



Attack, flare-up, or exacerbation? The terminology preferences of patients with severe asthma

Kimberley A. Jones, Peter G. Gibson, Janelle Yorke, Robert Niven, Amber Smith & Vanessa M. McDonald

To cite this article: Kimberley A. Jones, Peter G. Gibson, Janelle Yorke, Robert Niven, Amber Smith & Vanessa M. McDonald (2019): Attack, flare-up, or exacerbation? The terminology preferences of patients with severe asthma, Journal of Asthma, DOI: [10.1080/02770903.2019.1665064](https://doi.org/10.1080/02770903.2019.1665064)

To link to this article: <https://doi.org/10.1080/02770903.2019.1665064>



Accepted author version posted online: 06 Sep 2019.
Published online: 16 Sep 2019.



Submit your article to this journal [↗](#)



Article views: 51



View related articles [↗](#)



View Crossmark data [↗](#)



Attack, flare-up, or exacerbation? The terminology preferences of patients with severe asthma

Kimberley A. Jones, PhD^{a,b,c,d}, Peter G. Gibson, MBBS, FRACP, PhD^{a,b,d,e} , Janelle Yorke, PhD, MRes, RN^{c,f,g}, Robert Niven, MD^h, Amber Smith, BNutDie^{b,c}, and Vanessa M. McDonald, RN, BN, PhD, FThorSoc^{a,b,c,d,e,f} 

^aNational Health and Medical Research Council Centre of Excellence in Severe Asthma, Newcastle, Australia; ^bPriority Research Centre for Healthy Lungs, The University of Newcastle, New Lambton, Australia; ^cSchool of Nursing and Midwifery, The University of Newcastle, Callaghan, Australia; ^dHunter Medical Research Institute, New Lambton, Australia; ^eDepartment of Respiratory and Sleep Medicine, John Hunter Hospital, Newcastle, Australia; ^fDivision of Nursing, Midwifery & Social Work, University of Manchester, Manchester, UK; ^gChristie NHS Foundation Trust, Manchester, UK; ^hManchester Academic Health Sciences Centre, University of Manchester, Manchester, UK

ABSTRACT

Background: People with severe asthma experience frequent life-threatening acute asthma events. A Lancet commission recently highlighted that terms “exacerbations” and “flare-ups” are seen to trivialize these episodes and recommended use of the term “attacks.” Clinicians however, preferentially use the term “exacerbation” and some guidelines recommend the use of “exacerbation” with patients.

Objective: This descriptive qualitative study aimed to understand the patient’s experience and perspectives of these events and language used to describe them.

Methods: Semi-structured one-on-one interviews were conducted in Australia and the UK in 18 people with severe asthma and 10 with mild-moderate asthma regarding their usage and preferences for such terminologies. Additionally, nine people with severe asthma participated in two focus groups in which use of preferred terminology was explored.

Results: Mean age of participants was 57 ± 14.03 yr and 65% were female. A total 67 quotes were recorded in which 16 participants with severe asthma spontaneously used either the term “attack,” “flare-up” and/or “exacerbation.” Of these quotes, all 16 participants used “attack,” one used all three terms and two used both “exacerbation” and “attack.” The term “attack” was used to describe frightening events having major impacts on participant’s lives, whereas “exacerbation” and “flare-up” were used to refer to both severe and mild, transient asthma-related events.

Conclusion: Usage of the term “attack” was preferred by patients with severe asthma. Adoption of this language may assist in patient-clinician communication and disease management and outcomes. Wider stakeholder engagement is needed to confirm this suggestion.

Abbreviations: FEV₁: forced expiratory volume in 1 second; ATS: American Thoracic Society; ERS: European Respiratory Society; ACQ: Asthma Control Questionnaire; ICS: inhaled corticosteroids; OCS: oral corticosteroids; BTS: British Thoracic Society; SIGN: Scottish Intercollegiate Guidelines Network; WAP: written action plan.

ARTICLE HISTORY

Received 29 May 2019
Revised 22 August 2019
Accepted 4 September 2019

KEYWORDS

Asthma; asthma attack; exacerbation; flare-up; terminology; patient-clinician communication; disease management

Introduction

Acute events in the form of increased symptoms, loss of control and lung function decline in severe asthma are common and have major impacts on patient outcomes (1). The 2017 Lancet Commission (2) on asthma called for zero-tolerance for attacks; the commissioners suggest that the terms “exacerbation” or “flare-up” trivialize and confuse loss of symptom control, and recommend replacing these terms with “attack”(2).

Asthma “attacks” claim the lives of over 380,000 people worldwide each year (2) and are associated with excessive decline in lung function (3). Patients with frequent “exacerbations” experience accelerated airway remodeling, with more than double the decline in forced expiratory volume in 1 s (FEV₁) than those with infrequent exacerbation (3,4), and are at a heightened risk for future events (5–8). In light of the consequence of these events, use of terminology that downplays their seriousness, or creates

CONTACT Vanessa M. McDonald  Vanessa.McDonald@newcastle.edu.au  Priority Research Centre for Healthy Lungs, The University of Newcastle, Level 2 West Wing, 1 Kookaburra Circuit, New Lambton, NSW 2305, Australia.

Color versions of one or more of the figures in the article can be found online at www.tandfonline.com/ijas.

© 2019 Taylor & Francis Group, LLC

misunderstanding between patients and clinicians, could act as a significant barrier to optimal patient outcomes, and may indeed contribute to adverse outcomes.

Results of a large survey of people with asthma and asthma healthcare providers in the United States indicated that the majority of patients were familiar with the terms “attack” (97%) and “flare-up” (71%) but few were familiar with “exacerbation” (24%). In contrast, physicians used “attack” less than “flare-up” or “exacerbation” during patient consultation (9). Furthermore, this study highlighted confusion about the meaning of these terms. These results were mirrored in an Australian sample of people with asthma, where “attack” was the only word volunteered by participants to describe worsening asthma and only 12% reported they would use the word “exacerbation.” Almost half (48%) of participants were not familiar with the term “exacerbation” (10). Despite these studies being published in the years 2012 and 2006 respectively, clinicians continue to use the terms “exacerbation” and “flare up” when communicating with patients.

These previous studies provide insight into the perspectives of people with asthma when referring to acute events (9,10). However, both studies sampled heterogeneous asthma populations and did not stratify by asthma severity. While all people with asthma can be burdened by increased symptoms and lung function variability at times, it is the severe asthma population the carries the heaviest burden from periods of asthma deterioration.

Severe asthma is a distinct disease with a unique pathogenesis. People with severe disease experience more frequent and more severe events and higher mortality due to these events (11,12). This population can present to the emergency department with acute asthma more than six times each year (13). It follows then, that the severe asthma population will have a unique experience of asthma worsening and a unique perspective on the terminology used.

The aim of this study was to explore perspectives of people with severe asthma regarding acute asthma events, to describe the terminology used by patients when referring to acute episodes, and to compare the severe asthma participants’ perspectives with those of people with mild to moderate asthma. In improving our understanding of the patients’ perspective we hope to inform clinician-patient communication regarding the importance of and response to these clinically important events.

Methods

Study design

A descriptive qualitative study was performed as a sub study of larger study in which the aim was to develop a patient reported outcome measure for severe asthma.

Recruitment and selection

Participants with severe asthma who were under the care of a respiratory physician were recruited by the clinicians involved in their care. Severe asthma diagnosis was defined according to the criteria of the American Thoracic Society (ATS)/European Respiratory Society (ERS) Taskforce (15). That is, people with asthma requiring high-dose inhaled corticosteroids and long-acting β_2 -agonists or frequent systemic corticosteroids to prevent “uncontrolled” disease or disease that remains “uncontrolled” despite therapy. In addition to the medication requirements we used the following criteria to determine severe asthma: the presence of a post beta₂-agonist FEV₁ of <80% or FEV₁/FVC < 70%; or an Asthma Control Questionnaire (ACQ) score ≥ 1.5 ; or a severe exacerbation within the previous 12 months requiring treatment with oral corticosteroids. Past evidence of confirmed asthma was also required, that is an FEV₁ or FVC post bronchodilator response of $\geq 12\%$ and 200 ml, or evidence of airway hyperresponsive or diurnal variation in peak flow of $\geq 15\%$ or >50 ml.

A group of people with mild-moderate asthma were recruited as a comparator group. This population had a confirmed diagnosis of asthma, with past evidence of a FEV₁ or FVC post bronchodilator response of $\geq 12\%$ and 200 ml, or past evidence of airway hyperresponsive, or diurnal variation in peak flow of $\geq 15\%$ or >50 ml, but did not meet the criteria for severe asthma.

Participants were recruited through the research database and clinics of the Department of Respiratory and Sleep Medicine at John Hunter Hospital, NSW Australia and the Severe Asthma Clinic of The University Hospital of South Manchester, United Kingdom. Proficiency in English language deemed by investigators to be sufficient to understand study requirements and age 18 yr or older were additional inclusion criteria.

Ethics approval was received from the Hunter New England Research and Ethics Committee (ref. no. 16/05/8/5.02) and the University of Newcastle (H-2016-0197), as well as the University of Manchester

Table 1. Questions participants were asked in one-on-one interviews to initiate discussion relating to exacerbations.

Questions
What does the term exacerbation or flare up of asthma mean to you?
Have you had an exacerbation or flare up of your asthma?
How did it make you feel?
Can you tell when your asthma is getting worse?
What are the signs?
What do you do when this happens?
What impacts do exacerbations/flare ups have on your life during and after?
Tell me about your health care experience during times of flare up?
What about in general?
What terms would you use to best describe your asthma exacerbations/flare up?

(ref. no. 16/SC/0230). The study was conducted in accordance with the International Conference on Harmonization Good Clinical Practice guidelines and all participants provided informed signed consent. Pseudonyms have been used to protect participant confidentiality.

Data generation

Baseline demographic data were collected prior to the interview by the research officer or investigator and included their ethnicity, current living arrangements, medical history including a review of comorbidities, and assessment of current respiratory and non-respiratory medications. Spirometry was captured from the source file and FEV₁% predicted is reported.

Interviews and focus groups were conducted by experienced qualitative researchers including three coauthors (VMcD, AS and JY). These investigators were not involved in the clinical care of the recruited participants. Participants were assured of confidentiality and that they could stop or pause the interview at any time. Semi-structured questions guided the interview. Field notes were recorded by the interviewer.

A semi structure interview guide (Table 1) was developed by the research team with a particular focus on the establishment of participant's perspectives of acute events. Interviews were structured to begin with broad questions that moved on to questions regarding more specific issues. Free speaking was facilitated by open-ended questioning. All interviews took place in a private office and the mean $\pm$ SD duration was 60 ± 34.3 min, range = 27–205 min.

Semi-structured qualitative interviews ($n=18$) and two focus groups ($n=4$ and $n=5$) were conducted with 27 adults (14 in Australia, 13 in UK) with severe asthma. Another group of 10 participants with mild-moderate asthma participated in a qualitative interview (Australia only) to provide a comparison. Interviews explored individuals' experiences with acute

asthma episodes and their perspective on asthma-related language. A subgroup of participants, those being the four that participated in the Newcastle focus group, were also asked to map their "individual experience" of acute events in relation to their daily life using a pictorial representation on an X,Y axis chart. They were asked to label events with words of their choice. All interviews were recorded using a voice recorder, which encrypts files in real time.

Analysis

Qualitative analysis

Sampling was purposive, and interviews were continued until no new themes emerged. Interviews were audio-recorded and written notes documented by the interviewer. Recordings of interviews were transcribed verbatim and transcripts anonymized. Transcription was performed by professional transcription services in Australia and UK and verified against the sound file by the interviewers. Data were analyzed using line-by-line analysis. Participants quotes were extracted and categorized into themes and subthemes of similar items. A summative content and frequency analysis was also used to determine the usage of terms that describe exacerbations, these were recorded as those being used spontaneously during the interview or in response to a question specifically addressing use and preferences for terminology.

Quantitative analysis

Descriptive statistics are presented as mean $\pm$ SD if normally distributed and non-parametric data are presented as a median with interquartile range (q1,q3). Quotes within themes and number of participants are reported as total numbers and percentage of total number of participants.

Results

The mean age of participants was 57 years, in both the severe asthma and mild/moderate asthma group. In the severe asthma and mild/moderate groups 70% and 40% respectively were female. The mean $\pm$ SD FEV₁% predicted was $63.15 \pm 21.21\%$ in the severe asthma group and 82.89 ± 15.54 in the mild/moderate group. Most participants, 82% in the severe asthma and 90% of the mild/moderate group, lived with a family/support. Daily inhaled corticosteroids (ICS) use was as expected by definition higher in the severe asthma group (1193.18 ± 689.90 mcg/day) compared to the mild/moderate group (260 ± 192.64 mcg/day)

beclomethasone equivalent. No participants in the mild/moderate group took oral corticosteroids (OCS) compared to a mean daily dose of 10.29 ± 14.94 mg in the severe asthma group (Table 2).

Frequency of spontaneous term use by participants to describe acute asthma events

During the severe asthma interviews a total of 67 quotes were recorded in which participants spontaneously used the term “attack,” “flare-up” and/or “exacerbation” to describe an acute episode of asthma. These quotes were recorded from 16 of the total 18 interview participants.

Table 2. Demographic data for severe asthma and mild-moderate asthma groups.

Characteristic	Severe asthma N = 27	Mild to moderate N = 10
Age in years (mean $\pm$ SD)	57.22 (12.08)	56.63 (19.13)
Female n (%)	19 (70)	4 (40)
FEV1% predicted (mean $\pm$ SD)	63.15 (21.21)	82.89 (15.54)
Living with family/support n (%)	21 (78)	9 (90)
ICS (mcg/d fluticasone equivalent) (mean $\pm$ SD)	1193.18 (689.90)	260 (192.64)
OCS daily dose (mg) (mean $\pm$ SD)	10.29 (14.94)	0

FEV1 = forced expiratory volume in 1 s, ICS = inhaled corticosteroids, OCS = oral corticosteroids.

Of these, all 16 (100%) participants used “attack,” 1 (6%) used all 3 terms and 2 (12.5%) used both “exacerbation” and “attack” (Figure 1). One participant simply referred to an acute episode as “bad.”

Only three participants (30%) from the mild-moderate group spontaneously mentioned acute events without being specifically asked. In all seven quotes by these three participants only the term “attack” was used (Table 3).

Spontaneous use of terminology in participants with severe asthma

The words “attack” and “exacerbation” were variably used to describe frightening events that had major impacts on participant’s lives. The term “flare-up” was used infrequently and largely then to refer to both severe and mild asthma-related events. Table 4 presents exemplars offered by participants with severe asthma during the interviews and focus groups.

Participant’s perception of terminology

When questioned on the meaning of different terms that are used to refer to acute asthma episodes,

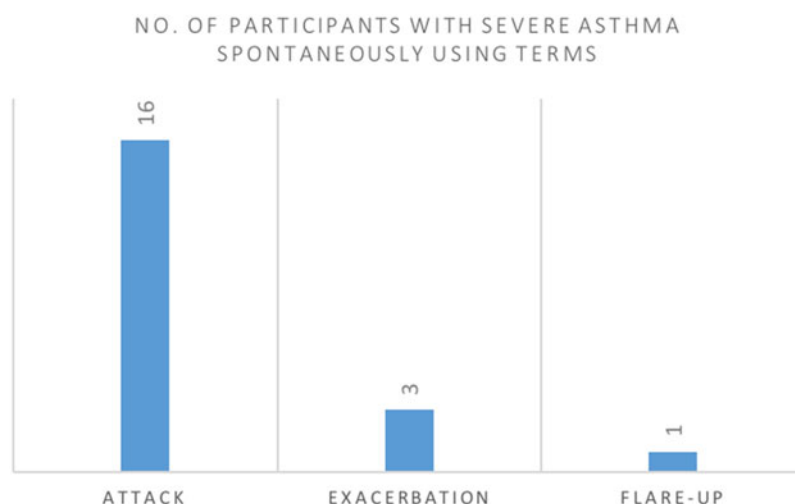


Figure 1. Spontaneous use of terms by participants.

Table 3. Spontaneous use of terminology to describe acute events by mild/moderate participants.

Quote	Participant
It's been a long time since I've had an actual full-blown asthma attack	Stephanie, 33 yr old female
A full-blown asthma attack, it was wheezing and just finding it so hard to breathe that it's scary.	Stephanie, 33 yr old female
I can remember having attacks as a small child and it was just - it's just scary. Not being able to breathe is terrifying.	Stephanie, 33 yr old female
What I really worry about is something triggering an actual attack, I'm so not prepared for it. I don't even know how I would deal with it as an adult,	Stephanie, 33 yr old female
I'm not concerned at all when I have little bouts, that doesn't worry me at all. But the idea of having an actual full-on asthma attack, that's a worry.	Stephanie, 33 yr old female
If you get an asthma attack type thing, well, you just treat it accordingly; go to hospital or a couple of more puffs of preventatives and stuff like that. Hopefully, it fixes it.	Michael, 70 yr old male
I haven't experienced an asthma attack, so I can't really be too scared about it or worried about it I've no idea what it would entail	Luke, 24 yr old male

Table 4. Spontaneous quotes using terminology for acute events by participants with severe asthma.

Term	Quote	Participant
Attack	The first time that my husband had actually witnessed an asthma attack. He thought I was going to die	Kirsty, 47, female
	Relating to the biggest concern about her asthma: the fear of having an attack, you know, and you wonder whether you're going to recover from it	Judy, 68 yr old female
	The attack was so bad I didn't think I was going to survive it. I just could not get my breath, no matter how much I used the puffers.	Bob, 71 yr old male
	I had an asthma attack and I thought I was going to die.	Penny, 60 yr old female
Exacerbation	I had a really bad exacerbation and the doctor at home, at the time, said you need the time off.	Elisa, 56 yr old female
	I'll probably have two, maybe three, exacerbations over the period of Christmas, that's become de rigueur.	Ian, 40 yr old male
	It's life threatening, my exacerbations. They um, they creep up. I could do a walk around the lake, I feel great, tired a little bit, but determined to get around that lake, but that night I would be wheezing and then I'd be progressively just get worse.	Tina, 33 yr old female
Flare-up	If it's a flare-up, it will just be caused by pollen, so again it might settle down.	Elisa, 56 yr old female
	When I get the flare ups, I get annoyed with myself.	Tracey, 48 yr old female
	I knew I needed more assistance when it came to my flare-ups. A flare up to me is bad.	Tina, 33 yr old female

Table 5. Exemplars of participant quotes when asked about different terminologies to describe acute asthma events.

Exemplar #	Quote	Participant
1	... an attack is when it's completely beyond your control.	Kirsty, 47 yr old female
2	I class an attack the worst. That's it.	Paul, 44 yr old male
4	... an attack, well I mean it's very frightening. So how do I feel? Obviously, it upsets me and scares me when it happens. It probably reinforces how - that it is life threatening.	Tracey, 48 yr old female
5	... an exacerbation implies to me that the condition is being controlled and what is happening is above and beyond, you know, your normal functioning. Whereas an attack seems to imply that there's no control of your asthma or you don't normally have asthma.	Thomas, 62 yr old male
6	I suffer from exacerbation quite often, see, so an attack is worse for me. You know what I mean? Exacerbation is a normal thing for me.	Paul, 44 yr old male
7	An exacerbation to me means just an increase in, a worsening of the symptoms.	Bob, 71 yr old male
8	Maybe you're coughing and puffing a bit more than usual. I think that's about what I think it (exacerbation) means.	Jackie, 58 yr. old female
9	Exacerbation is when your asthma is particularly worse but it's not hospital.	Kirsty, 47 yr old female
10	If there's a severe exacerbation, walking up the stairs becomes difficult, I just take it slow.	Ian, 40 yr old male
11	An asthma attack is a lot - to me it sounds so much more serious than an asthma flare-up. A flare-up to me sounds like it's a more mild, controllable version of an attack.	Stephanie, 33 yr old female
12	... you have a flare up, you go to the action plan and feed off that. That seems to settle everything down.	Tim, 62 yr old male
13	Well any of the precursors or whatever you want to call them - you know, the dust, the smoke ... all that - that is what exacerbates me. So it's as simple as that.	Peter, 71 yr old male
14	I think an exacerbation actually just means anything that changes it or chest infection	Penny, 60 yr old female
15	What does the word exacerbation mean to you? Frustration, um shortness of my temper	Joe, 73 yr old male
16	I actually took offence to it (the term exacerbation) to start with, because I thought, for me to get into hospital, I'm having an attack. I'm in hospital - I'm having an attack. They would write it down as an exacerbation of your asthma, and I'm thinking, it's not a fricking exacerbation.	Kirsty, 47 yr old female
17	I don't use exacerbation to anyone else. Usually the only reason you'd use exacerbation is because well that's what most medical practitioners use.	Bob, 71 yr old male
18	I only use 'asthma attack' when ... I was admitted to hospital ... I would call those asthma attacks because I really felt ... like I was gasping all the time for breath and no matter what I did I was ... I just could not breathe. So, that to me is an asthma attack.	Judy, 68 yr old female

participants reported that they understood the term “attack” to refer to serious, life-threatening events. Exemplars offered by participants with severe asthma during the interviews and focus groups are presented in Table 5.

Conversely, participants with severe asthma tended to consider the terms “exacerbations” and “flare-ups” to reflect less severe events. They described the events as being more transient, common increases in their symptoms that might last hours or days but generally led to a return to baseline (exemplars 5–11, Table 5).

The use of the term “exacerbation” was also perceived as being used by health professionals to “medicalise” participants’ asthma.

A focus group participant described this by saying “I would say perhaps an exacerbation is a more medical term and the medical model [sic]. An attack is more a layman’s term and has more significance.” Monica, 57 yr old, female.

The focus group participant commented “I find exacerbation puts up that barrier that they’re the professional and you’re just the person with it.” Monica, 57 yr old, female.

Whereas Bob described how he changes the language he uses when he speaks with his doctors. “To doctors I do (use the word exacerbation) but to my friends I just say ‘asthma’s flared up’ ... asthma attack is the word is probably what I would be saying to

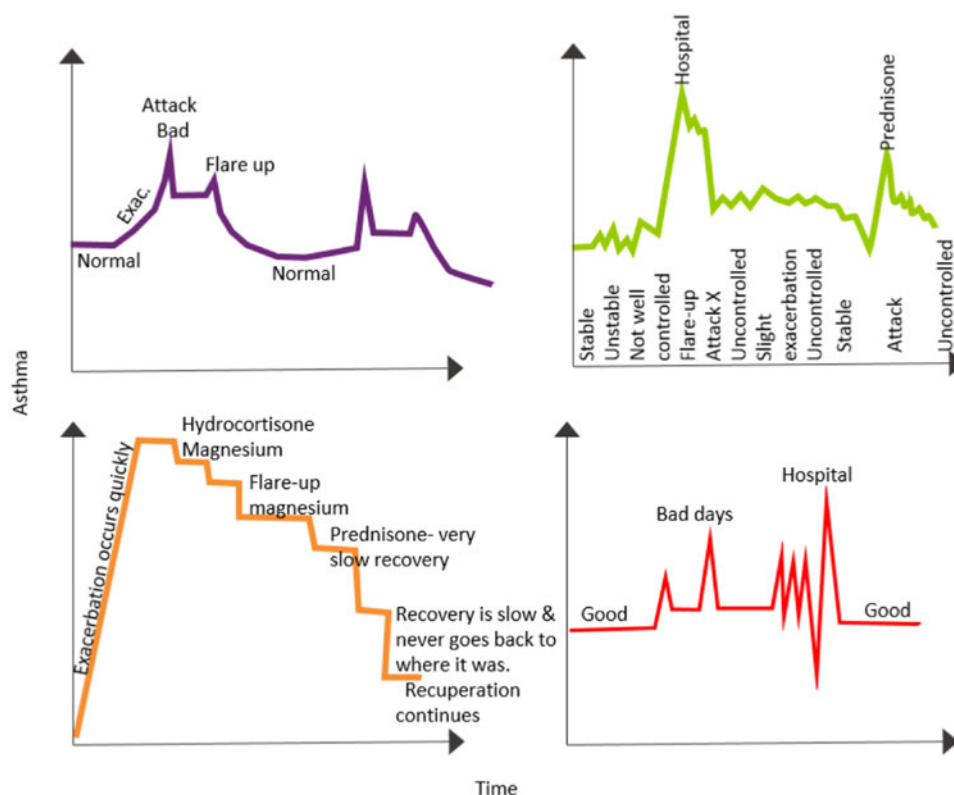


Figure 2. Four individual participant pictorial representations of their experience of exacerbations in relation to their daily life. Labels are participants own choice of words. Drawings have been graphically recreated.

most of my friends ... Usually the only reason you'd use exacerbation is because well that's what most medical practitioners use." Bob, 71 yr old male.

Similarly, Monica, 57 yr, female stated "I would be more comfortable – familiar with the term attack – amongst my peers, my family ..."

In some cases, the term "exacerbation" was associated with negative connotation or could lead to adverse events from the patients' perspective. The use of the term "exacerbation" by health professionals was described as "insulting" as it trivialized their experience, this is exemplified in the following two comments from focus group participants:

"I actually took offense to it (the term exacerbation) to start with, because I thought, for me to get into hospital, I'm having an attack. I'm in hospital – I'm having an attack. They would write it down as an exacerbation of your asthma, and I'm thinking, it's not a fricking exacerbation." Kirsty, 47 yr old female

"I feel that an exacerbation is dulling it down a bit. It's making it seem not as bad. To me it's like, oh yeah, you're an asthmatic and it's just a little bit worse. That's what it feels like." Paul, 44 yr old male

One participant described how use of "exacerbation" by clinicians could lead to failure to report important acute events;

"(Exacerbation) it's a longer word and it sounds confronting. If you're not entirely sure of the meaning it might worry you and then you might not even want to say it. You might say, oh I have no problems. Nothing's gone wrong, I don't want to talk about it." Stephanie, 33 yr old female.

Pictorial representations of acute asthma events for severe asthma participants

Participants' pictorial representations of their day-to-day experiences are shown in Figure 2. Participants could represent their baseline at any point along either the X or the Y axis. All chose to represent this on the Y axis. Of the four participants, three chose to represent the baseline level of asthma above "zero" on the Y axis indicating that their perception of their asthma was that it was never at a zero starting point. Peaks in asthma severity were labeled by participants as "attack," "bad" and "hospital." The term "exacerbation" was used by three participants to refer to the lead up period before an attack and three participants used "flare-up" to refer to milder worsening of symptoms either just prior or subsequent to the "attack." Following an acute event three participants tended to return to their own baseline, while one

indicated that their lung health is permanently impaired by each event.

Discussion

This qualitative study provides insights into the perspectives of patients with asthma in regard to their acute events. It highlights the language used by patients when referring to these acute events. Most participants with severe asthma preferred the term “attack” to describe episodes of acute asthma. In people with severe asthma “flare-up” and “exacerbation” were perceived as terms for less severe episodes or used by healthcare providers to medicalise the experience of an acute asthma episode.

Internationally, there is a lack of consensus over the most appropriate usage of exacerbation terminologies. The Global Strategy for Asthma Management and Prevention (16) acknowledges “exacerbation” as a useful term for scientific and clinical literature, however, it recommends “flare-up” for use with patients. “Attack” is not recommended due to the perception that it may not be understood to include gradual worsening. Participants quotes in the current study indicate that patients do however include gradual worsening when they describe an “attack”; “An attack, it creeps up to the point where you can’t, you can’t deal with it yourself.” These data also highlight the importance of patients and clinicians using consistent language that is accepted and understood by patients. This is supported by the results from a study by Blaiss et al. (9) who also highlighted that confusion about the meaning of terminologies is common. While 65% of physicians thought that the terms “attack,” “flare-up” and “exacerbation” meant the same thing, only 36% of patients with asthma held this view. Another 38% of patients thought that “attacks” were more “sudden,” “severe” and “serious” than “flare-ups” or “exacerbations,” requiring medical care or OCS, whereas physicians were more likely to say OCS was the discriminating factor (9).

In 2014, the Scottish Intercollegiate Guidelines Network and British Thoracic Society (SIGN/BTS) guideline replaced the term “exacerbation” with “attack” stating that “It is more understandable and gives a clearer indication of the need for action.” (17). However, data from the current study collected in two different countries, suggest that this recommendation has not translated to practice, at least in the two large regional centers included in the current study.

We recruited patients with severe asthma and a comparison group of people with milder asthma. By

definition people with severe asthma had more airflow limitation and increased medication requirements but were of similar age as the milder group, with similar living arrangement. Consistent with populations of mixed asthma severity in previous studies (9,10), people with severe asthma in the current study perceived the terminology used to describe acute asthma episodes differently to how it is intended. People with severe asthma experience a different disease profile to people with mild-moderate disease, particularly in relation to acute and life-threatening events. The current study provides the first insight into how this population use and perceive terminology used by healthcare providers and the general public. These important insights should be considered by clinicians when communicating with patients with severe asthma, in an effort to have patients better recognize and respond to their acute events, and better engage with this patient group.

The 2017 Lancet commission on asthma calls for zero tolerance of asthma attacks, and recommends the abandonment of the terms exacerbations and flare ups in an effort to highlight the importance of these events and reduce the current “weak responses” (2). This has been previously proposed in COPD (18), another obstructive airway disease in which exacerbations are common, important and have long term negative consequence (19). This approach has also been taken in other diseases including cardiovascular disease, where the term “heart-attack” activates a more aggressive response accompanied by routine risk stratification, implementation of care bundles and referral to well-funded cardiac rehabilitation programs (18). Similarly neurology has also reevaluated the nomenclature, referring to stroke as a “brain attack” in an effort to highlight the urgency of the event and prompt patients to take immediate action (20). On the other hand, flare ups are used in other conditions such as gout and fibromyalgia, these flare ups signify painful events that are temporary and not necessarily life threatening, as an acute myocardial infarct and stroke may be. Given the life-threatening nature of acute severe asthma events the use of the term attack seems fitting for this population in line with other disease areas.

Unlike people from the general asthma population, the severe asthma population represented in the current study had a high level of familiarity with the term “exacerbation.” Of the severe asthma interviewees, 90% were familiar with the term “exacerbation” in the current study compared to 24% (9) and 51% (10) in previous studies of mixed severity asthma populations.

This is likely due to the severe asthma population experiencing more frequent and more severe acute episodes, as well as a higher symptom burden in general, resulting in increased contact with healthcare providers in relation to their asthma management. Healthcare providers use the term “exacerbation” preferentially (9) and thus people with severe asthma have increased exposure to the term. Even so, this population expressed limited and highly variable understanding of the word. While some participants perceived “exacerbation” to imply that their asthma is worse but is being controlled, others described “exacerbations” as life-threatening. Some participants were familiar with the term but when asked to explain what it means their understanding was inaccurate. These results directly support the suggestion by the Lancet commission that the use of the term “exacerbation” leads to a failure to discriminate between loss of symptom control and genuine attacks. Furthermore, participant’s views supported the suggestion that the term downplays the seriousness of acute attacks, and implies that they are reversible and merely irritating.

Several participants made a distinction between terms according to whether they were communicating with friends or healthcare providers. These participants reserved “exacerbation” for use within the healthcare system and “attack” or “flare-up” for conversing with friends and family, reasoning that people without asthma would not understand the term. When Blaiss et al. (9) surveyed clinicians on their preferred terminology, 77% of clinicians reported that they used the word “exacerbation” when discussing acute episodes with patients (9). Furthermore, while participants in the current study, in line with results from Blaiss et al. (9) and Vincent et al. (10), reported “attack” to be their preferred term, clinicians have been shown to prefer this term the least (9). Thus, there is a disconnect between severe asthma patient and clinician preferred terminologies. Patient misunderstanding of terms combined with clinician preferential use may lead to poor communication and negative outcomes for severe asthma patients (2,21–23). Poor clinician-patient communication has been associated with poor use of asthma self-management plans and guidelines as well as suboptimal treatment adherence (24). A systematic review of the experiences of people living with severe asthma confirms these findings, with participants stating that they felt disempowered when their health care providers were authoritarian or paternalistic and they reported the importance of an equal two way relationship (25). Further when shared decision making is implemented

in asthma, that is shared communication between patients and clinicians, it results in improved treatment adherence, quality of life and clinical outcomes (26).

Written actions plans (WAPs) have been shown to facilitate improved asthma outcomes (27,28). Differences in the ways patients and clinicians communicate, including incongruous language use, has been identified as a limiting factor to WAP use (23,29). Thus, while WAP use may overcome some of the communication barriers between patients and clinicians via increased self-management, differences in communication and failure to use patient-preferred terminology regarding asthma management may contribute to under-utilization of WAPs that exist (30) and hinder the efficacy of existing plans. Greater concordance between patients and clinician terminology use may facilitate increased use and efficacy of what is an essential component of optimal asthma management.

The chronicity of the burden of severe asthma on people’s lives was highlighted in the pictorial representation participants produced, with three of the four participants indicating that they felt their baseline was above zero. The terminology used by participants reflected that in interviews with the terms “flare up” and “exacerbation” used to label either small increases in asthma symptoms or lead up to acute events that were labeled as “attacks.”

This study has a number of strengths and some limitations. The study was conducted in both the UK and Australia strengthening the representativeness of the findings. Additionally, the preferences for terminology have not been reported previously in people with severe asthma, this, in combination with the inclusion of a mild-to-moderate asthma comparison group provides novel findings for a high burden population. The study could be strengthened by the collection of data on past year exacerbation frequency so as to enable a comparison between people who experience frequent and non-frequent attacks. The sample size may appear small but is consistent with qualitative studies and as data were collected until saturation was achieved we do not believe that this is a limitation. Finally, given the focus on terminology we acknowledge that in non-English speaking populations and in patients from different cultural areas the experiences and perspectives of participants may be very different.

Conclusion

Our findings highlight that “exacerbation” and “flare-up” have different meanings to patients with severe asthma than how they are intended. These data

provide important person-centred support to the recommendations of the Lancet commission (2) in regard to the use of the term “attack.” The term “attack” better reflects the severity of events from the severe asthma patient’s perspective.

Declaration of interest

The study was supported by the Center of Excellence in Severe Asthma, The Hunter Medical Research Institute and the John Hunter Charitable Trust. All authors have no conflicts of interest to declare.

ORCID

Peter G. Gibson  <http://orcid.org/0000-0001-5865-489X>
Vanessa M. McDonald  <http://orcid.org/0000-0001-9890-3408>

References

- McDonald V, Gibson P. Exacerbations of severe asthma. *Clin Exp Allergy*. 2012;42:670–7. doi:10.1111/j.1365-2222.2012.03981.x.
- Pavord ID, Beasley R, Agusti A, Anderson GP, Bel E, Brusselle G, Cullinan P, Custovic A, Ducharme FM, Fahy U, et al. After asthma: redefining airways diseases. *Lancet*. 2018;391:350–400.
- Bai T, Vonk J, Postma D, Boezen H. Severe exacerbations predict excess lung function decline in asthma. *Eur Respir J*. 2007;30:452–6. doi:10.1183/09031936.00165106.
- Matsunaga K, Hirano T, Oka A, Tanaka A, Kanai K, Kikuchi T, Hayata A, Akamatsu H, Akamatsu K, Koh Y, et al. Progression of irreversible airflow limitation in asthma: correlation with severe exacerbations. *J Allergy Clin Immunol Pract*. 2015;3:759–64.e1. doi:10.1016/j.jaip.2015.05.005.
- Adams RJ, Smith BJ, Ruffin RE. Factors associated with hospital admissions and repeat emergency department visits for adults with asthma. *Thorax* 2000;55:566–73. doi:10.1136/thorax.55.7.566.
- Eisner MD, Katz PP, Yelin EH, Shiboski SC, Blanc PD. Risk factors for hospitalization among adults with asthma: the influence of sociodemographic factors and asthma severity. *Respir Res*. 2000;2:53–60. doi:10.1186/rr37.
- Lieu TA, Quesenberry CP, Sorel ME, Mendoza GR, Leong AB. Computer-based models to identify high-risk children with asthma. *Am J Respir Crit Care Med*. 1998;157:1173–80. doi:10.1164/ajrccm.157.4.9708124.
- McDonald VM, Hiles SA, Godbout K, Harvey ES, Marks GB, Hew M, Peters M, Bardin PG, Reynolds PN, Upham JW, et al. Treatable traits can be identified in a severe asthma registry and predict future exacerbations. *Respirology* 2019;24:37–47. doi:10.1111/resp.13389.
- Blaiss MS, Nathan RA, Stoloff SW, Meltzer EO, Murphy KR, Doherty DE. Patient and physician asthma deterioration terminology: results from the 2009 asthma insight and management survey. *Allergy Asthma Proc*. 2012;33:47–53. doi:10.2500/aap.2011.32.3520.
- Vincent SD, Toelle BG, Aroni RA, Jenkins CR, Reddel HK. “Exasperations” of asthma: a qualitative study of patient language about worsening asthma. *Med J Aust*. 2006;184:451–4.
- Suruki R, Daugherty J, Boudiaf N, Albers F. P221 Evaluation of exacerbation frequency and re-hospitalisation, and risk for subsequent exacerbations in asthma patients in a UK primary care setting. *Thorax* 2015;70:A188. doi:10.1136/thoraxjnl-2015-207770.357.
- Tough SC, Hessel PA, Ruff M, Green FH, Mitchell I, Butt JC. Features that distinguish those who die from asthma from community controls with asthma. *J Asthma*. 1998;35:657–65.
- Griswold SK, Nordstrom CR, Clark S, Gaeta TJ, Price ML, Camargo CA. Jr. Asthma exacerbations in North American adults: who are the “frequent fliers” in the emergency department? *Chest* 2005;127:1579–86. doi:10.1378/chest.127.5.1579.
- Gibson PG, Powell H, Coughlin J, Wilson AJ, Abramson M, Haywood P, Bauman A, Hensley MJ, Walters EH. Self-management education and regular practitioner review for adults with asthma. *Cochrane Database Syst Rev*. 2003;3:CD001117. doi:10.1002/14651858.CD001117.
- Chung KF, Wenzel SE, Brozek JL, Bush A, Castro M, Sterk PJ, Adcock IM, Bateman ED, Bel EH, Bleecker ER, et al. International ERS/ATS guidelines on definition, evaluation and treatment of severe asthma. *Eur Respir J*. 2014;43:343–73. doi:10.1183/09031936.00202013.
- Global Initiative for Asthma. Global Strategy for Asthma Management and Prevention 2014. Available from: www.ginasthma.org [last accessed 2 March 2019].
- British guideline on the management of asthma: a national clinical guideline. Edinburgh, Scotland and London, England: British Thoracic Society, Scottish Intercollegiate Guidelines Network; 2016.
- FitzGerald JM. Targeting lung attacks. *Thorax* 2011; 66:365–6. doi:10.1136/thx.2010.156760.
- McDonald VM, Osadnik C, Gibson PG. Treatable traits in acute exacerbations of chronic airway diseases. *Chron Respir Dis*. 2019;16:147997311986795. doi:10.1177/1479973119867954.
- Brown MM. Brain attack: a new approach to stroke. *Clin Med*. 2002;2:60–5. doi:10.7861/clinmedicine.2-1-60.
- Apter AJ, Reisine ST, Affleck G, Barrows E, ZuWallack RL. Adherence with twice-daily dosing of inhaled steroids. *Am J Respir Crit Care Med*. 1998; 157:1810–17. doi:10.1164/ajrccm.157.6.9712007.
- Partridge MR, Hill SR. Enhancing care for people with asthma: the role of communication, education, training and self-management. 1998 World Asthma Meeting Education and Delivery of Care Working Group. *Eur Respir J*. 2000;16:333–48.
- Ring N, Jepson R, Hoskins G, Wilson C, Pinnock H, Sheikh A, Wyke S. Understanding what helps or hinders asthma action plan use: a systematic review and

- synthesis of the qualitative literature. *Patient Educ Couns*. 2011;85:e131–43. doi:[10.1016/j.pec.2011.01.025](https://doi.org/10.1016/j.pec.2011.01.025).
24. Moffat M, Cleland J, van der Molen T, Price D. Poor communication may impair optimal asthma care: a qualitative study. *Fam Pract*. 2007;24:65–70. doi:[10.1093/fampra/cml062](https://doi.org/10.1093/fampra/cml062).
 25. Eassey D, Reddel HK, Foster JM, Kirkpatrick S, Locock L, Ryan K, Smith L. “...I’ve said I wish I was dead, you’d be better off without me”: a systematic review of people’s experiences of living with severe asthma. *J Asthma*. 2018;56:311–22. doi:[10.1080/02770903.2018.1452034](https://doi.org/10.1080/02770903.2018.1452034).
 26. Wilson SR, Strub P, Buist AS, Knowles SB, Lavori PW, Lapidus J, Vollmer WM. Shared treatment decision making improves adherence and outcomes in poorly controlled asthma. *Am J Respir Crit Care Med*. 2010;181:566–77. doi:[10.1164/rccm.200906-0907OC](https://doi.org/10.1164/rccm.200906-0907OC).
 27. Zemek RL, Bhogal SK, Ducharme FM. Systematic review of randomized controlled trials examining written action plans in children: what is the plan? *Arch Pediatr Adolesc Med*. 2008;162:157–63. doi:[10.1001/archpediatrics.2007.34](https://doi.org/10.1001/archpediatrics.2007.34).
 28. Gibson P, Powell H. Written action plans for asthma: an evidence-based review of the key components. *Thorax* 2004;59:94–9. doi:[10.1136/thorax.2003.011858](https://doi.org/10.1136/thorax.2003.011858).
 29. McDonald VM, Higgins I, Simpson JL, Gibson PG. The importance of clinical management problems in older people with COPD and asthma: do patients and physicians agree? *Prim Care Respir J*. 2011;20:389. doi:[10.4104/pcrj.2011.00025](https://doi.org/10.4104/pcrj.2011.00025).
 30. Tan DJ, Burgess JA, Perret JL, Bui DS, Abramson MJ, Dharmage SC, Walters EH. Non-pharmacological management of adult asthma in Australia: cross-sectional analysis of a population-based cohort study. *J Asthma*. 2018;1–8. doi:[10.1080/02770903.2018.1545030](https://doi.org/10.1080/02770903.2018.1545030).