employers because of fear of discrimination. Such perceptions, which may persist despite improved awareness of asthma through public education campaigns,[10] may reduce patients' willingness to attend review appointments during working hours.

For communication with doctors, participants did not wish to use diagnostic labels for worsening asthma, instead assuming it was the doctor's role to provide these. There is now an emphasis on the use of lay language in doctor–patient communication. Patients may perceive medical language to be beneficial to them in validating the sick role, and in justifying sick leave,[11] much as with use of "attack" at work. However, use of matched lay terminology by doctors may result in higher patient satisfaction and stronger intention to comply with treatment than use of medical terminology.[12] Further studies are needed to explore the terminology currently used by health care providers.

Our findings have highlighted gaps in language about worsening asthma. Without readily understood and unambiguous words for use in educational material and asthma action plans, communication breakdown may occur, impeding appropriate and timely management of worsening asthma. Despite evidence that action plans reduce morbidity and mortality,[2,13] their uptake is falling.[14] While it may not be possible to find a single term which is useful for all patients, health care providers may find it easier to discuss action plans if they first find out the terminology which each patient already uses for worsening asthma. Health care providers should be encouraged to establish a relationship with patients in which patient language is understood and reflected back by the provider, to ensure effective communication about worsening asthma.

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COMPETING INTERESTS

None identified.

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REFERENCES

1 National Health and Medical Research Council. Communicating with patients: advice for medical practitioners. Canberra: NHMRC, 2004. Available at: http://www.nhmrc.gov.au/publications/synopses/e58syn.htm (accessed Apr 2006).
2 Gibson PG, Powell H, Coughlan J, et al. Self-management education and regular practitioner review for adults with asthma. *Cochrane Database Syst Rev* 2003; (1): CD001117.
3 Abramson MJ, Bailey MJ, Couper FJ, et al. Are asthma medications and management related to deaths from asthma? *Am J Respir Crit Care Med* 2001; 163: 12-18.
4 Douglass J, Aroni R, Goeman D, et al. A qualitative study of action plans for asthma. *BMJ* 2002; 324: 1003-1005.
5 Strauss A, Corbin J. Basics of qualitative research: grounded theory procedures and techniques, Newbury Park, Calif: Sage Publications, 1990.
6 Pope C, Ziebland S, Mays N. Qualitative research in health care: analysing qualitative data. *BMJ* 2000; 320: 114-116.
7 Kessler R, Stahl E, Vogelmeier C, et al. Patient understanding, detection, and experience of COPD exacerbations: an observational, interview-based study. *Chest* 2004. In press.
8 Aroni R, Goeman D, Stewart K, et al. Enhancing validity: what counts as an asthma attack? *J Asthma* 2004; 41: 729-737.
9 Janson S, Becker G. Reasons for delay in seeking treatment for acute asthma: the patient's perspective. *J Asthma* 1998; 35: 427-435.
10 National Asthma Campaign. A decade of asthma management in Australia. 1998. Available at: http://www.nationalasthma.org.au/html/strategy/cam/cam003.asp (accessed Feb 2006).
11 Ogden J, Branson R, Bryett A, et al. What's in a name? An experimental study of patients' views of the impact and function of a diagnosis. *Fam Pract* 2003; 20: 248-253.
12 Williams N, Ogden J. The impact of matching the patient's vocabulary: a randomized control trial. *Fam Pract* 2004; 21: 630-635.
13 Gibson PG, Powell H. Written action plans for asthma: an evidence-based review of the key components. *Thorax* 2004; 59: 94-99.
14 Wilson DH, Adams RJ, Appleton SL, et al. Prevalence of asthma and asthma action plans in South Australia: population surveys from 1990 to 2001. *Med J Aust* 2003; 178: 483-485.

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