Debate & Analysis

Paediatric asthma care in the UK:

fragmented and fatally fallible

INTRODUCTION

The National Review of Asthma Deaths (NRAD) report entitled *Why Asthma Still Kills*,[1] published on World Asthma Day in May 2014, concluded that only one of the 28 children and young people (CYP) who died had been adequately managed by health professionals. Of the 19 NRAD recommendations only one has been initiated nationally in the UK, namely setting up a National Asthma Audit, which has yet to report after nearly 5 years.

Care for children with asthma in the UK is mainly provided in primary care, and is often limited to the few tasks set out in the Quality and Outcomes Framework (QOF)[2] to provide data to qualify for payments. Currently the QOF requires a recorded asthma diagnosis confirmed by measures of airflow reversibility, smoking status, and evidence of an asthma review in the preceding 12 months that includes an assessment of asthma control using the Royal College of Physicians' three questions (RCP 3 Questions); the latter are not validated and nor are they recommended for children aged <16 years by the UK Asthma Guidelines.[3]

IDENTIFYING KEY THEMES IN PREVENTION OF ASTHMA DEATHS

The aim of the NRAD was to identify potentially preventable factors related to care preceding these tragic (and often preventable) deaths. The confidential inquiry identified a number of key themes associated with potentially preventable asthma deaths, which included: lack of objective evidence for the diagnosis of asthma and certification of death due to asthma; excess prescriptions and overreliance on reliever medication; insufficient prescriptions (and collection) of preventer (controller) medications; lack of provision of education for patients (in the form of personal asthma action plans [PAAPs]); and, importantly, a marked failure by health professionals, patients, and their carers to recognise risk of poor outcome in those who have already had at least one asthma attack. All these factors were previously known from reviews of asthma deaths over 50 years.

Since NRAD we know that the UK has the highest number of asthma deaths in CYP in Europe[4] and persisting high rates of preventable admissions for acute asthma. The conclusions summarised in Regulation 28 statements following inquests by HM Coroners on three preventable childhood asthma deaths since NRAD provide very depressing evidence that the management of childhood asthma is well below the standard expected by reasonable clinicians acting in accordance with advice from responsible authorities.[1,3,5,6] Common themes (in primary and secondary care) were clear in all three of these deaths including: failure to understand the chronic nature of asthma (attacks were treated as isolated clinical events) and poor asthma control without recognising the known risks; failure to refer to respiratory experts; failure to take an overview of their care by any one single clinician, leading to fragmentation of care both in primary and secondary care; and failure to ensure clear, accurate contemporaneous records for reference by colleagues caring for these children.

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ASTHMA DEATHS IN CHILDREN AND YOUNG PEOPLE

TM, a girl who died just before her 14th birthday,[7] suffered from 47 asthma attacks in her last 4.5 years of life. She was seen by 16 clinicians at her GP surgery on the 19 occasions she attended due to poor control, despite which there was little use of objective measurements. Despite four hospital admissions, one for a severe life-threatening attack in the previous year, she was sent home from Accident & Emergency 2 days before she died.

MU died aged 9 years following 11 missed opportunities by clinicians in the year of his death,[8] including failure to refer him for specialist advice and care.

SH had suffered 48 asthma attacks in her 10 years of life;[9] during this time she was seen by 10 GPs and six different practice nurses, and admitted to three hospitals on numerous occasions without any referral for specialist respiratory care. Of note, she was 'discharged from hospital care' on three occasions because her parents failed to bring her to hospital appointments, because of 'hospital policy' and without any safeguarding alerts. This was despite NRAD highlighting that failure to engage with routine asthma checks was a marker of future risk.

All three of these extremely sad and preventable asthma deaths in childhood illustrate major problems in the way this disease is managed and the lack of knowledge among GPs, practice nurses, and hospital doctors on the management of asthma. The main issue is that the acute management of an asthma attack is usually good, but it is considered as if this was an acute, one-off condition such as lobar pneumonia. There was no implementation of guideline and common-sense recommendations to perform a post-attack review or to ensure adequate follow-up. Asthma attacks are a signal that something serious has occurred and delineate patients at high risk of a future attack. The 48-hour post-attack review provides, first, an opportunity to assess whether the attack is over, and if not to take appropriate action; and, second, to identify modifiable risk factors for poor outcome and to optimise care, and if appropriate refer for specialist advice.[1,6] Of course, there are difficulties in asthma management: these include large workloads leading to short consultation times and difficulty in optimising lifestyle and adherence to standard effective medications. While this needs to be tackled, these issues cannot excuse healthcare professionals failing to meet standards in accordance with those of responsible bodies of opinion.[5] A key component of the review after an acute asthma attack, or in the event of poor control, involves respecting the CYP perspectives, which may require compromise, to discuss the risks and agree a management plan. Reaching an accord is more likely to achieve concordance.

In effect the QOF has resulted in a 'tick box' system operated by primary care staff, mainly nurses (and recently non-medically trained healthcare assistants) without much

training in the management of asthma, and who in most cases have not had much, if any, training in the care of CYP with asthma despite this being the commonest chronic disease of childhood. Hospitals do not appear to be providing sufficient respiratory expertise (consultant respiratory paediatricians or trained respiratory nurses) and community provision of respiratory expertise is scantily spread throughout the UK. One of the greatest failings of QOF (and to some extent the British Thoracic Society/Scottish Intercollegiate Guideline Network guidelines) is the failure to emphasise that simply asking the RCP 3 Questions is insufficient in assessing the state of the child's asthma: all these questions ascertain is the patient's current symptom control and say nothing about future risk. Of course, poor current symptom control is important to identify and deal with effectively; however, risk of future poor outcome should also be ascertained.[1,6]

REDUCING ASTHMA MORBIDITY AND MORTALITY

The NRAD and the three example cases above have highlighted our failure in the UK to provide anything like adequate primary and secondary care for these patients, above all by not identifying future risk and providing access to specialist advice for these children. Furthermore, the current planned changes in QOF to reduce requirements for good asthma care and trends in paediatrics to treat children with unlicensed, non-evidence-based, high doses of salbutamol ('weaning plans') post-attack is extremely worrying.[10]

Although many in the UK state that asthma deaths are rare events (and by implication that there isn't a need to prevent these), deaths result from asthma attacks that are extremely common and in most cases in CYP are potentially avoidable if good care is provided by competent clinicians. Above all, should not every child with an asthma diagnosis have a named doctor who has overall responsibility for their care? And why can that person not get electronic alerts for every admission, every missed appointment, and every asthma prescription, which NRAD shows give important indications of future risk? Isn't it time for clear national directives for provision by all commissioners of good-quality asthma care and access to specialist advice and care where appropriate, especially moving beyond immediate firefighting and control to risk assessment? The Finnish National Asthma Programme managed it.[11] The programme stressed that asthma requires anti-inflammatory treatment from diagnosis and they instituted an effective national network of asthma-responsible professionals; the result was a dramatic reduction in asthma morbidity, mortality, and overall costs of asthma health care. Why not the UK? We should have zero tolerance for asthma attacks.[12]

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John O Warner: PI and Scientific Advisory Board membership for trials of infant milk formulae for the prevention of allergy — Danone/Nutricia; investigator and Scientific Advisory Board membership for trials of and environmental control system for allergic conditions — Airsonett; bursaries for lectures at conferences for Danone/Nutricia, Airsonett, UCB, Novartis, and Allergy Therapeutics; medical advisor for the Anaphylaxis Campaign; member of Scientific Advisory Board for a UK government Home Office inquiry into potential toxic health hazards from the Grenfell Tower fire; academic early-years theme lead for the Collaboration for Leadership in Applied Health Research and Care for Northwest London. The views expressed in this publication are those of the author and not necessarily those of the NHS, the National Institute for Health Research, or the Department of Health.

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