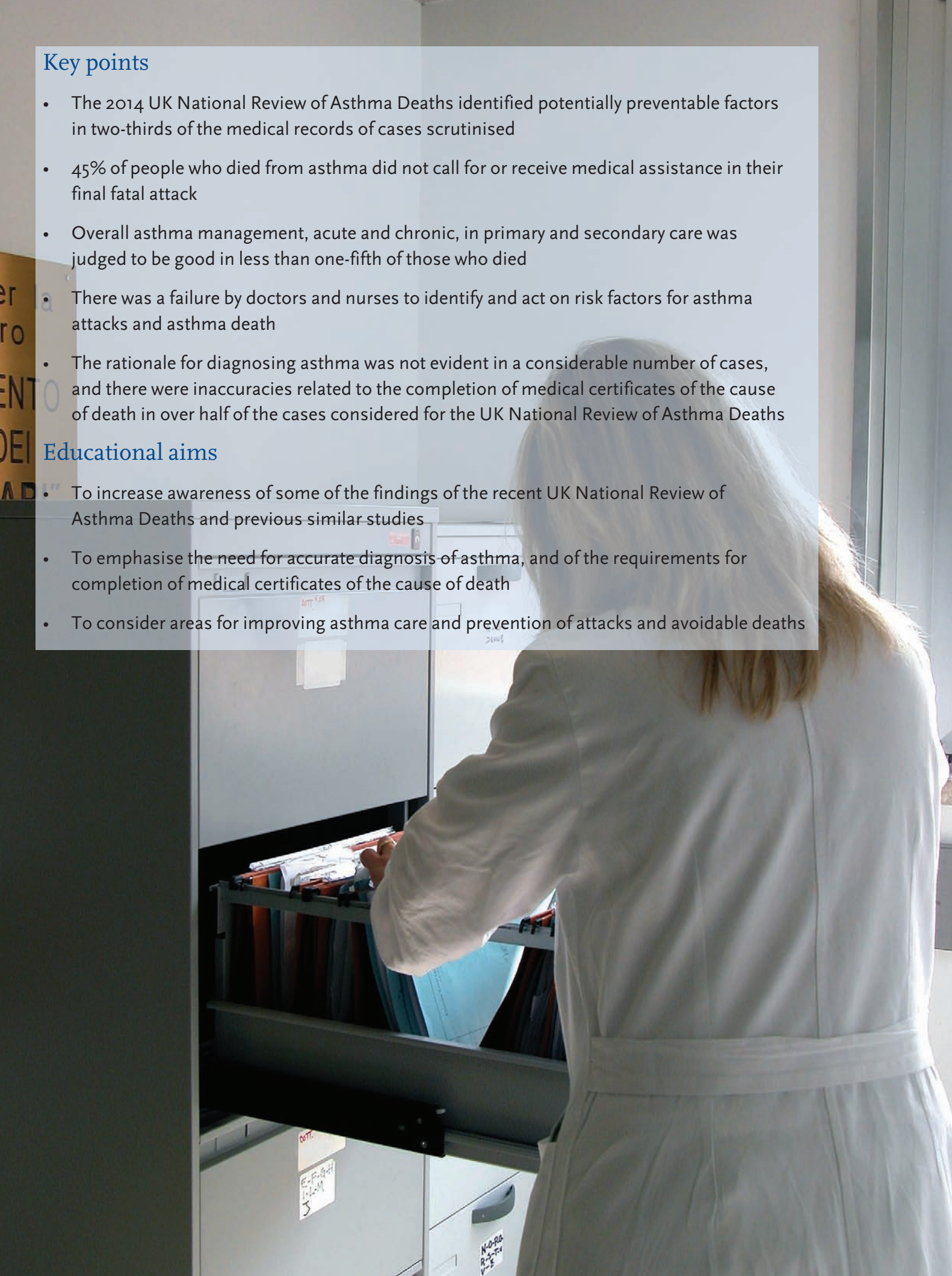


Key points

- The 2014 UK National Review of Asthma Deaths identified potentially preventable factors in two-thirds of the medical records of cases scrutinised
- 45% of people who died from asthma did not call for or receive medical assistance in their final fatal attack
- Overall asthma management, acute and chronic, in primary and secondary care was judged to be good in less than one-fifth of those who died
- There was a failure by doctors and nurses to identify and act on risk factors for asthma attacks and asthma death
- The rationale for diagnosing asthma was not evident in a considerable number of cases, and there were inaccuracies related to the completion of medical certificates of the cause of death in over half of the cases considered for the UK National Review of Asthma Deaths

Educational aims

- To increase awareness of some of the findings of the recent UK National Review of Asthma Deaths and previous similar studies
- To emphasise the need for accurate diagnosis of asthma, and of the requirements for completion of medical certificates of the cause of death
- To consider areas for improving asthma care and prevention of attacks and avoidable deaths





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The national review of asthma deaths: what did we learn and what needs to change?

Summary

Despite the development and publication of evidence-based asthma guidelines nearly three decades ago, potentially preventable factors are repeatedly identified in studies of the care provided for patients who die from asthma. The UK National Review of Asthma Deaths (NRAD), a confidential enquiry, was no exception: major preventable factors were identified in two-thirds of asthma deaths. Most of these factors, such as inappropriate prescription and failure to provide patients with personal asthma action plans (PAAPs), could possibly have been prevented had asthma guidelines been implemented.

NRAD involved in-depth scrutiny by clinicians of the asthma care for 276 people who were classified with asthma as the underlying cause of death in real-life. A striking finding was that a third of these patients did not actually die from asthma, and many had no recorded rationale for an asthma diagnosis.

The apparent complacency with respect to asthma care, highlighted in NRAD, serves as a wake-up call for health professionals, patients and their carers to take asthma more seriously. Based on the NRAD evidence, the report made 19 recommendations for change. The author has selected six areas related to the NRAD findings for discussion and provides suggestions for change in the provision of asthma care. The six areas are: systems for provision and optimisation of asthma care, diagnosis, identifying risk, implementation of guidelines, improved patient education and self-management, and improved quality of completion of medical certificates of the cause of death.

Conflict of interest

M.L. Levy reports personal fees and non-financial support from GSK, Novartis, Teva and Chiesi, personal fees from Clement Clarke International and Astra Zeneca, employment as Clinical Lead, NRAD 2011–2014, and a grant from Consorzio Futuro in Ricerca, outside the submitted work. He is a member of the Executive Board of the Global Initiative for Asthma (GINA), but receives no payment for this work.

Introduction

The National Review of Asthma Deaths (NRAD) report, “Why asthma still kills” [1],

published on World Asthma Day in 2014, attracted a lot of media attention in the UK and elsewhere in the world. Surprisingly, despite modern drugs, devices and evidence-based



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guidelines [2, 3], the findings of NRAD were extremely disappointing; potentially preventable factors were identified in over 60% of the asthma deaths studied. Clearly, this is unacceptable and it is the responsibility of the respiratory community to do what is necessary to bring about a radical change in the management of asthma. Some countries, particularly Finland and Brazil [4, 5], have reduced asthma attacks and deaths to a minimum and there is no reason whatsoever that the people of other countries should accept substandard care.

Despite modern medication and the inhaler delivery devices available, numerous studies worldwide over the past 50 years have repeatedly identified potentially preventable factors in the majority of asthma deaths [6–36]. In addition, despite national and international [2, 37, 38] guidance for asthma management, coupled with a heightened awareness of and research on asthma in primary care [39], the age standardised prevalence, morbidity and mortality due to asthma, at all ages, varies considerably throughout Europe [40]. Identified shortcomings in the provision of care for this common condition include problems with the accuracy and timing of asthma diagnosis, classification of severity and identification of risk as well as deficiencies in both chronic and acute management. Furthermore many of these studies identified deficiencies in asthma knowledge among health professionals, and inadequate education of patients and their carers on recognising risk and the appropriate action needed when asthma control is poor. Many patients who die from asthma are classified as having mild or moderate asthma; this results in inadequate treatment in those cases with unidentified underlying severe asthma.

Most of the previous studies on asthma death were small, locally based investigations and it seemed from these, particularly the ongoing confidential, East of England enquiry into asthma deaths [36, 41, 42], that a current assessment of circumstances and management in people who die from asthma was required. The UK Health Quality Improvement Partnership commissioned the NRAD on behalf of the UK Department of Health. This review was performed by the Clinical Effectiveness and Evaluation Unit of the Clinical Standards Department at the Royal College of Physicians (RCP), London, UK.

The findings of the NRAD serve as a call to action for clinicians, healthcare commissioners and governments to consider potential ways

forward for the future management of asthma and eradication of preventable asthma deaths.

Methodology of NRAD

NRAD was conducted as a confidential enquiry, with approval from the UK National Information Governance Board under section 251 of the National Health Service (NHS) Act (2006) (approval reference: ECC 8-02(FT2)/2011), to obtain identifiable clinical information on people who died from asthma without permission from the deceased families. This was not an epidemiological study of asthma deaths in the UK and, therefore, does not reflect the management or prevalence of all UK asthma deaths.

Medical certification of cause of death in the UK

The UK system (as in many other countries) utilises a medical certification of cause of death (MCCD) with two parts. Part I is for reporting disease related to the chain of events which directly leads to death (*e.g.* 1a: cardiorespiratory failure; 1b: acute asthma; 1c: chest infection). Part II should only include diseases that contributed to the death but did not directly cause it [43]. The World Health Organization (WHO) International Classification of Diseases (ICD)-10 codes are then allocated, by national statistics departments, according to an algorithm, which in some cases where asthma is entered in part II of the MCCD results in asthma being classified as the underlying cause of death (ICD codes J45/J46 for asthma) [44].

Selection of cases for the confidential enquiry

MCCDs were made available to NRAD teams at the RCP (for England, Wales and Scotland) and to the local NRAD team in Northern Ireland for those deaths in that country. A total of 3544 deaths had the word asthma on their MCCDs during the 12 months from February 2012. Of these 1414 (40%) deaths were classified according to the WHO ICD-10 [44] coding system with asthma or anaphylaxis (*i.e.* ICD-10U – J45–J46, T78.2) [44] as the underlying cause of death. 2644 (75%) of the cases were excluded from consideration by NRAD: these included 2130 (60%) who were not classified with asthma as the underlying cause of death

and 514 (15%) deaths in people over 75 years of age where asthma was entered in part II of the MCCD. The reasons for excluding the latter group of patients included the workload involved for the small NRAD team and also, based on correspondence from clinicians, the assumption that clinicians had not seriously considered asthma as the cause of death and had completed the certificates erroneously by entering asthma in part II [43]. While some of these cases may have died from asthma, 382 (74%) had additional comorbid conditions listed in part II of the MCCD, and 401 (78%) had “pneumonia” entered in part Ia of the MCCD; therefore, other diseases may have been responsible for death in many of these people.

A total of 900 (25%) deaths were selected for detailed consideration by NRAD. Health professionals who cared for these people were requested to provide detailed copies of medical records for the 2 years preceding death, as well as any treatment provided during the final fatal attack and any details related to comorbid conditions and previous attacks [45].

Medical records containing sufficient information for analysis were returned by only 628 (70%) of the doctors caring for these 900 patients. Insufficient or no information was received from professionals caring for 127 (14%) and 145 (16%) patients, respectively. This lack of response occurred despite a clear statement in the General Medical Council booklet “Good Medical Practice” [46] that UK registered doctors have a duty to comply with requests from confidential enquiries for information!

352 (39%) of the 900 cases were excluded, despite being classified according to the MCCD with asthma as the underlying cause of death, as they were not asthma deaths according to clinical records and correspondence from clinicians. The remaining 276 (31%) of the cases were considered in detail by confidential enquiry panels, comprising 174 clinicians from primary, secondary and tertiary care, convened on 37 days (with an average of 10 clinicians and 10 cases each time). 36 out of the 900 deaths occurred in children and young people under 20 years of age; only 28 of these were included in the cases assessed by the confidential enquiry (data from the other eight were not received from the clinicians).

The remit of these panels was to determine whether the people who died actually did have asthma, and if so whether their deaths were

due to asthma and what recommendations could be made on the basis of the available information.

Summary of NRAD findings and suggested changes

The confidential enquiry panels considered, in detail, the records of 276 people who had been classified with asthma as the underlying cause of death. They concluded that 195 (71%) of these people had died from asthma. Details are shown in table 1.

A summary of the demographics of the 195 cases that died from asthma are shown in table 2. While the real-life findings of NRAD relate to current care in the UK, they are very similar to reported outcomes from studies on asthma deaths and acute asthma care worldwide. The NRAD identified major preventable factors in both primary and secondary care and, therefore, there is a need to consider changing systems for the provision of asthma care. Some of the key findings of the NRAD [1] are detailed in table 3.

What needs to change?

Based on the NRAD, six areas for change in the provision of asthma care are discussed in the following sections: systems for provision of care, diagnosis, identifying risk, implementation of guidelines, improved patient education and self-management, and improved quality of completion of medical certificates of the cause of death. (The full report, including

Table 1 Main conclusion of the confidential enquiry panels

	Cases n (%)
People who died from asthma	195 (71)
People who did not have asthma	27 (10)
People who had asthma but did not die from it	36 (13)
Insufficient information	
To decide whether the person had asthma	14 (5)
To decide whether the person died of asthma	4 (1)

Total cases=276.

Table 2 Demographics

Characteristic [#]	
Duration of asthma (n=104)	0–62 years (median 11 years)
Age at diagnosis (n=102)	10 months–90 years (median 37 years)
Age at death (n=193)	4–97 years (median 58 years)
Severity of asthma (n=155) [¶]	
Mild	14 (9%)
Moderate	76 (49%)
Severe	61 (39%)
Previous hospital admission (n=190)	90 (47%)
Accident and Emergency attendances (n=115)	40 (34%)
Intensive care admissions (n=181)	27 (15%)
Current smokers (n=193)	39 (20%) ⁺
Psychosocial and learning disability factors (n=190)	84 (44%)
Obesity (BMI ≥ 30 kg·m ⁻² at most recent assessment) (n=121)	38 (31%)

Data are presented as n (%), unless otherwise stated. [#]: data return from doctors was incomplete; n assessable data for each parameter are shown in parentheses. [¶]: classified by clinicians, 12 out of 28 children and young people (under 20 years-old) were classified with mild or moderate asthma by their clinicians. ⁺: a further 27 (10%) were exposed to smoke at work.

Table 3 Key findings of the NRAD

- 1) 195 (71%) out of 276 cases considered by the panels died from asthma; and 27 (10%) had no evidence in their records confirming that they had asthma.
- 2) The panels concluded that overall asthma management (acute and chronic) was satisfactory in only 31 (16%) out of 195 people who died, and in only one (4%) of the 28 children and young people.
- 3) The panels identified at least one major potential avoidable factor in 130 (67%) cases out of the 195 who died from asthma.
- 4) 45% of those who died from asthma either did not call for or receive medical assistance in their final fatal attack. This surprise finding was coupled with the observation that 77% of those who died had no evidence in their medical records of being provided with a PAAP detailing how their medication was to be taken, how to recognise danger signals and when to call for help.
- 5) The panels identified a number of missed opportunities by the healthcare professionals to intervene and reduce the risk of asthma attacks and death. These were related to:
 - a) Prescribing issues; with overprescribing of short-acting reliever inhalers (SABA) and insufficient provision of inhaled corticosteroid preventer medication
 - b) Failure to monitor asthma control and to provide follow-up assessment and optimisation of medication after asthma attacks; irrespective of whether these were treated in hospital or the community by primary care clinicians
 - c) Failure to refer patients to an asthma specialist (within hospital and from primary care)
 - d) There were potentially avoidable factors related to non-implementation of the current UK BTS/SIGN asthma guidelines [3] in 89 (46%) out of the 195 deaths

BTS: British Thoracic Society; SIGN: Scottish Intercollegiate Guidelines Network.

an executive summary with 19 recommendations for change is available online [1].)

Systems for providing care

The NRAD panels concluded that overall care (primary and secondary care) was poor in over 80% of those who died from asthma.

In the UK, and probably in other countries, more and more patient care is being devolved into the primary care sector, without the necessary resources and training. Historically, care for asthma has moved from secondary to primary care. In addition, the UK political control of the NHS is such that systems for care change fairly frequently, without true long-term planning; and chronic care (particularly for asthma) has deteriorated. In the 1990s most general practices employed trained asthma nurses to provide chronic care [39, 47, 48]. However this has changed, NRAD reported that 46% of general practice nurses doing asthma reviews had no training in this field, and none as far as we were aware had any paediatric training.

Challenges for doctors and nurses working in primary care include time limitation (5–10 min for consultations in most countries) coupled with the need to have some familiarity with the hundreds of different clinical conditions that patients may present in any 1 year. This contrasts with the average of 10–20 conditions that secondary care specialists deal with. While respiratory physicians and paediatricians are able to manage asthma, this may not be the case for specialists in other disciplines. It is sad that in many countries the “general physician”, *i.e.* a specialist in internal medicine with an in-depth knowledge of the different medical (*i.e.* non-surgical) disciplines dealing with most common conditions encompassed in internal medicine, is virtually extinct. This increases the challenge for general practitioners who need to get the initial diagnosis as accurate as possible in order to make referrals to the appropriate specialists. For example a patient with breathing difficulties and undiagnosed asthma, who is mistakenly referred to a cardiologist, will undergo a series of cardiac investigations without necessarily reaching the correct diagnosis, which may or may not lead to a referral to a pulmonologist; with inevitable delays in diagnosis and initiation of appropriate treatment. By contrast, someone attending an emergency department may see whichever specialist medical team is on

duty, with the result that someone with acute asthma may be treated by a non-respiratory team and discharged without, for example, an asthma self-management plan or follow-up arrangements. In some cases of acute asthma care assessed by NRAD, a junior doctor in the emergency department failed to recognise that high normal carbon dioxide tension levels were life-threatening and didn't seek expert help.

Suggested changes

It may be necessary to revert back to a system where specialists have more involvement in the care of people with asthma, particularly after attacks. This needs to be coupled with ongoing asthma training for generalists.

Diagnosis

The NRAD highlighted a number of problems related to diagnosis of asthma. These included a failure to diagnose asthma as well as erroneous death certification due to asthma. 39% of the 900 cases classified with asthma as the underlying cause of death did not die from asthma, according to medical records and correspondence from their doctors. 10% of the 276 cases scrutinised in detail by the NRAD panel did not have any evidence justifying an asthma diagnosis in their medical records and one-third did not die from asthma (table 3).

NRAD reported that the median age of asthma diagnosis in those who died was 37 years. While the data were insufficient to provide an explanation for this observation, some of these people may have had “late-onset asthma” which may be a possible risk factor for asthma death; however, some were possibly diagnosed after long delays and the remainder were possibly people who had come out of remission following childhood asthma. A number of these “late diagnosed cases” may well have had occupational asthma; however, occupational asthma was not recorded in any of the medical notes of the NRAD cases. Furthermore, a few cases may have died from anaphylaxis; however, there was insufficient evidence (such as mast cell tryptase) to conclude on these cases with confidence. Interestingly, in response to the NRADs request for data on some older patients doctors responded by saying their patient, despite having asthma on the MCCD, actually had chronic obstructive pulmonary

disease (COPD) and was being treated as such. In fact, a number of these patients had evidence of longstanding, chronic asthma and had developed fixed airflow obstruction. Inhaled steroid medication had been discontinued in some of these patients in accordance with the guidelines for management for mild COPD [49]. As a result, a new code was agreed for inclusion in the general practice computer record: “Chronic asthma with fixed airflow obstruction”.

Suggested changes

Systems for early, accurate diagnosis of asthma need to be reviewed and revised if necessary. This may require more involvement of clinicians with asthma expertise, perhaps a requirement for confirming diagnosis of variable airflow obstruction could be incorporated into management pathways as well as a requirement for detailed records in the notes justifying the diagnosis. This may include more joint specialist clinics for assessing patients with breathing problems (*e.g.* cardiologists and respiratory clinicians) and also joint asthma clinics for patients in transition from paediatric to adult medicine.

The NRAD identified a need for research to establish whether “late-onset asthma” is a risk factor for asthma death; this is perhaps a research priority for the respiratory community.

In older patients, specialist review of the diagnosis should be considered in patients with asthma or COPD. They may have asthma–COPD overlap syndrome [2, 50]. Some of those NRAD cases who died were prescribed long-acting β -agonist therapy as monotherapy; perhaps because they were considered to have COPD. However, this was not the case in a few young people prescribed in this manner.

Finally, patients who are admitted to hospital or treated for attacks of asthma should be seen by respiratory specialists and have the diagnosis confirmed as part of the post-attack review.

Identification of risk

Severity of asthma is defined as the amount of medication required to control asthma [51, 52]. 58% of those who died were classified as having mild or moderate asthma (42% of children and young people); however, only 37 (19%) and 5 (6%) had their asthma control assessed in primary and/or secondary care, respectively.

It seems that many clinicians define asthma severity empirically by the amount of treatment prescribed.

Excess short-acting β -agonist (SABA) usage has been clearly identified in the past as a risk factor for asthma attacks and death [2, 34, 53]. Yet, the NRAD identified that a significant proportion of patients were prescribed more than 12 SABA inhalers in the year before they died with correspondingly low prescriptions for preventer (controller) medication (on average, less than four controller inhalers in the previous year).

Exposure to cigarette smoke is clearly hazardous for people with asthma and all efforts should be made to encourage people with asthma to stop smoking, and to prevent children from being passively exposed to smoke.

A history of an asthma attack (particularly if treated in hospital) has long been recognised as a risk factor for future asthma attacks and death. However, the NRAD found that among people who died from asthma, 10% had recently been discharged from hospital following treatment for an attack, and that 21% had attended an emergency department at least once for asthma in the year before they died. Clearly systems are required that ensure post-asthma attack reviews are performed by appropriately trained clinicians. The purpose of the review is to determine what led to the attack, assess the patient’s current asthma control and future risk factors, and to optimise treatment.

The NRAD panellists commented on the poor quality of medical records, in particular a lack of detailed recording of asthma reviews, the assessments made and any action taken. While avoidable factors were identified in this regard in both primary and secondary care; the panellists commented that primary care clinicians seemed to regard asthma reviews as a “tick box” exercise, tied to the payment system for these reviews under the UK Quality Outcome Framework [54].

Suggested changes

Attitudes to asthma management need to change, the disease is characterised by stable periods with “flare-ups” and treatment therefore needs to focus on chronic as well as acute care. Clinicians need to prescribe more responsibly, patients need to be more involved in their care, risks need to be recognised and exposure to triggers (such as cigarette smoke) should

be avoided. A system for assessing and optimising asthma control in adults and children is clearly described in the latest Global Initiative for Asthma (GINA) strategy report [2]; and in the case of adults by Farah and Reddel [55].

Implementation of guidelines

Evidence-based asthma guidelines were first published nearly 25 years ago; however, studies repeatedly demonstrate a failure by clinicians to implement these. Much time is spent developing and writing guidelines; however, little attention is paid to their implementation [56, 57]. The NRAD identified potentially avoidable factors related to non-implementation of asthma guidelines (table 3) in about half of the deaths. In the opinion of the NRAD panels half the deaths occurred in cases where the guidelines had been implemented in an appropriate manner. However, the fact that half of the deaths occurred despite implementation of the guidelines possibly suggests that guidelines alone don't address all of the issues related to care of people with asthma.

Suggested changes

The latest GINA strategy document has a clinical focus (with all the academic material in appendices). There is a whole chapter on assessing and optimising control, and one devoted to implementation, with tools for implementation of the strategy. Perhaps implementation of a post-asthma attack review, along the lines of the GINA strategy, focused on assessing current control and future risk, with optimisation of care in all cases, could reduce asthma attacks [2, 56]. For an example of a template for a review, see the author's website [58].

Patient education and provision of PAAPs

One of the surprise findings reported by NRAD was that just under half of those who died from asthma either failed to call for or receive medical assistance during their final fatal attack. It might be that many of these cases had sudden severe attacks and didn't have time to call for help. A more likely explanation is that they did not recognise the danger signs leading to, or during, their final attack because they had never been taught about the signs. 77% of those who died had no evidence in their medical records of

being provided with a PAAP or a self-management plan, detailing how their medication was to be taken, how to recognise danger signals and when to call for help (table 3).

Self-management plans were first suggested by Beasley *et al.* [59], in 1989, with subsequent studies proving their benefit in terms of increased patient well-being, and reduced attacks and healthcare utilisation [60–64].

Suggested changes

Systems need to be implemented to facilitate asthma self-management by provision of agreed PAAPs, by trained healthcare professionals. These should be provided during routine or post-acute asthma reviews, if not previously provided, and updated following an asthma attack [2, 65].

Improve quality of MCCD and post mortem reports

The NRAD found that a very high proportion of those classified, according to WHO ICD-10 codes, with asthma as the underlying cause of death did not actually die from asthma. Surprisingly, in some cases, based on the medical records the panels disagreed with the *post mortem* conclusions that asthma was the cause of death. Inaccuracy of death certificates and unreliable classification of the underlying cause of death are not new findings [41, 66–68].

Two pathologists assessed a sample of 68 out of 136 *post mortem* reports stating that asthma was the cause of death; they agreed that asthma was the cause of death in 33 cases and that it was not the cause in 10 cases; they were unable to reach a conclusion for five of the reports (agreement in 48 (71%) out of 68 cases, kappa statistic=0.49) (see appendix 12 in [1]).

39% of the 900 NRAD cases classified with asthma as the underlying cause of death (ICD-10, J45 or J46) were not asthma deaths; and 30% of the 276 cases considered in depth by the NRAD panels were not asthma deaths (table 1). From correspondence received from hospital doctors it seemed that the majority of MCCDs had been completed by junior doctors.

Suggested changes

There is a clear need for better education on completion of MCCDs and how the information is used to determine the underlying cause of death,

Educational questions

1. Which of the following are risk factors for asthma attacks?
 - a) Well-controlled asthma
 - b) Inadequate use of preventer (controller) medication
 - c) Poor inhaler technique
 - d) Excess use of SABA
 - e) Previous asthma attack
2. What should always be included in a post-asthma attack review?
 - a) Step-down therapy
 - b) Assessment of asthma control
 - c) Identification and recording of risk factors for future asthma attacks
 - d) Optimisation of treatment according to level of control
 - e) Change inhaler device
3. Which of the following should be included in an opportunistic or routine asthma review?
 - a) Assessment of inhaler technique
 - b) Provision/modification of a PAAP
 - c) Assessment of lung function
 - d) Assessment of adherence with medication
 - e) Advice on avoidance of trigger factors including avoidance of exposure to cigarette smoke
4. Which of the following are risk factors for asthma death?
 - a) Upper normal P_{CO_2} levels.
 - b) Reliever (SABA) medication required more frequently than four hourly
 - c) Previous admission to Intensive care for an asthma attack
 - d) Failure to identify previous asthma risk factors and include these in a patients PAAP
 - e) Family history of asthma death
5. Which of the following pertain to MCCDs?
 - a) The entry in part Ia of the MCCD is used to assign an ICD code for the "Underlying Cause of Death"
 - b) All medical conditions in the deceased's past history should be entered in part II of the MCCD
 - c) The medical conditions leading to death should be entered in parts Ia, Ib and Ic in any order
 - d) Conditions contributing to but not causing death should be entered in part II of the MCCD
 - e) Part I is for reporting disease related to the chain of events which directly leads to death, proceeding from immediate cause of death (the final disease, injury, or complication directly causing death) to the underlying cause of death (the disease or injury that initiated the chain of morbid events which lead directly to death)

which is used internationally both as an outcome measure and also in healthcare planning.

Medical students need to be taught how to complete MCCDs; furthermore, consultant physicians could perhaps spend more time teaching junior doctors and agreeing

the content before completion of certificates. Finally, in cases where anaphylaxis may be related to the death, appropriate samples for mast cell tryptase should be taken for analysis.

Conclusions

The NRAD findings provide an opportunity to examine and reconsider the provision of asthma care by healthcare professionals, including doctors, nurses, pharmacists, emergency paramedics, asthma patient groups, healthcare providers and politicians. The NRAD also provided an opportunity to consider the quality and accuracy of death certification, as well as the conclusions drawn by pathologists on the cause of death based on *post mortem* findings. Of course many of the lessons learnt by NRAD are not specific to asthma deaths, but have implications for prevention of asthma attacks as well as improving the care of people suffering from other long-term conditions. The author has suggested six areas for change, no doubt others will have additional ideas. Let's eradicate avoidable asthma deaths in the next 5 years!

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Suggested answers

- b, c, d and e.
- b, c and d.
- a, b, c, d and e.
- a, b, c and d.
- d and e.

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