

# Meeting the health, social, and educational needs of children who have survived meningitis and septicaemia: the parents perspective

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## Background and aims

- ❖ A recent global review of the risk of disability after bacterial meningitis suggested that nearly 10% of survivors in Europe experienced major sequelae including cognitive deficit, bilateral hearing loss, motor deficit, seizures, visual impairment and hydrocephalus (Edmonds et al 2010). Psychological and emotional problems are also common after-effects.
- ❖ Current guidelines on the management of bacterial meningitis (NICE 2010) recommend a hearing assessment within four weeks of being fit to test and a further follow-up appointment with the paediatrician 4-6 weeks post-discharge
- ❖ There is, however, little published information on the needs for aftercare of children surviving meningitis.
- ❖ We used a mixed methods approach to gain a more comprehensive understanding of parents' and childrens' needs and experiences when accessing follow-up services.

## Methods

- ❖ Participants were recruited from Meningitis Research Foundation's member database and social media sites.
- ❖ Eligible participants were parents of children who survived meningitis or septicaemia between January 2000 and May 2010, living in the UK or Ireland.
- ❖ In stage one, participants completed a multiple choice questionnaire, either online or by post.
- ❖ In stage two, twenty participants were invited to take part in a follow-up interview, based on their answer to the survey question, 'overall, to what extent does / did the aftercare and support received meet your child's needs?'
- ❖ Interviews were designed to explore the factors affecting parents' opinions of whether their child's needs for aftercare had been met.
- ❖ Here we report on findings from follow-up interviews with 18 parents.

## Results

- ❖ Interview participants were from a range of socioeconomic classes and professions.
- ❖ In response to the question, 'Overall, to what extent does the aftercare meet your child's needs?' 6 parents reported that it 'failed to meet', 4 that it 'almost meets', 6 'meets', and in 1 case 'exceeds'
- ❖ Their affected children were at various points in follow-up after meningitis or septicaemia, with a range of physical, cognitive and emotional needs.
- ❖ Services accessed included physiotherapy, occupational therapy, educational support, orthopaedics, neurology, visual impairment services, audiology, and speech and language therapy.
- ❖ We identified 3 major themes from the interviews; (1) accessing support and follow up care, (2) communication and (3) relevance of aftercare and support

## Accessing support and follow-up care

### Navigating the system

Most parents could access services, although sometimes with difficulty. The need to learn how to navigate the system was a common issue that emerged.

*because her needs are so complicated and they're in so many different areas... there is physio, speech and language, OT, neurology...so many different people for us to learn, to keep up with and to learn the language, we didn't know what to ask...we're just completely ... overwhelmed*

### Provision of services

Almost all parents interviewed had experienced difficulties in gaining sufficient or timely care, due to a lack of staff or restricted budgets.

*[physiotherapy] was once a week, how are you supposed to keep him supple? Everything was just seizing up. One time a week just wasn't good enough.*

In cases where the child had a statement of educational needs the school could facilitate access to aftercare and support.

### Young age as a barrier to gaining a clear diagnosis and support

Gaining access to services was often difficult when the child was very young. This could be because of difficulty testing young children (as in the case of hearing assessments), or because disabled children may be perceived to have similar needs to very young children.

*[social worker] wrote to say that [her] needs were no greater than a child of her own age...it was very clear to see when she came to visit us that, she can't move, she can't talk, we have equipment all over our house...that was a huge thing to us, they said 'yes she meets our criteria but that doesn't mean she meets the criteria for services*

### Poorly appreciated link between meningitis and educational needs

The less visible, psychosocial and cognitive after effects of meningitis often made it hard to access support at school and there was little appreciation of the link between meningitis and long term psychosocial after effects

*I don't think they're even taking the meningitis [into account], school never take on how this has all stemmed from [meningitis]...I think that's a big problem, meningitis is seen as an acute thing that happens and they don't see the after effects... it's gone, it's like they've taken their cough medicine, got over their cold, now they've moved on*

## Communication

### Debrief before discharge

It may be difficult for health professionals to predict the likelihood of cognitive after effects at the time of discharge, particularly in young children who are still to reach key developmental milestones. This frequently posed a real challenge to parents and was a source of worry and distress. Often parents were not 'warned' or told that there could be potential cognitive and behavioural after-effects, others were told to 'wait and see'.

*[hospital] said, 'he might be ok you know he might have problems, but you won't know at the moment'...which I felt wasn't really helpful either because it was kind of like well you have to go home and you just wait and see how he turns out...I don't think I had the right support for that*

### Involving parents and understanding their views and wishes

Parents wanted to be involved and informed about their child's care and support. In cases where the parents felt listened to and involved, the care the child consequently received was tailored to the parent's and child's needs.

*Yeah I think they've listened to whatever we thought about, you know we've always been of the mind that we wanted [him] to be as independent as he can be and so they've worked with that*

### Communication between professionals involved in care and support of child

Poor communication between different specialists resulted in support that was unresponsive to the child's needs.

*Parent: they've just given her some words to practise, she doesn't say the endings of any of the words...probably because she can't hear them...speech and language can't sort her hearing out, they can just try and help her with pronouncing the words, but if she can't hear them then they're hitting their heads against a brick wall*

*Interviewer: Do speech and language and the audiology people, do they talk to each other?*

*Parent: :No no*

When professionals did communicate parents felt that there were shared plans and goals which facilitated meeting their child's needs.

*and nothing was ever planned without [consultant]'s say so...to me that said we have got your son's best interests at heart we have a plan and we know what we're doing*

## Relevance of aftercare and support

Just as important as access to services, was the appropriateness of those services.

*she has a helmet from orthopaedics because of her epilepsy...it fits poorly and she pushed it back so the bit of the head it's supposed to protect, it doesn't protect. I went back and said, 'is there something better we can do with it?', and she said, 'no that's it', really, she cannot be the only child to be doing this*

In cases where follow up was designed with the individual in mind parents felt services were more useful

*they spent a lot of time on his spatial awareness, and those types of things because he does seem to be quite clumsy...they picked up this constant need he has of stimulation to the head, which I hadn't noticed*

## Conclusions and recommendations

- ❖ Our survey showed that parents' satisfaction with aftercare and support services was variable
- ❖ The interviews provided richer data that offered possible explanations as to why parents were not happy with follow up, or why services were not useful.
- ❖ This research highlights three particular areas for improvement:
  - accessing services,
  - communication
  - relevance / appropriateness of services.
- ❖ A follow up package that was tailored to the child's needs, instead of a 'one size fits all' approach was vital.
- ❖ The experience of many of the families in this study predates the NICE<sup>1</sup> and SIGN<sup>2</sup> guidelines, which provide a clear framework for assessing aftercare needs.
- ❖ Our findings provide additional support for these recommendations, such as the need for a comprehensive debriefing with the discharging doctor to explain the potential for long term sequelae to parents and an explicit strategy for helping parents cope with an uncertain prognosis for their child
- ❖ Clinical audits assessing adherence to these guidelines in a larger group of discharged children should be carried out regularly

## References

1. National Institute for Health and Clinical Excellence. Management of bacterial meningitis and meningococcal septicaemia in children and young people younger than 16 years in primary and secondary care. London: NICE;2010.
2. Scottish Intercollegiate Guidelines Network. Management of invasive meningococcal disease in children and young people. Edinburgh: SIGN, 2008.

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