

A confidential enquiry into deaths caused by asthma in an English health region: implications for general practice

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SUMMARY

Aim. To determine the factors contributing to death from asthma in patients aged under 65 years in East Anglia in the early 1990s.

Method. We have performed an ongoing confidential enquiry since January 1992. For the first time a general practitioner was included in the enquiry team.

Results. A review of the clinical and pathological data of the 50 patients reported in the first 3 years suggested that 36 of these deaths were attributable to asthma. Thirty-one patients died out of hospital (3 en route to the hospital), 2 in the Accident and Emergency department, and only 3 in hospital. Adverse social factors were found in 25 out of 34 patients, and adverse psychological characteristics in 23 of the 31 patients where these could be assessed. Only 7 appeared to have no adverse psychological or social factors. Routine medical care was considered appropriate in 20 patients, and inappropriate in 14. Twenty-four had received appropriate advice and education. Nine of the 21 patients, where this could be assessed, and half the relatives, failed to respond appropriately to worsening asthma symptoms during the fatal attack. No potentially preventable factors were identified in two women who died of end stage asthma.

Conclusion. This enquiry has demonstrated that inadequacies in the medical care of asthma continue to occur, although less frequently than in previous asthma-death studies. In addition, 79% of the patients had experienced psychosocial factors which appeared important in contributing to their deaths. Recommendations for identifying and managing such 'at risk' patients have been circulated to all general practitioners and chest physicians in the region.

Keywords: asthma, social factors, psychological characteristics

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Introduction

The three main, potentially preventable factors in the majority of deaths caused by asthma, and surveyed since 1975, were: under-estimation of the severity of the asthma by the doctor; under-estimation of the severity of the asthma by the patient; and not enough treatment using systemic steroids.¹ An additional problem, namely psychosocial deprivation first noted in the New Zealand study,² has been found in recent asthma mortality surveys in Australia^{3,4} and Britain.⁵

Since 1992 we have been performing an ongoing confidential enquiry into asthma-related deaths in East Anglia. The aim of this paper is to report the results of the first three years of this regional enquiry and suggest characteristics which might help identify patients who are at particular risk of dying from their asthma.

Method

All deaths with asthma recorded in the first part of the death certificate, for subjects aged under 65 years, were collected via the region's computerized death-reporting system in the Department of Public Health Medicine in Norwich. General practitioner records and, where appropriate, hospital records were reviewed.

General practice and home assessment

A general practitioner (GP), a key member of the review team, reviewed the general practice notes of the deceased and met the patient's doctor to review all relevant factors pertaining to the death. He also asked permission for the deceased's next-of-kin to be visited by the specialist respiratory nurse, who then sought to visit the next-of-kin in their home.

Other records and the enquiry forms

Hospital records were reviewed by the co-ordinating chest physician and by the chest physician from the relevant district. Standard questionnaires (available from the authors) developed from earlier studies^{5,6,7} were completed during the general practitioner and next-of-kin interviews and from the hospital notes. They enabled a comparison to be made between the actual quality of care and the national guidelines.^{8,9} These and earlier questionnaires^{5,6,7} included the questions, 'were there significant social factors that might have contributed to death?' and, 'were there psychological characteristics that might have contributed to death?' Under the term 'social factors' we recorded major stresses, including life events, isolation and poverty; under 'psychological factors', psychiatric illnesses were included such as: denial,^{2,5,10} alcohol, drug or sexual abuse, and deliberate self-harm.

The asthma was graded as being severe if the patient had required hospital admission in the past year,^{2,11} had needed oral steroids daily or more frequently than four times a year, had been prescribed three or more categories of asthma drugs at the time of death,¹¹ or had been woken from sleep by asthma symptoms more than twice a week. The asthma was graded as mild if inhaled anti-inflammatory treatment was required either not at

all, or infrequently for seasonal or infective exacerbations. Moderately severe asthma fell between these two grades. The review team, supported by two research assistants, met twice yearly at the time when the public health physician completed the final review form. An annual report has been circulated to all GPs and chest physicians in the region.

Results

Between 1992 and 1994, 50 deaths caused by asthma were reported in patients aged under 65 from a population of 2.1 million. The enquiry team concluded that 14 of these deaths were due to other causes: smoking-induced chronic airway obstruction (9), pulmonary emboli (2), and respiratory muscle myopathy, ischaemic heart disease, and infective mediastinitis (one each). One of the patients with pulmonary emboli, the patient with myopathy, and the patient with mediastinitis had asthma, but this was not considered severe before death occurred. Eighteen of the 36 people who died from asthma were male, and 18 were aged 50-64 years. Only two asthmatics died under the age of 20 years. The GP who treated 34 of the patients was interviewed. Three of these patients had never attended hospital. In the remainder of the patients, their hospital notes were reviewed. Four patients had attended hospital but not for asthma. The next-of-kin of 12 of the fatal-asthma patients were interviewed. Nine patients had no next-of-kin. Fifteen interviews with the next-of-kin could not be conducted because: they refused; there was no suitable next-of-kin; there was a possibility of evoking a complaint; no GP was available; or the spouse of the patient was registered at a different practice. Thirty-one asthmatics (86%) died out of hospital, three en route to the Accident and Emergency department. Two asthmatics died in the Accident and Emergency department and three in hospital. Twenty-seven patients (75%) had an autopsy. In the year before death the asthma was considered severe in 22 patients, moderate in six, and mild in five of the 33 patients where this could be assessed.

Psychosocial factors

Adverse social factors, which were considered to have contributed to the death, were found in 25 of the 34 patients (Table 1), and adverse psychological characteristics were found in 23 of the 31 patients (Table 2) where these could be assessed. Only seven patients appeared to have no adverse psychological or social factors contributing to their death.

Medical care and supervision

Routine care was considered appropriate in 20 patients, and inap-

propriate in the other 14 patients for one of the following reasons (numbers of patients in brackets): no objective monitoring by peak flows at GP consultations (12); no recorded evidence of receiving appropriate advice and education (10); regular β -agonist therapy, but no regular inhaled steroids (5); cromoglycate as sole anti-inflammatory therapy despite severe asthma (1); no follow-up for patients who did not attend routine appointments in a general practice or hospital (7); non-referral or delayed referral for specialist advice (5); no recall of patients being given repeat prescriptions (3); premature discharge from hospital or no follow-up after admission for a severe attack (3); and attendance at a hospital out-patients department, but not at a specialist respiratory medical clinic (2), or assessment by junior doctor only (1). Twenty-four patients had received appropriate advice and education,^{8,9} but the interviews suggested that the next-of-kin would frequently have liked more information and education about asthma. Only 15 were considered to have had a good understanding of their disease, and only eight seemed willing to cope with their disease.

In 16 of the 27 in whom this could be assessed, the fatal attack occurred against a background of undercontrolled asthma, and in 18, peak flow was not monitored appropriately.^{8,9} In the 21 patients where this could be assessed, nine did not respond to their worsening symptoms appropriately and eight out of 16 relatives also failed to respond appropriately.

One patient died when a post-operative deterioration in their asthma was treated as a pulmonary embolus. No preventable features were identified in the other two patients who died in hospital. Both had chronically severe asthma which had become largely irreversible and necessitated many admissions to hospital. Both had been receiving oral prednisolone for between one and two decades.

Discussion

Asthma is the most common chronic disease affecting all age groups in Britain today. Earlier mortality studies were one-off surveys. During the two decades from 1970, death rates from asthma have steadily increased,¹² and asthma was the only one of nine 'avoidable' causes of death in England and Wales for which the standardized mortality ratio was higher in 1987 than in 1979.¹³ This was the main reason for establishing the ongoing confidential enquiries into deaths caused by asthma – the first in Britain for a medical condition. As with the confidential enquiries into maternal deaths¹⁴ and perioperative deaths,¹⁵ there was no control group in this enquiry.

Potentially preventable factors were found in over 80% of

Table 1. Adverse social factors found in 25 of the 34 patients studied

Social factors	Amount of patients experiencing these factors
Domestic stress (emotional; caring for relatives; living with alcoholics, family disharmony, autistic child, being battered)	11
Homeless, living alone	6
Unemployed, self-employed, threatened redundancy, work stress	5
Smoking, passive smoking	8
Separated, single parenthood	4
Extreme poverty	4

Table 2. Adverse psychological characteristics found in 23 out of 31 patients studied

Psychological characteristics	Amount of patients showing signs of these characteristics
Denial (non-attendance, self discharges, non-compliance)	15
Depression, taking antidepressants	6
Drug, alcohol abuse	4
Sexually abused, morbid obesity	5
Deliberate self harm	3
Anger with asthma	2
Learning disability	2
Repeated failure to recognize potential severity	1

deaths in the British Thoracic Association's study.⁶ Encouragingly, routine care was considered appropriate in 59% of cases in the present study, although recommendations contained in the guidelines of the British Thoracic Society^{8,9} are still not being followed in every case.

What this study has demonstrated is that a high proportion of patients had psychosocial factors which seemed to have contributed to the deaths attributable to asthma in East Anglia. In the New Zealand study² in 1981/1982, no more than 39% had documented psychosocial problems. In Victoria, Australia³ in 1986/1987, a definite psychosocial disturbance was reported in 15% of the overall study. In South Australia⁴ in 1988/1991, 86% had psychosocial features which could have contributed to their fatal asthma episode. In the present study, 79% of patients were considered to have important adverse psychosocial factors in their lives. These results extend the findings from a preliminary enquiry in 1988/1991, restricted to a single district, in which 71% of patients had adverse psychological or social factors.⁵ Corroborative evidence for the importance of social deprivation is provided by recent epidemiological studies from the USA¹⁶ and South Africa,¹⁷ where deaths caused by asthma are highest amongst poor people, minority groups, and in inner cities.

It is difficult to imagine how the patient's asthma could be high on their list of priorities when considering some of the difficulties they experienced which were associated with their not attending appointments and not following advice. Psychosocial problems,^{10,18,19} including denial and poor compliance, have also been shown to be important factors in patients suffering from near fatal attacks of asthma, and conflict, depression and denial are all factors associated with death from asthma in childhood.²⁰ Thus, even when the medical management of such patients is optimized, their behaviour would still present major impediments to effective treatment of severe asthma. Maintaining contact with the patient is of overwhelming importance. When patients fail to attend appointments, health care professionals with expertise in asthma care need to attempt to see the patients themselves. Clearly, additional resources, which might include an extended community role for asthma nurses or respiratory specialist nurses, would be required for the management of such patients. In an attempt to address these problems we have circulated recommendations (see Box 1) for the care of patients with asthma to all doctors and nurses caring for asthmatics in the East Anglia region. These recommendations suggest ways of identifying and managing this particularly high-risk group of asthmatics.

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Box 1. Recommendations for the care of asthma patients

RECOMMENDATIONS FOR THE CARE OF ASTHMA PATIENTS

- **Follow BTS Guidelines**²⁰ for prescription of regular anti-inflammatory medication, specialist referral and follow up, and recognition and treatment of severe asthma.
- **Check and record peak flow** at every GP consultation for asthma (even if patient is charting peak flow at home).
- Many patients with asthma, and certainly all patients with severe asthma, should have an agreed **written management plan** and their **own peak flow** meter with regular checks on inhaler technique and compliance.
- Ensure Practice (Asthma) or Clinic Nurse or **Doctor contacts asthmatics who do not attend their appointments**.
- **Always** try to involve a **close relative**, including the relatives of adult patients, in education and understanding about asthma, and share the agreed management plan.
- **Never prescribe beta blockers**, including eyedrops, to patients with asthma.
- In patients presenting with worsening symptoms, always agree a plan of care with the patient, ideally based on peak flow recordings and symptoms, to include appropriate use of inhaled or oral steroids. Always arrange and ensure an early follow-up appointment

Make a register of patients '**at risk**' of developing severe or fatal asthma available to all partners and out-of-hours emergency doctors.

PATIENTS 'AT RISK' OF DEVELOPING SEVERE OR FATAL ASTHMA are those:-

- With **psychiatric morbidity, behavioural difficulties, especially denial, and socio-economic deprivation** (recognize denial by non-attendance, unwillingness to comply with therapy or monitoring, unwillingness to accept the diagnosis or the need to take regular medication).
- Ever **admitted** to hospital as a result of their asthma.
- Requiring **emergency** steroids and/or nebulized treatment
- Calling out a GP, or attending Surgery, or A & E Department with **emergency deterioration**
- Requiring courses or regular **oral steroids**
- Requiring **high dose inhaled steroid**
- Whose **peak flow falls below 50%** of their best or predicted value
- Requiring **two or more** bronchodilator inhalers **monthly**

Discuss these issues frankly with the patient and their relative

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