

Management of diagnostic uncertainty in children with possible meningitis: a qualitative study

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SUMMARY

Background: *Neisseria meningitidis serogroup B* is the most common cause of bacterial meningitis in children and young adults. Early recognition and prompt intervention with antibiotics are thought to be key to preventing serious complications.

Aim: Explore how general practitioners evaluate and manage febrile children with possible meningitis or meningococcal septicaemia.

Design of the study: Qualitative study using one-to-one, semi-structured interviews.

Setting: General practices in the Avon Health Authority district.

Method: Twenty-six general practitioners were purposefully sampled, using a sampling frame to ensure a range of experience and practices in a variety of settings. Data management and analysis were conducted using a grounded theory approach.

Results: Key themes to emerge were the effect that fear of meningitis has upon parents and general practitioners; the difficulties associated with reaching a diagnosis; and the existence of barriers to the use of guidelines and pre-hospital penicillin. When assessing a febrile child, participating general practitioners rarely thought that meningitis or meningococcal septicaemia were likely, but were aware that this was frequently the principal parental concern. They relied upon intuitive rather than systematic methods to distinguish serious from self-limiting conditions, rarely making a definitive diagnosis. Although concerned about 'missed cases', interviewees doubted that current management could be improved. They questioned the assumption that guidelines could be sufficiently discriminating to be helpful and thought it unlikely that they would be followed in everyday clinical practice. Pre-hospital penicillin was only given if the diagnosis of meningitis or septicaemia was thought to be certain.

Conclusions: There is a substantial gap in perception between primary and secondary care in the diagnostic and management approach to children who may have meningitis or meningococcal septicaemia. Until this is addressed, further attempts to improve early intervention in primary care are unlikely to succeed.

Keywords: meningitis; meningococcal infections; primary health care; diagnosis; emergency treatment.

Introduction

THE most common cause of bacterial meningitis in children and young adults is *neisseria meningitidis* serogroup B, and it is a frequent cause of septicaemia and shock.¹ In 2001 there were nearly 2500 cases of meningococcal infection in England and Wales, which accounted for 4.2% of deaths in children under five years — excluding neonates.² In the absence of an effective serogroup B vaccine,³ and in view of the continuing prominence of pneumococcal infection in childhood,⁴ early recognition and prompt intervention with antibiotics are thought to be key to preventing serious complications.⁵

The potential for improvement in the management of individuals who may have bacterial meningitis or meningococcal septicaemia has been identified at all levels of health care.⁶⁻⁸ Considerable attention has focused on clinical practice in primary care, following several reports suggesting that as little as one-third of confirmed cases of meningococcal disease receive pre-hospital penicillin.⁹⁻¹¹ Although not strongly supported by direct evidence,⁵ it is a widely held view in public health and hospital-based medicine that, to reduce the associated morbidity and mortality, children with evolving meningitis or septicaemia could and should be identified and treated at an earlier stage in the illness, ideally in primary care.⁸⁻¹² Indeed, the benefits of early detection and the early use of penicillin in the community have been re-emphasised to all doctors in England by the Chief Medical Officer.¹³

Children with a high fever but without an obvious cause are a common clinical dilemma.^{14,15} Although many children presenting to primary care have a self-limiting viral illness, parents frequently worry about the possibility of a serious infection, particularly meningitis.^{16,17} The process of clinical assessment and treatment in primary care is complex and significantly different from the disease-focused specialist.¹⁸ Previous work suggests that this distinction may apply to the assessment of the febrile child who may have meningitis or meningococcal septicaemia and that this may impact on the implementation of recommended practice.^{19,20}

In a primary care-based study of general practitioners (GPs) from a variety of backgrounds, a qualitative approach was used to extend these initial observations. Semi-structured interviews were used to explore how GPs evaluate and manage febrile children with possible meningitis or meningococcal septicaemia, with the aim of identifying methods to improve early intervention.

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HOW THIS FITS IN*What do we know?*

Early recognition and prompt antibiotic treatment are key components in the avoidance of the severe consequences of meningitis and meningococcal septicaemia. There is a widespread perception from outside primary care that the identification and management of these patients in the community could be improved.

What does this paper add?

This study shows that there is a substantial disparity between the views and management approach of general practitioners and their colleagues in secondary care and public health. Many general practitioners were reluctant to initiate pre-hospital treatment and in general felt there was little scope to improve outcome in these children.

**Method**

Ethical approval for this study was gained from the local research ethics committees of the United Bristol Healthcare Trust, the North Bristol Healthcare Trust and the Weston Area Healthcare Trust.

Sample

The sample was selected to ensure that the views and experiences of a broad range of GPs were included in the study. Previous work suggested five professional and practice characteristics: sex, age, practice setting, practice size, and previous paediatric experience, as important sources of variation.²¹ Using a sampling frame, GPs were selected purposefully from the Avon Health Authority General Practitioner Directory. Each selected GP was invited to participate first by letter and then by a follow-up telephone call. As the emergence of new themes gradually declined from the twenty-first interview and no new codes were identified after the twenty-fourth interview, it was decided to cease the interviews after the twenty-sixth. The final interviews were used to ensure that no further themes emerged and to validate and explore established themes in more depth.

Interviews

The information given to the interviewees before obtaining consent stated that the aim of the project was to explore the current primary care management of suspected meningitis and septicaemia. A topic guide was developed from a review of the available literature and the findings of pilot interviews with four GPs. Topics included the child with fever, what the interviewee felt were the main issues regarding meningitis and meningococcal septicaemia, signs or symptoms of meningitis or meningococcal septicaemia, administration of pre-hospital antibiotics, improvements in the management of the febrile child and the use of guidelines for treatment. However, each interview varied in accordance with the priorities of the interviewee and questions concerning themes that had emerged in earlier interviews were incorporated as the study progressed. The interviews took place in each participant's practice and lasted from 20 to 60

minutes. They were audiotaped and transcribed in all but one case, in which, to concur with the participant's wishes, notes were made during and immediately after the interview.

Analysis

AtlasTI™ software was used to facilitate data management and the analysis, which was conducted using a grounded theory approach.²² Transcripts of the interviews were scrutinised. Phrases that were meaningful in the context of the research were highlighted and a descriptive code was applied. The codes were explored in subsequent interviews to test their relevance and to explore insights and emerging hypotheses. Gradually a list of codes was drawn up. The list was constantly checked to ensure that similar codes were merged and redundant codes were removed. Gradually, remaining codes were collated and assembled under broader themes that captured the essence of the subsumed codes. Categorisation was complete when no further codes were emerging from the data and key themes had been established. Relationships between these themes and the central research question were considered, clarified and described. The validity of the findings was investigated by ensuring that the categorisation and interpretation were checked by three researchers independently, and then jointly; by searching for negative cases, that is, incidences where the emerging interpretation was not supported; and by responder validation, sending the completed account to the interviewees for their inspection and comment.

Results

Three key themes emerged from the study: the effect that fear of meningitis has upon the actions of parents and GPs; the difficulties associated with reaching a diagnosis of meningitis; and the barriers to initiating penicillin treatment and to the use of guidelines.

Fear about meningitis and septicaemia

Many interviewees commented that, at some point, most parents fear their child has contracted meningitis:

'In the general population there is such a lot of concern about meningitis, it's the first thing on parents' minds when their child is ill.' [GP11]

'I think all GPs are burdened by the meningitis fear of the parents you know, which is an understandable, justifiable fear as far as the parents are concerned. And it's an understandable, justifiable problem the GPs have. I'm not sure there's any easy way round it.' [GP16]

The GPs interviewed contended that meningitis awareness campaigns have contributed to a public understanding that the disease is very serious and has frightening consequences. While not denying the importance of such information, they suggested that the fear parents now experience is out of all proportion with the actual incidence of the disease:

'I mean the awareness campaigns have been so successful that now everybody thinks that any child with a

cold has meningitis, which is to some extent counter-productive.' [GP5]

When examining a febrile child, GPs rarely thought that meningitis or septicaemia were likely causes, but they were aware that these possibilities were frequently considered by the parents. Nevertheless, they were reluctant to propose that meningitis awareness campaigns should cease. Unnecessary consultations with anxious parents were preferable to missing a case:

'I've been a doctor for 20 years and I have yet to see a case of meningococcal septicaemia. I don't think that I am particularly lucky in that because, thank God, it is not that common. However, rashes and viral illnesses are very common. And you know that the flipside of educating people is that you will end up seeing vast numbers of terribly anxious people for no very good reason. But I think you could probably argue that if it's one life saved then that doesn't matter.' [GP24]

Reaching a diagnosis of meningitis or septicaemia

Most interviewees had very little or no experience of meningitis or septicaemia. However, they frequently commented that, from their limited experience, these conditions rarely present as described in medical textbooks:

'Because it comes in all guises. You know, I haven't had a lot of experience of it but it does range from the completely clapped out to the running around the place perfectly happy with a meningococcal rash, which makes you think "oh can't be this; far too well", and it is. And that's actually very difficult, you know, for such a potentially serious illness, it's very difficult to know for sure that something is what it is.' [GP25]

Consequently, they relied upon intuitive rather than systematic methods to distinguish serious illnesses from those that are self-limiting. Doctors frequently relied on gut feeling or intuition to identify illnesses that are potentially serious:

'I think, despite what somebody might say, general practising is more of an art than a science. And there are all sorts of things I do which are, sailing by the seat of your pants is perhaps not quite the right word, but you are doing intuitively rather than actually because of any great logic behind it.' [GP16]

Distinguishing serious from self-limiting disease was regarded as an extremely important aspect of the GP's work, but making a definitive diagnosis of meningitis or septicaemia was not considered a priority.

When asked how they would assess a febrile child to determine whether or not the illness was serious, GPs were well aware of classic meningeal and septicaemic symptoms, such as neck stiffness, photophobia, or the presence of a characteristic rash. However, those interviewed stressed that these were not always helpful as indicators of serious illness as they often saw children in the early stages of illness when

symptoms were non-specific. They felt it was uncommon for them to be presented with classic symptoms such as a rash:

'The thing about being a general practitioner is you usually see illness in its first presentation, and the diagnosis made could be a multitude of things. Because often time will tell whether something is serious or something isn't. I do think hospital practitioners fail to appreciate this.' [GP24]

In determining the seriousness of febrile illness there was therefore a reliance on less systematic indicators. Several interviewees proposed that general practice is experience-based as much as it is evidence-based. Children considered to have more serious illness were those who just generally looked unwell or not quite right, or didn't seem him/herself. It was difficult to define what was meant by 'unwell', but often decisions were influenced by the degree of concern expressed by parents:

'Experience-based practice as opposed to evidence-based practice, and there is an awful lot of general practice, despite what people would say, that is based on experience. You make an awful lot of decisions just for reasons that you can't define.' [GP5]

'Often there is very little to go on except mother's instinct really that the child isn't quite right.' [GP15]

There was a recognition that the reliance on intuitive methods of diagnosis was by no means infallible. Several interviewees talked of employing 'safety nets' to anticipate this possibility, such as warning parents to look out for specific danger signs.

Treating suspected cases and the value of guidelines

There was general awareness of Department of Health guidelines concerning the administration of parenteral penicillin in situations where meningitis or septicaemia was suspected. However, although the underlying principles were appreciated, most GPs maintained that they would only give pre-hospital penicillin if the child had very definite clinical features. If there was the slightest uncertainty about the diagnosis it was considered preferable to withhold penicillin:

'I would only give pre-hospital penicillin if it was barn door, if there were spots, petechial spots, or a positive sign of meningism. I wouldn't be shovelling penicillin in without those two symptoms.' [GP6]

Several interviewees expressed anxiety about their personal lack of experience of administering parenteral antibiotics to children and were happier to relinquish responsibility to their colleagues in secondary care. It was better to get the child to hospital where they could be treated appropriately:

'I carry benzyl penicillin because I am meant to. I have never had to use it and I am not sure that I would. The

most important thing is to get the child to hospital. If I am faffing around trying to find a vein and the ambulance crew is waiting for me, then I'm not sure it is helpful.' [GP11]

When asked to suggest methods that may result in an improvement in detection in primary care, some interviewees contended that there was very little scope for such an achievement. There was a sense of inevitability that a tiny number of children would be diagnosed late and that this may lead to an adverse outcome:

'How you make the diagnosis of meningococcal disease in a small child reliably I don't know, and we will all make mistakes. As Dr Green on ER said last night, "we're not perfect". You are basically trying to do your best and hopefully do the right thing most of the time. I think it's unreasonable to expect anybody to be able to make difficult correct decisions 100% of the time and every so often we are going to make mistakes.' [GP5]

When asked specifically if the use of guidelines or algorithms would enhance detection, it was acknowledged that guidelines could be useful in some circumstances. In particular, a number of interviewees mentioned the usefulness of the 'tumbler test' when discussing potential rashes with parents. However, most used a diagnostic approach that favoured intuitive feelings over systematic assessment of symptoms, and doubted whether guidelines would be sufficiently discriminating to identify cases accurately in the absence of classic meningeal symptoms or whether they would be implemented in everyday clinical practice. The GPs felt inundated with guidelines and were reaching 'guidelines saturation', finding it difficult to keep track of them all. Algorithms or guidelines were thought to depersonalise the doctor-patient relationship, exclude intuitive methods of diagnosis and undervalue the role of experience:

'I think guidelines are, I think they are useful. I think it gives you something to focus your mind on a little bit. Although I think we tend not to like to be ruled by guidelines. Guidelines should be thought of as guidelines and not strict protocols. So I think in that way they can be useful... I guess the things that GPs worry about guidelines is whether they get to be a stick that we are beaten up with.' [GP3]

'You could follow the guidelines and be ignoring your sixth sense. So I think you have to take everybody on their own merits really, every patient on their own merits. And the guidelines, they're not rules that you adhere to rigidly, they're just sort of a skeleton to hang your experience on I think.' [GP20]

Discussion

Main findings

In this study we have shown that the views and practices of GPs when managing febrile children differ from the reported concerns of parents,^{16,17} and the perceptions of secondary

care and public health medicine physicians.^{6,9,10,15} The possibility that a febrile child without an obvious focus could have evolving meningitis or meningococcal septicaemia was widely recognised by the GPs in this study. However, few prioritised these conditions in everyday practice as they were perceived to be uncommon. Indeed, it was suggested that little more could be done to improve their management and that some missed cases are inevitable. The GPs interviewed perceived that there are difficulties in implementing advice regarding pre-hospital penicillin and expressed considerable scepticism about the value of additional guidelines to aid diagnosis.

When faced with a febrile child with no apparent focus of infection, the GPs interviewed seemed to place less importance on making a definitive diagnosis than on discriminating between self-limiting and potentially serious illness. They talked of 'acting as a filter' when deciding which children to refer to hospital. These decisions were often made without recourse to specific signs or symptoms but with a generalised impression of the patient and their family. In the absence of specific features characteristic of meningitis or meningococcal septicaemia, such as a rash or neck stiffness, those interviewed had little confidence in making a definitive diagnosis and children were often referred without one. This clinical approach is an important obstacle to the implementation of guidelines for the administration of pre-hospital antibiotics that are based on a more definitive diagnostic process.⁹⁻¹¹

There is considerable, yet not entirely conclusive, evidence linking early diagnosis and intervention to outcome.^{9,10,23-25} Occult bacteraemia may lead to serious complications such as pneumonia, meningitis, and septicaemia, and has been reported in between 3% and 15% of children aged between three and 36 months, who have a high fever without a source.²⁶ Many children subsequently diagnosed with meningitis or meningococcal disease present to primary care with non-specific symptoms in the early phases of the disease.¹⁹ Some GPs interviewed in this study felt that it was therefore inevitable that cases would be missed and treatment delayed. Indeed, in contrast to the views expressed in secondary care and public health medicine where improving early diagnosis is considered essential,^{9-11,15} many felt that there was no more they could do to improve management. None of the GPs interviewed challenged the need for early intervention but frequently commented that parenteral antibiotic treatment in the community is impractical, may delay transfer to hospital, and is only applicable to individuals with clear features of meningitis or septicaemia. These views suggest that widespread implementation of current guidelines is unlikely.

Strengths and limitations of the study

Semi-structured interviews enabled the GPs to challenge established preconceptions and to define the relevant issues in their own terms. Purposeful sampling ensured that as many as possible of the personal characteristics that may affect variability were represented, and that the final sample included interviewees with a range of experience, in a variety of settings. GPs practising in rural, suburban, urban, and inner-city areas of Avon were all adequately represented.

Those who chose not to take part typically cited an excessive workload as the reason for non-participation. Experience with cases of meningitis did not appear to affect recruitment. Potential limitations of the study were: observer bias by investigators with an interest in the field; inappropriate categorisation and selection of the data; and misinterpretation of themes and concepts. However, there was good concordance between the independently categorised and analysed data. There was little disagreement between responders within each theme. The responder validation did not reveal any significant disagreement with the analysis. The results therefore appear to reflect the views of the interviewees and are likely to have relevance elsewhere in the UK and in a variety of health systems.

Agreement with existing literature

In line with previous studies, these findings highlight the difficulties in managing diagnostic uncertainty in primary care.²⁷⁻²⁹ Contrary to hospital-based medicine where the emphasis is on decision-making based on certainty, illness is frequently identified in general practice without necessarily forming a diagnosis.^{18,28,30} The reluctance of the GPs in this study to give pre-hospital penicillin in the absence of clear diagnostic signs is consistent with published reports highlighting low rates of pre-hospital antibiotics in children subsequently diagnosed with meningococcal disease.^{9,10,12} These findings go some way to explain why, despite high-profile government and charity-sponsored information campaigns, this rate remains low.

Implications for clinical practice or policy

This study highlights the substantial gap in perception between primary and secondary care in the diagnostic and management approach to children who may have meningitis or meningococcal septicaemia. Guidelines for widely perceived important interventions in common conditions where implementation should be straightforward, such as hypertension, hyperlipidaemia, and the secondary prevention of myocardial infarction, have not been uniformly adopted in primary care.³¹ There is guidance highlighting the clinical features of meningococcal disease and the recommendations for diagnosis and management that has been disseminated widely in primary care.³² However, existing systems designed for the assessment of febrile infants, such as the BabyCheck³³ or the Yale Observation Score,³⁴ have not been widely implemented in UK general practice. Meningitis and meningococcal septicaemia create an additional dilemma for the GP. These are rare diseases that are not prioritised in everyday practice but have a high profile in the mind of the public.

Febrile children are common in general practice and the identification of those at risk of serious bacterial illness is an important, if challenging, issue. These findings indicate that it is essential to start a dialogue between primary and secondary care over the important issues of diagnostic uncertainty and early intervention in such potentially life-threatening conditions. Until the disparity in perception is addressed, further attempts to improve the diagnosis and management of meningitis and septicaemia in primary care are unlikely to succeed.

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