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ORIGINAL RESEARCH

An ongoing Confidential Enquiry into asthma deaths in the Eastern Region of the UK, 2001–2003

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KEYWORDS

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Summary

Introduction: The Eastern Region Confidential Enquiry into asthma deaths started in 2001. It incorporates the Norwich and East Anglian Enquiries started in 1988 and 1992, respectively. The aim of this study was to analyse all asthma deaths in the Eastern region between 2001 and 2003, to elicit any factors contributing to the patients' deaths, and to make comparisons with the previous Norwich and East Anglian data.

Method: Patient details were obtained for all deaths in the Eastern Region under the age of 65 with asthma recorded in the first part of the death certificate. Patients' notes were reviewed by members of the Working Group - a consultant chest physician and a general practitioner (GP). In most cases, the patient's GP was contacted. Data were obtained on the patients' asthma care, asthma severity, terminal attack, psychosocial and behavioural factors, allergies, precipitating factors, and post-mortem findings. The quality of medical care was assessed and compared with national guidelines.

Results: Total study population was 5.25 million. Only 57/95 notified deaths (60%) were confirmed as asthma deaths. 311 asthma deaths have been studied between 1988 and 2003. In 2001–2003, male:female ratio was 3:2. Further data were unavailable on three cases. 53% of patients had severe asthma and 21% moderately severe disease. In 19 cases (33%) at least one significant co-morbid disease was present. Monthly death rates peaked in August, with a smaller peak in April. In 11 cases (20%), mostly males aged under 20, the final attack was sudden and 10/11 occurred between April and August. In 81% of cases there were significant behavioural and/or psychosocial factors such as poor compliance (61%), smoking (46%), denial (37%), depression (20%) and alcohol abuse (20%). The overall medical care of the patient was appropriate in 33% of cases.

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Conclusions: Between 1988 and 2003 there was a downward trend in asthma mortality rate in East Anglia. In 2001–2003, misclassification of deaths attributed to asthma was still common. Most patients who die of asthma have severe asthma. In 81% of cases, behavioural and psychosocial factors contributed to the patient's death. In 80% of deaths the final attack was not sudden, and may have been preventable. Almost all sudden deaths occurred between April and August, suggesting a seasonal allergic cause. In two-thirds of asthma deaths, medical management failed to comply with national guidelines. 'At-risk' asthma registers in primary care may improve recognition and management of 'at-risk' patients.

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Introduction

Studies into asthma deaths began in the 1960's in response to concern over increasing mortality rates [1]. In 1982, the then British Thoracic Association (BTA) published a survey on asthma deaths from two regions of England, showing that preventable factors had been identified in 79% of the deaths studied [2], the main ones being underestimation of the severity of asthma by the doctor and patient, and insufficient treatment with systemic steroids [2,3]. In 1985, data over a two-year period from New Zealand showed that in 39% of asthma deaths there were psychosocial factors which had probably contributed to the patient's death [4]. These early studies contributed to the increasing interest in primary care management of asthma over the next fifteen years, as shown by the development of groups such as the General Practice Airways Group (GPIAG) [5] and the evolving role of the primary care asthma nurse [6–8].

In 1988, a Confidential Enquiry into asthma deaths was started in the Norwich Health District [9], an area with a population of 500,000, based on methods developed for the BTA and New Zealand studies [2,4]. This enquiry was extended to East Anglia (Norfolk, Suffolk and Cambridgeshire - population 1.75 million) in 1992, and importantly, for the first time, the enquiry team included a general practitioner (GP) who reviewed the deceased's general practice notes and interviewed the patient's GP [10]. Results showed that in 79% of cases the patient had adverse psychosocial factors such as denial, poor compliance, depression and domestic stress, which put them 'at risk' of a fatal or near-fatal asthma attack. Data from the East Anglian enquiry were incorporated into a later national enquiry [11], and despite some variation in the incidence of psychosocial factors shown in other UK regional confidential enquiries [12,13] and studies of asthma deaths in Australia [14], the importance of psychosocial and behavioural factors

for developing fatal or near-fatal asthma [14,15] is now well established and documented in UK national guidelines [17].

In 2001, the East Anglian Confidential Enquiry was extended to cover the whole of the Eastern Region of the UK with a total study population of 5.25 million. The aim of this study was to analyse retrospectively all asthma deaths in patients under the age of 65 in the region over the three-year period 2001–2003, to elicit possible contributory factors to the patients' deaths, and to draw comparisons with data from the smaller Norwich [9] and East Anglian [10] studies as well as other national and international studies.

Method

The Medical Co-ordinator requested patient details from the Office of National Statistics (ONS), relating to all deaths under the age of 65 in the region over the previous year with asthma recorded in the first part of the death certificate. For the purposes of this study, the Eastern Region of the UK consists of the counties of Norfolk, Suffolk, Cambridgeshire, Bedfordshire, Essex and Hertfordshire (excluding those areas within the M25 London orbital motorway), as well as the Unitary Authorities (Districts) of Peterborough, Luton, and Southend-on-sea.

Each year, patient details were distributed to two other members of the Working Group - a consultant chest physician in the District General Hospital (DGH) nearest to where the patient lived, and a GP responsible for covering that part of the county. The chest physician obtained the local hospital notes (if available) and completed a detailed proforma related to the patient's asthma, asthma care, terminal attack and other appropriate relevant factors. At the same time, the GP obtained the general practice records and made a detailed review of the patient's notes.

Patients were excluded from the enquiry at this stage if it was clear from the hospital and/or general practice records that the main cause of death was not asthma.

The GP member then contacted the deceased's GP if possible, arranging a meeting or telephone discussion, and completed a detailed proforma similar to those used previously [9,10], focussing on the patient's asthma, ongoing asthma care, terminal attack, and other relevant details such as psychosocial factors which had impacted on the patient's care. An assessment was made of the patient's asthma severity based on information within the hospital and general practice records. Severity was categorised according to national guideline treatment step [16,17], whether or not rescue oral steroids had been prescribed over the previous year, and whether there was pre-existing high morbidity such as sleep disturbance [10]. Details of post-mortem examinations, if undertaken, were summarised on a third form. Where available, data on atopy, known allergies, previous sudden asthma attacks, and possible anaphylactic precipitating factors, were also obtained.

The final Panel Form, incorporating all information gleaned from the records and the interview with the deceased's GP, was then completed by the relevant chest physician and GP following a full discussion with other members of the Working Group at the twice-yearly Group meetings. National guidelines on asthma management [16,17] were used throughout in order to define standards and to make judgements on the appropriateness of medical care received by the patient.

A report drafted annually by the Medical Co-ordinator is circulated to all members of the Working Group for comments, and the final Enquiry Report is sent to all Consultant chest physicians in the region and Primary Care Trust (PCT) chief executives for distribution to all GPs.

Results

The total study population, according to the 2001 Census [18], was 5,245,012 (see Table 1).

Within this region, according to the ONS data, 95 deaths were attributed to asthma over the three-year period 2001–2003. However, only 57 deaths (60%) were confirmed as asthma deaths. The other 38 deaths (40%) were not due to asthma, but were due to chronic obstructive pulmonary disease (COPD) in 13 cases, cardiac disease (11), pneumonia

Table 1 Population of the Eastern Region of the UK according to County or District (Unitary Authority), as per the 2001 Census

Norfolk	796,728
Suffolk	668,553
Cambridgeshire	552,658
Essex	1,310,835
Bedfordshire	381,572
Hertfordshire	1,033,977
Luton	184,371
Peterborough	156,061
Southend-on-sea	160,257
Total	5,245,012

(9), and overdoses (4), as well as anaphylaxis (1), tracheal stenosis (1), sarcoid (1), Addison's disease (1), and diabetes (1). Some patients had more than one cause contributing to their death.

Of the 57 deaths due to asthma, in only three cases was there insufficient information to make any further analysis, and all were from 2003. In 19 asthma deaths, the patient had one or more significant co-morbid diseases such as COPD in 11 cases, ischaemic heart disease (2), cerebral palsy and epilepsy (1), Hodgkins disease (1), acute renal failure (1), rheumatoid arthritis (1), hypertension (1), severe osteoarthritis and breast cancer (1), alcoholic hepatitis (1), morbid obesity (1), and eczema and nut allergy (1).

Figure 1 shows the number of asthma deaths per year within the Norwich Health District from 1988 onwards, the number of deaths annually in East Anglia (incorporating the Norwich figures) from 1992 onwards, and the number of deaths per year in the Eastern Region (incorporating the East Anglia figures) for 2001–2003.

Figure 2 shows the ages of the 57 patients who suffered asthma death in the Eastern region in 2001–2003 according to the age ranges 0–14, 15–24, 25–34, 35–44, 45–54, and 55–64.

Figure 3 shows the number of asthma deaths per month in 2001–2003 ($n=57$) and also shows the

Table 2 Sex ratio and asthma severity of patients who suffered asthma death in 2001–2003 ($n=57$), and comparison with data from 1988–1991 ($n=24$).

	1988–1991	2001–2003
N	24	57
M:F	7:17	34:23
Severe	17 (71%)	30 (53%)
Moderately severe	6 (25%)	12 (21%)
Mild		9 (16%)
Severity not known	1	6 (11%)

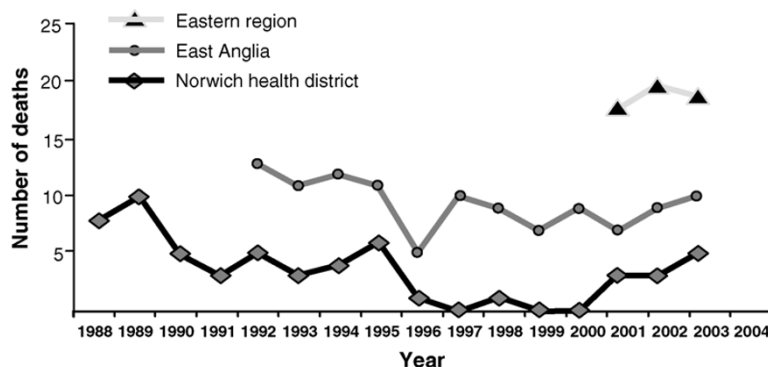


Figure 1 Total number of asthma deaths/year in the Norwich Health District, East Anglia, and the Eastern Region of the UK, 1988–2003.

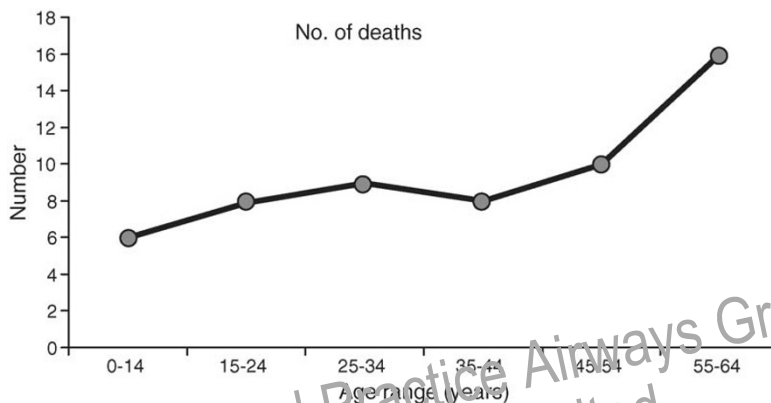


Figure 2 Number of asthma deaths ($n = 57$) according to age range, 2001–2003.

deaths per month for the whole period (1988–2003) covered by the Norwich, East Anglian and Eastern Region Enquiries ($n = 311$). From 1988 to 2003 there was a peak in death rate in December (41 deaths), a plateau between May to September with about 30 deaths/month, and about 20 deaths/month in January to April and October to November. In

2001–2003 there was a peak in mortality rate in August and a smaller peak in April.

Table 2 shows the sex ratio and asthma severity for the patients who died during 2001–2003, and compares this with the 1988–1991 figures for the Norwich Health District first published in 1993 [9]. In 2001–2003, the ratio of men to women was

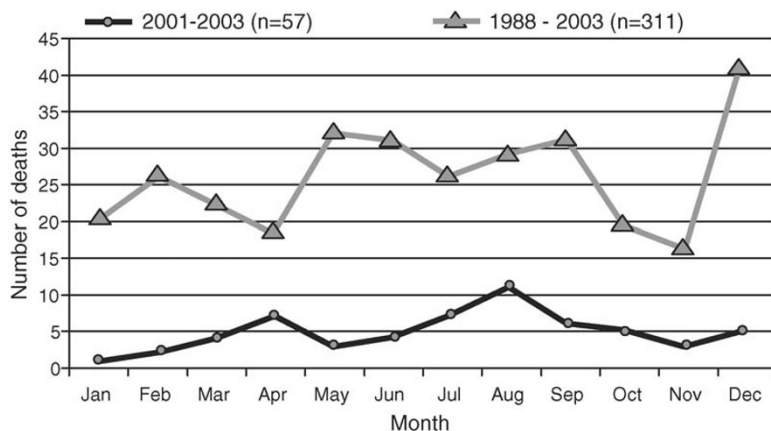


Figure 3 Asthma deaths by month for the period 2001–2003 ($n = 57$) and for the total period 1988–2003 ($n = 311$).

Table 3 Patient characteristics of the 11 patients who suffered sudden death from asthma, Eastern Region, 2001–2003.

Pt no	Age	Sex	DoD	Severity	Inhaled steroids	Oral prednisolone	Previous admissions/ near fatal asthma (NFA)	Atopy	Poor compliance/ psychosocial adversity	Other
1	47	M	Aug 01	Moderate seasonal	None	No	?	Attacks in July/August	Smoker	
2	51	F	Dec 01	Severe chronic	Yes	Yes	Yes	Yes		Died at Horse of the Year Show
3	10	M	Aug 01	Severe	?	?	?	?	Possible inhaled steroid compliance problems	No regular GP assessment/not referred to hospital despite previous sudden attacks
4	15	M	Aug 01	Severe	Yes	In courses	Yes, out of area	Died after walking dog	Smoker/domestic problems	Not referred for hospital FU after admission out of area
5	11	F	Jul 01	Mild	? probably ran out	?	No	Sudden attack at a party		Inadequate GP FU
6	20	M	May 02	Mild	Erratic use	?	No	?	Poor compliance & denial	Student at university
7	15	M	Jun 02	Mild	No	No	No	?		Found dead in bed 5 days after SCUBA diving
8	57	F	Jul 02	Moderate	Yes, but probably needed higher dose in July	?	Previous attacks in July, August & September		Poor compliance & denial	Also had rheumatoid arthritis & ischaemic heart disease
9	16	M	Apr 02	Severe brittle	Yes	?	3 previous NFAs	Pet rat. Allergic rhinitis	Family discordance/Child psychiatrist referral/school absence/very strict parents/smoker	Delayed OP FU/discharged Feb 02 with 6/52 FU appointment
10	11	M	Apr 03	Severe	Yes	Under treated with oral prednisolone. Not discharged on them 3 days before death	Previous admissions	Died after acute diarrhoea & vomiting	Mother left home 1/12 before death. Used A&E and Out of Hours service rather than GP	Hospital FU probably not sufficiently frequent
11	18	M	Aug 03	Mild	No	No	No	Urticaria		Died at Reading Festival. Had used brother's Salbutamol occasionally in past. PM asthma

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Table 4 Behavioural or psychosocial factors contributing to patients' deaths from asthma, Eastern Region, 2001–2003, (*n* = 54).

	<i>N</i> = 54
None	10 (19%)
Poor compliance/failure to attend	33 (61%)
Denial	20 (37%)
Depression	11 (20%)
Alcohol abuse	11 (20%)
Significant smoking	25 (46%)
Family disharmony	8 (15%)
Adolescents alone during fatal attack	2 (4%)
Single parent with toddler	2 (4%)
Severe learning disability	2 (4%)
Redundancy, spouse with cancer, long distance lorry driver	1 each

approximately 3:2, whereas in 1988–1991 it was approximately 2:5. 53% of the patients who died in 2001–2003 had severe asthma, and 21% moderately severe disease.

In 2001–2003, 11 deaths (20.4%) were due to sudden severe asthma attacks. Table 3 shows data on these 11 patients. Eight out of 11 were male, and only three were over the age of 20. Five of the patients were on regular inhaled corticosteroids. Five patients had a history of previous hospital admissions and one of these (patient number 9) had severe brittle asthma and had had three previous near-fatal attacks. Four of the patients died in August, two in July, two in April, and one in May, June, and December. Three patients (numbers 2, 9 and 11) had a definite history of atopy (longstanding atopy, allergic rhinitis and urticaria), patient number 1 had had previous attacks in July and August and died in August, patient number 4 died after walking his dog in August, and patient number 3 had had previous sudden attacks and died

in August. In four cases (numbers 5,6,7 and 11) the patient's asthma was considered mild: one had used his sibling's salbutamol inhaler only occasionally in the past and died suddenly at a pop festival; one developed her fatal attack in the vicinity of a night club after inadequate GP follow-up; another had his fatal attack four and a half days after scuba diving; and one was a student with poor compliance and denial. However, in the other 43 cases (79.6%), the final fatal attack definitely was not sudden.

Table 4 shows the adverse behavioural or psychosocial factors contributing to the patients' deaths, which were present in 81% of cases. The commonest adverse factor was poor compliance with treatment and/or failure to attend for follow-up (61% of cases), followed by significant smoking (46%), denial (37%), depression (20%), and alcohol abuse (20%). Twenty-one of 30 patients with severe asthma had evidence of poor compliance; two of these were 17-year old men with previous hospital admissions who died whilst their parents were away from home. One patient was a long-distance lorry driver who was often unable to attend his GP's surgery. About a quarter of these poorly-compliant patients with severe asthma also had co-existing depression and/or alcohol abuse, and there were two patients with learning difficulties or cognitive impairment. In one case, there was a family history of poor compliance. Three patients had been removed from a previous GP's list at least once in the past.

Table 5 shows the doctor, hospital, or general practice factors which the Working Group considered to have contributed to the patients' deaths, and shows a comparison with the 1988–1991 data. The overall care of the patient was considered appropriate in 33% of cases. In secondary care, there was inadequate hospital follow-up in 21% of cases, and in over a quarter of cases (28%) care was not transferred to a specialist chest physician whilst the patient was in hospital. In primary care, follow-up was deemed

Table 5 Medical care factors contributing to patients' deaths from asthma, Eastern Region, 2001–2003, (*n* = 54), and comparison with data from the Norwich Health District, 1988–1991, (*n* = 24).

	1988–91 <i>n</i> = 24	2001–03 <i>n</i> = 54
Overall routine care appropriate	4 (17%)	18 (33%)
Oral/inhaled steroids not prescribed or doses inadequate	5 (21%)	16 (33%)
Not referred to specialist chest physician	3 (12.5%)	15 (28%)
Inadequate PF monitoring	9 (37.5%)	9 (17%)
No documented education	15	—
Inadequate GP follow-up	Not recorded	18 (33%)
Inadequate hospital follow-up	Not recorded	11 (21%)

inappropriate in 33% of cases, including 13 patients who were not referred to hospital appropriately or in a timely manner. In one case, a patient with presumed mild asthma was diagnosed and treated as a result of telephone consultations only, each August over a two-year period, and then died in August the following year. Other issues included not having systems in place to chase up patients who regularly failed to attend their appointments and not recognising the serious prognostic implications of severe asthma and co-existing psychiatric illness.

Discussion

This Eastern Region Confidential Enquiry incorporates the longest continuous confidential enquiry into asthma deaths reported from any country in the world, with data on 311 asthma deaths from 1988 onwards. For the years 2001–2003 it provides data on 57 asthma deaths occurring within a study population of over 5 million people (Table 1), and is therefore similar in size to previous UK large regional enquiries [12,13].

Limitations of this study

The main limitations of this study are inherent in its methodology. As with other confidential enquiries into deaths (for example, enquiries into maternal [19] and perioperative [20] deaths), this study is retrospective and uncontrolled and is simply a form of audit or significant event analysis. In terms of data collection, data can sometimes be absent or of poor quality. In the UK, some general practices are fully computerised, and some partially so, and it is common to receive patient records where consultation data was recorded manually on record cards whereas prescribing data was computerised. In some cases, practices had returned paper-based clinical records to the Health Authority after the patient's death without a printout of the computerised record. In both general practice and in hospital, the quality of clinical recording, be it manual or computerised, varied considerably. These factors can make data collection by members of the Working Group difficult, and this explains, for example, some of the absent data related to oral steroid prescribing in Table 3.

In terms of data analysis, the main limitation is the potential for subjectivity when making judgements about patient characteristics or the quality of asthma care, and these aspects are discussed more fully below.

Potential impact of this study

Though there are recognised inherent methodological weaknesses with any retrospective study, audit and significant event analysis can be a potent mechanism for education and learning. This has been confirmed by a survey investigating the impact on GPs of written reports from the East Anglian enquiry [21]. Almost 70% of East Anglian GPs had read at least one report over the previous few years and half of these stated that the reports had influenced their patient management. In addition, 80% of those who read the report could identify risk factors for asthma death, compared to 22% of those who had not read enquiry reports.

Misclassification of asthma deaths

This study confirms that the raw ONS data on asthma deaths based on death certificates is unreliable, and that the true figure for asthma deaths is about 30–40% lower, in accordance with all previous studies [10,12,13,22–24]. As before [10], we studied deaths only in patients under the age of 65 in an attempt to minimise diagnostic confusion with COPD; this allows comparison with the BTA [2] and Welsh [13] studies, as well as the 5–64 year age subgroup of the Scottish study [12].

Asthma or COPD?

There are national and international guidelines which include sections on the diagnosis of asthma [17] and COPD [34,35], and we defined asthma and COPD accordingly. In 13 cases, patients were excluded from the study because data (such as previous lung function tests or post-mortem data) showed that they died of COPD rather than asthma. Conversely, asthma and COPD are two common but distinct conditions with differing pathology [36], aetiology, and natural histories, which can occur simultaneously in the same patient [37]. In 11 of the 57 asthma deaths the patient died of asthma but also had co-morbid COPD.

Trend in asthma mortality rates

National asthma mortality rates have fallen by approximately 40% between 1979 and 1999 [25]. As shown in Figure 1, during the course of the confidential enquiries in the Eastern region from 1988 to 2003 there has been a downward trend in asthma mortality rates. However, because of the uncontrolled nature of the methodology it is not possible to say whether publication of annual

reports and the improved awareness of local GPs [21] and hospital consultants is responsible.

Psychosocial and behavioural factors

A high proportion of patients, 81%, had psychosocial or behavioural factors contributing to their death from asthma (Table 4), in accordance with previous data [10]. However, psychosocial and behavioural factors which can impact sufficiently to contribute to a patient's death from asthma may be perceived and assessed differently by different people, thereby making an absolute definition difficult. If the patient was regularly taking psychotropic medication and had a recognised mental illness requiring regular input from their GP or Mental Health Team, and/or if the patient's GP was confident that mental health issues played a significant role in the events leading up to the patient's death from asthma, then the psychological factors were considered significant. Similarly, the significance of behavioural factors such as poor compliance, denial, and alcohol abuse, and social factors such as family disharmony, single parenthood, and recent redundancy, often depended upon verification by the patient's own GP.

Asthma severity and 'difficult' asthma

Just over half of the patients (53%) who died had severe asthma, and 21% had moderately severe disease (Table 2). Yet 'severe' and 'difficult' asthma may not be the same. In a recent review [26], 'severe' asthma was defined as occurring in a patient who has been admitted to hospital with an acute severe attack [16,17] or who requires Step 4 or 5 treatment [16,17]. 'Difficult' asthma was defined as being present in a patient with a confirmed diagnosis of asthma whose symptoms and/or lung function abnormalities are poorly controlled with prescribed treatment which experience suggests would usually be effective [26]. Moffat et al. showed that there were qualitative differences in perception of the terms 'severe' and 'difficult' asthma amongst a group of GPs [27], with 'severe asthma' being a medical term and 'difficult asthma' implying poor control due to a variety of reasons including social and psychological problems.

Quality of care

Overall, routine asthma care of the deceased patients was considered appropriate in 33% of cases (Table 5). This figure compares with 17% in the original study from the Norwich Health District

[9], 50% in the East Anglian [10] and Scottish [12] studies and 71% in the Welsh study [13]. Again, this illustrates some of the difficulties of retrospective analysis even when using criteria published in guidelines in order to aid objectivity. However, all of these studies identify continuing problems. In secondary care there is inadequate hospital follow-up, and patients admitted with severe asthma are still not being transferred to the care of a specialist chest physician as recommended in national guidelines [17]. In primary care, inadequate follow-up, inappropriate telephone consultations, failure to refer to a specialist chest physician, and failure to treat acute asthma exacerbations with appropriate doses of oral steroids, are all still occurring.

Sudden asthma deaths and seasonality

A fifth (11/54) of patients had sudden severe attacks. Almost all of these (10/11) occurred between April and August (Table 3). This seasonality is mirrored in the monthly mortality rates for 2001–2003 (Figure 3) which show clear peaks in April and August. Furthermore, the monthly death rates for the 311 asthma deaths from 1988–2003 show a clear increase in May to September compared with January to April and October to November, albeit that the peak death rate is in December. Despite the peak death rate in December, which we presume could possibly be due to influenza or other viral asthma trigger factors, this suggests that a seasonal allergen could be responsible, at least for a substantial number of asthma deaths. It is well recognised that sensitisation to the fungal allergen *Alternaria alternata* is a risk factor for near-fatal and fatal asthma [31].

Eight out of 11 sudden deaths were in male patients under the age of 20. Three patients had a history of atopy, two other patients had had previous attacks in August and died in August, and one died walking his dog in August. It is possible, therefore, that at least half of the patients who suffered sudden asthma death were atopic. In addition, patient number 2 died suddenly at the Horse of the Year Show in December, but we have been unable to elicit a history of allergy to horses. Skin testing is rarely performed on asthma patients in the UK, and therefore general atopy and specific allergies are not routinely identified in these patients. We have begun to address this by enquiring about atopy and known allergies when reviewing the deceased's medical records.

Sudden death in atopic patients can result from anaphylaxis. Serum assays of mast cell

tryptase obtained up to 72 hours post-mortem could be used to identify this group of patients [32,33].

Non-sudden fatal asthma attacks and the 'at-risk' asthma patient

In about 80% of the 57 asthma deaths, the fatal asthma attack was not sudden. There should therefore be time for the patient, their relatives or friends, or healthcare professionals, to initiate effective action. The same applies to patients admitted to hospital with severe asthma [17]. There are many similarities between patients who die from asthma, patients with near-fatal attacks of asthma, and patients admitted to hospital with severe asthma [28,29].

This emphasises the importance of identifying 'at-risk' patients with a combination of severe asthma and one or more adverse behavioural or psychosocial features [17]. It is now well established that such patients are at risk of serious adverse outcomes including death [10,12,13,17]. Not attending scheduled appointments identifies the majority of patients with severe asthma and co-existing adverse behavioural or psychosocial characteristics [30]. In a recent controlled retrospective study of an 'at-risk' asthma register in one general practice, 26 'at-risk' patients (about 3% of the total number of asthma patients in the practice) were compared to 26 controls. Prior to the introduction of the register, the 'at-risk' group had more hospital admissions for asthma, more accident and emergency attendances, more nebulisations and more out-of-hours consultations than controls. One year after the introduction of the register, service use by the 'at-risk' group was reduced down to control levels, at a cost of £17 per patient [38].

The concept of an 'at-risk' asthma register is reinforced annually in this region with the publication and dissemination of the Confidential Enquiry Annual Report [10,21].

Improved communication regarding 'at-risk' asthma patients should improve care. We recommend that future Quality Outcomes Framework (QOF) payments for primary care management of asthma in the UK should require production of an 'at-risk' asthma register, which can be used to prioritise care for these patients. Based on this study and previous evidence from this longstanding Confidential Enquiry [10], other Confidential Enquiries [11–14], and in line with national guidelines [17], we suggest that the criteria listed in Box 1 are used to construct such a register.

Box 1: Patients at risk of developing fatal or near-fatal asthma or being admitted to hospital with asthma

A COMBINATION OF SEVERE ASTHMA RECOGNISED BY ONE OR MORE OF:

- previous near-fatal asthma, e.g. previous ventilation or respiratory acidosis
- previous admission for asthma especially if in the last year
- requiring BTS/SIGN Step 4 or 5 treatment
- brittle asthma, with previous sudden severe attacks

AND ADVERSE BEHAVIOURAL OR PSYCHOSOCIAL FEATURES RECOGNISED BY ONE OR MORE OF:

- non-compliance with treatment or monitoring including
 - failure to attend appointments
 - self-discharge from hospital
- psychosis, depression, other psychiatric illness or deliberate self-harm
- current or recent major tranquiliser use
- denial
- alcohol or drug abuse
- obesity
- learning difficulties
- employment problems
- income problems
- social isolation
- childhood abuse
- severe domestic, marital or legal stress

Modified from Table 3, page i32; BTS/SIGN Guideline on the Management of Asthma [17]

Conclusions

Raw ONS data overestimates asthma death rates, and study of 311 deaths between 1988–2003 shows a downward trend in annual mortality rate in East Anglia. In 2001–2003, four-fifths of patients who suffered fatal asthma had adverse behavioural or psychosocial factors contributing to their death. In 80% of deaths the final attack was not sudden, and was potentially preventable; prevention requires better recognition of the prognostic importance of severe asthma in combination with adverse behavioural and psychosocial risk factors. 'At-risk' asthma registers in primary care may help. 20% of deaths were sudden, occurred largely in males under the age of 20, and almost all occurred between April and August, suggesting a seasonal allergic cause. There continue to be inadequacies in asthma management in both hospital and primary care, with national guideline recommendations

not being followed in two-thirds of asthma deaths.

Implications for future study

Future study on anaphylactic sudden death in atopic patients requires better identification of atopic disease in UK general practice and more widespread use of mast cell tryptase assays by pathology departments within 72 hours post-mortem. Secondly, even though national asthma guidelines recommend the identification of 'at-risk' asthma patients [17] as per previous Confidential Enquiries [10–14], we know of only one retrospective study yet to be published [38] showing the benefits of an 'at-risk' asthma register in primary care. For 'at-risk' asthma registers to be incorporated into the QOF criteria in the UK, additional evidence such as prospective controlled studies of 'at-risk' registers is now urgently needed.

Conflict of interest: There are no directly relevant conflicts of interest to be declared

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Contributors

BH was the Medical Co-ordinator for the study, and compiled and collated all the results. PS wrote the initial manuscript and made the manuscript revisions, and BH and SN contributed to the final version. GM was the lead GP for the Working Group. SN is the current Medical Co-ordinator and PS the current lead GP. BH is the guarantor.

Some of this data was initially presented by BH at the Winter meeting of the British Thoracic Society

(BTS) in December 2004, and by PS at the Annual Conference of the GPIAG in July 2005.

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