

What is already known on this topic

Meningitis in infancy is associated with important long term consequences

There is considerable variation in outcome depending on which organism caused the infection

What this study adds

This follow up study of 1717 children who had meningitis in infancy found that they had a 10-fold increase in risk of severe or moderate disabilities at age 5 years compared with children in the control group

The outcome of having meningitis was associated with the age at infection, and children who had meningitis in the neonatal period were more likely to have health and development problems than those older than 1 month

Subtle deficits, such as middle ear disease and visual and behavioural problems, were more prevalent among children who had had meningitis in infancy

provide a complete picture of the range of problems experienced by children from England and Wales who have had meningitis in infancy.¹⁰

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Prevalence of permanent childhood hearing impairment in the United Kingdom and implications for universal neonatal hearing screening: questionnaire based ascertainment study

Heather M Fortnum, A Quentin Summerfield, David H Marshall, Adrian C Davis, John M Bamford

Editorial by Russ

MRC Institute of Hearing Research, University Park, Nottingham NG7 2RD

Heather M Fortnum
epidemiologist

A Quentin Summerfield
deputy director

David H Marshall
statistician

Adrian C Davis
epidemiologist

continued over

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Abstract

Objective To estimate the prevalence of confirmed permanent childhood hearing impairment and its profile across age and degree of impairment in the United Kingdom.

Design Retrospective total ascertainment through sources in the health and education sectors by postal questionnaire.

Setting Hospital based otology and audiology departments, community health clinics, education services for hearing impaired children.

Participants Children born from 1980 to 1995, resident in United Kingdom in 1998, with permanent childhood hearing impairment (hearing level in the better ear > 40 dB averaged over 0.5, 1, 2, and 4 kHz).

Main outcome measures Numbers of cases with date of birth and severity of impairment converted to prevalences for each annual birth cohort (cases/1000 live births) and adjusted for underascertainment.

Results 26 000 notifications ascertained 17 160 individual children. Prevalence rose from 0.91 (95% confidence interval 0.85 to 0.98) for 3 year olds to 1.65 (1.62 to 1.68) for children aged 9-16 years.

Adjustment for underascertainment increased estimates to 1.07 (1.03 to 1.12) and 2.05 (2.02 to 2.08). Comparison with previous studies showed that prevalence increases with age, rather than declining with year of birth.

Conclusions Prevalence of confirmed permanent childhood hearing impairment increases until the age of 9 years to a level higher than previously estimated. Relative to current yields of universal neonatal hearing screening in the United Kingdom, which are close to 1/1000 live births, 50-90% more children are diagnosed with permanent childhood hearing impairment by the age of 9 years. Paediatric audiology services must have the capacity to achieve early identification and confirmation of these additional cases.

Introduction

Permanent childhood hearing impairment can have a devastating impact on communication skills,¹ educational attainment,² and quality of life,^{3,4} with a high cost to society.⁵ Improved outcomes for children with congenital impairment are associated with confirma-

Glossary

Confirmation of hearing impairment—The outcome of the process of establishing that a child is hearing impaired

Notification—The contribution by an informant of data describing a child who meets the inclusion criteria for the study

Ascertainment—The identification by the research team of an individual child from one or more notifications

Total ascertainment—The process of attempting to ascertain all cases in a population

Prevalence of confirmed cases—The number of children per thousand live births in an annual birth cohort with confirmed permanent bilateral childhood hearing impairment

tion and intervention by 6 months of age.⁶ Yet the median age of confirmation of congenital impairments has exceeded 18 months, even in regions of the United Kingdom and United States with good paediatric audiology services.^{7,8} Universal neonatal hearing screening^{9,10} has the potential to reduce the age at confirmation of congenital impairments.¹¹ However, not all hearing impairments manifest themselves at birth, and screening programmes must be complemented by services that can confirm and manage cases where impairment first shows itself postnatally. No national register of hearing impaired children exists for the United Kingdom, and accurate estimates of the prevalence of permanent childhood hearing impairment and of its profile across age and degree of impairment are unavailable. We have provided such estimates at a time when paediatric audiology services in the United Kingdom are being transformed by the introduction of universal neonatal hearing screening¹² and the modernisation of hearing aid services.¹³

Previous studies of the prevalence of permanent childhood hearing impairment display two limitations.^{7,8,14-16} Firstly, they ascertained relatively small samples (under 700 children) and so did not define the relation between prevalence, age, and degree of impairment precisely. Secondly, they did not estimate the extent of underascertainment. We examined these issues by estimating prevalence from a total ascertainment of hearing impaired children in the United Kingdom (>17 000) and by employing capture-recapture analysis^{17,18} to adjust for underascertainment. Full details of these methods can be found in the long version of this paper on the *BMJ's* website. We estimated the prevalence of confirmed cases of permanent hearing impairment, including congenital, late onset, and acquired cases.

Methods

Case definition—Cases were children resident in the United Kingdom during 1998, born between 1 January 1980 and 31 December 1995 inclusive, with confirmed permanent bilateral hearing impairment exceeding 40 dB HL (hearing level).

Ascertainment—Children were ascertained through professionals with responsibility for the provision of audiological health care (n=473) and education (n=434) to hearing impaired children. During 1998, professionals were asked by mail to complete a one

page form for each case known to them. We sent one reminder to non-responders after four months.

Analysis—We applied capture-recapture techniques using conventional formulas to estimate the size of populations from restricted samples.¹⁷ We used live birth statistics¹⁹ to convert counts of children into prevalence rates per 1000 live births.

Results

Response rate

Geographical coverage was comprehensive: professionals reported children from every postcode area in the United Kingdom, and only two of 122 postcode areas were not covered by professionals from both health and education. We received data from 191 (54%) of the 473 health professionals contacted. Of the 434 education professionals contacted, 295 (72%) provided data.

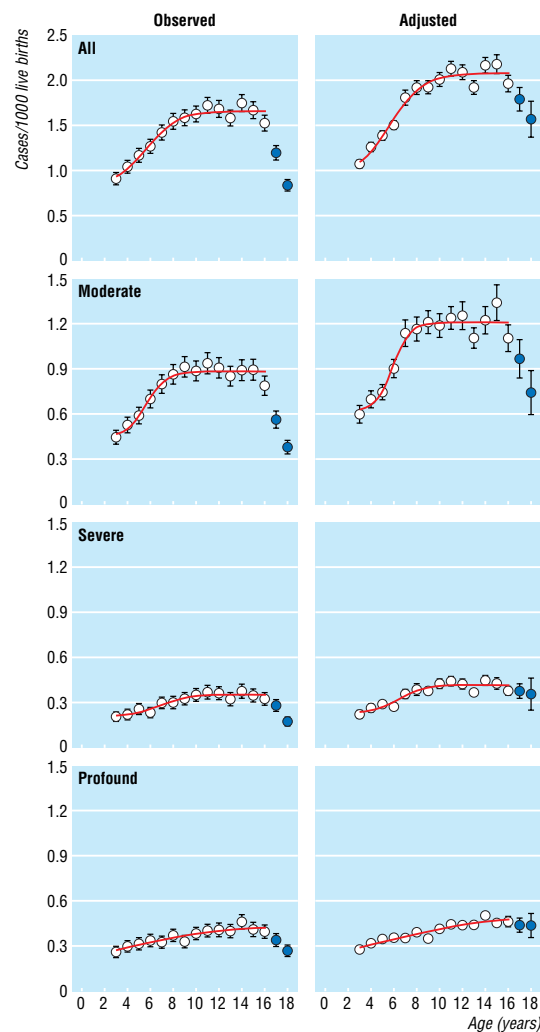
Prevalence

We received over 26 000 ascertainment forms. After we eliminated duplicate notifications the number ascer-

Human Communication and Deafness Group, University of Manchester, Manchester M13 9PL

John M Bamford
professor of audiology and education of the deaf

Correspondence to:
Dr Fortnum
hf@ihr.mrc.ac.uk



Profiles of observed and adjusted prevalence of permanent childhood hearing impairment with age and by degree of impairment (all: >40 dB HL; moderate: 41-70 dB HL; severe: 71-95 dB HL; profound: >95 dB HL).²⁰ Points plotted as filled circles were excluded from some analyses

Observed and adjusted prevalences as cases per 1000 live births (95% confidence intervals) for single birth cohort with age of 3 years (1995) and for aggregate of birth cohorts with ages ranging from 9 to 16 years (1982-9)

Severity (dB HL)	Observed prevalence		Adjusted* prevalence	
	1995	1982-9	1995	1982-89
>40	0.91 (0.85 to 0.98)	1.65 (1.62 to 1.68)	1.07 (1.03 to 1.12)	2.05 (2.02 to 2.08)
41-70	0.45 (0.40 to 0.50)	0.89 (0.86 to 0.91)	0.60 (0.54 to 0.66)	1.21 (1.18 to 1.24)
71-95	0.20 (0.17 to 0.24)	0.35 (0.33 to 0.36)	0.22 (0.21 to 0.24)	0.41 (0.40 to 0.42)
>95	0.26 (0.22 to 0.29)	0.39 (0.38 to 0.41)	0.27 (0.26 to 0.29)	0.44 (0.43 to 0.44)
Not stated	0.01	0.02		

*Adjusted by capture-recapture.

tained was 17 160 individual children. We calculated prevalence from observed counts and from counts adjusted by capture-recapture (figure). Prevalence declined for children in the oldest two cohorts (1981 and 1980), who were aged from 16 to 18 years when the ascertainment was conducted. Some would have left school and not been included in the education list; some would have transferred from paediatric to adult hearing services. Both effects violate a requirement for capture-recapture to be valid. Hence these cohorts were excluded.

Using observed data for all severities combined, we compared prevalence in each cohort in turn with prevalence aggregated across all older cohorts. This procedure distinguished the 1982-9 cohorts as a group from the younger cohorts (Poisson probabilities, $P < 0.05$). The table shows a rise in prevalence from age 3 to age 9 of 81% in observed values for impairments >40 dB and 92% with adjustment by capture-recapture. A significant rise was also seen for each degree of impairment.

Two hypotheses may explain these results: either confirmed prevalence increases with age or prevalence has decreased with time. Our study did not follow cohorts over time, so we compared current data with data obtained in studies conducted earlier,^{7 8 14} aligning the data by birth cohort and separately by age. The most relevant earlier study was a total ascertainment of children with permanent hearing impairment in the Trent health region (population 4.7 million) in 1995.⁷ This study reported an aggregate prevalence for the birth cohorts 1985-90 (age 5-10 years) of 1.33/1000 live births (95% confidence interval 1.22 to 1.45). In the present study, the observed aggregate prevalence in the

same cohorts (age 8-13 years) was significantly higher at 1.63/1000 (1.59 to 1.67), whereas prevalence among children matched for age (cohorts 1988-93) was not significantly different at 1.44/1000 (1.41 to 1.48). We conclude that prevalence has not decreased with time, but rather that age is the main determinant of prevalence. To corroborate this conclusion, in September 2000 we reapproached six informants who maintain computerised records of large numbers of children. Two years previously they had notified 233 children in the cohorts 1992-5 inclusive. They now notified 336 children in the same cohorts. The increase is compatible with the hypothesis that confirmed prevalence rises with age.

Discussion

The prevalence of permanent childhood hearing impairment rises over a wider age range and to a higher plateau than has been reported previously. Previous ascertainment studies have included fewer children and a narrower range of cohorts and hence could not map the rise in prevalence across birth cohorts with the precision displayed in the figure. The profile of the rise in prevalence with age has important implications for service delivery, which can be dealt with only when the variables underpinning the rise are understood. Three effects are likely to contribute.

Some children acquire impairment postnatally—Impairments that are acquired, as distinct from progressive or of late onset, account for 4-9% of overall prevalence^{7 15-16} and 7% in the present study. Thus they explain only a small proportion of the rise.

Confirmation of impairment is delayed in some children—Delayed confirmation of congenital cases may contribute to the rise, particularly for lesser degrees of impairment.^{7 8 21} If universal neonatal hearing screening identified all congenital impairments the yield from screening would be close to the aggregate prevalence seen in the table. In the United Kingdom the yield of children with bilateral hearing impairment ≥ 40 dB HL per 1000 live births has been reported as only 1.18 (34/28 890)²¹ and 0.94 (24/25 609),²² giving an aggregate yield of 1.06 (95% confidence interval 0.84 to 1.44). This is close to the overall prevalence in the youngest cohort in our study, and the upper confidence limit is below the aggregate prevalence (table). Thus it is unlikely that delayed confirmation fully accounts for the unexplained portion of the rise.

Some inherited causes of hearing impairment manifest themselves only postnatally—Many of the dominant genes for deafness are associated with late onset progressive hearing impairment.^{23 24} The protracted rise in the prevalence of severe and profound impairments (figure) is more compatible with the idea that some

What is already known on this topic

The prevalence of confirmed permanent childhood hearing impairment (>40 dB HL) in the United Kingdom has been estimated to rise with age to 1.33/1000 live births among children aged 5 years and older

It has been predicted that only an additional 16% of children will remain to be detected in the postnatal years, given current yields from universal neonatal hearing screening

What this study adds

The prevalence of confirmed permanent childhood hearing impairment (>40 dB HL) in the United Kingdom has risen with age to at least 1.65/1000 live births (and may be as high as 2.05/1000 live births) among children 9 years of age and older

If the current yield from screening is sustained, then an additional 50-90% of children will remain to be detected in the postnatal years

children have impairments of progressively increasing severity than with the alternative that many congenital cases with severe and profound impairments were not confirmed until several years after birth.

The implementation of universal neonatal hearing screening should result in a well documented screening history for all children. That information, together with the results of genetic investigations in children with a newly confirmed diagnosis of permanent hearing impairment, would permit the rising profile of prevalence with age to be confirmed prospectively and would allow us to unravel the relative contributions of the three effects to the rise.

Conclusions

In the United Kingdom the prevalence of confirmed cases of permanent childhood hearing impairment >40 dB HL has risen with age to a significantly higher plateau than previous studies have estimated. Assuming that the yield from universal neonatal hearing screening will remain close to 1.06 per 1000 live births, we estimate that for every 10 children with a permanent bilateral hearing impairment >40 dB HL detected another five to nine children (50-90%) would manifest such a hearing impairment by the age of 9 years. These additional children would comprise some with congenital impairments who either miss neonatal hearing screening or pass the screening despite having a hearing impairment, some who acquire an impairment postnatally, and others who manifest late onset or progressive impairments. Paediatric audiology and associated services will need the capacity and skills to identify and then confirm impairments in these children.

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Conflict of interest: None declared.

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Commentary: Universal newborn hearing screening: implications for coordinating and developing services for deaf and hearing impaired children

Adrian Davis, Christine Yoshinaga-Itano, Sally Hind

The prevalence of permanent childhood hearing impairment of 40 dB HL or greater, and the probability that late onset and progressive hearing impairment may be more prevalent than previously indicated, has been discussed by Fortnum et al in their paper. There is no estimate available of the number of children with "mild" (20-40 dB HL) bilateral permanent impairment or those with unilateral impairment, but current programmes that screen for hearing problems in the newborn in the United States suggest that such impairment, identified by screening at birth, is at least as prevalent.¹

Screening hearing in newborns has been shown to be efficient² and cost effective,³ with a sensitivity in the

range of 80-90%, a false positive rate of <2%^{4,5} and a positive predictive value of 17%. The proposed costs of such screening in the United Kingdom are much lower than the costs of the current infant distraction screen test,⁸ and the cost per child identified as having bilateral permanent hearing impairment is considerably less. There is little evidence that screening all newborns for hearing raises anxiety among mothers.⁶

The benefits of universal newborn hearing screening for children with permanent hearing impairment are that early identification is associated with better expressive and receptive language, speech, and social and emotional development. Children who are identi-

Public Health and Clinical Section, MRC Institute of Hearing Research, University Park, Nottingham NG7 2RD

Adrian Davis
head of epidemiology,
public health and
clinical sections
Sally Hind
developmental
psychologist

continued over

Department of
Speech, Language,
and Hearing
Sciences, University
of Colorado,
Boulder
80309-0409,
Colorado, USA
Christine
Yoshinaga-Itano
professor

Correspondence to:
A Davis
Adrian@ihr.
mrc.ac.uk

fied before the age of 6 months show substantial benefit in the first five years of life, and there is some evidence that earlier enrolment in intervention programmes is associated with better outcomes.⁷ A higher level of expressive language in young children is linked with levels of parental stress and better attachment as measured by emotional availability.^{8,9} However, if early identification and intervention is not handled well at the service level, it can generate anxiety and grief and bring about negative outcomes for the family.¹⁰

The Department of Health has started a universal newborn hearing screening programme in England, beginning with a pilot implementation with a hospital or clinic based protocol in 17 areas and a community based protocol in three areas. Concerns over the quality of services for the assessment of children's hearing for those referred from screening and of early intervention programmes for parents and their children who have a confirmed permanent hearing impairment have been raised. Family Friendly Hearing Services are being developed that have three main characteristics. Firstly, service provision by all professional sectors in a positive family friendly culture should encourage "seamless" collaboration, responsiveness that meets the family's real needs, and provision of appropriate information between all agencies and for parents that enables families to make informed choices about services for their children. Secondly, paediatric audiology should exceed a minimum standard in terms of quality and accessibility. Thirdly, there must be a culture of service evaluation, including peer review, with an element of feedback from parents and their children with impaired hearing. Data from screening and assessments will be kept nationally on a database integrated with other child services. This will facilitate the monitoring of later development of permanent childhood hearing impairment and the effectiveness of the screening programme.

The implementation team will rigorously assess access to and quality of health and social care for these families, and outcomes of the programme will be evaluated. Coordination of these services and support

options are key factors in the success of the programme, and availability of the range of options would be severely restricted by a lack of appropriately trained staff and resources. The aim is to detect bilateral moderate to profound congenital permanent childhood hearing impairment to enable high quality parent-child intervention services.

The advent of a national newborn hearing screening programme creates the opportunity to help these children to develop their true potential, provided that the training, resources, and coordination are made available. We will need to monitor the outcomes of the children at different ages to enhance the evidence base concerning the most effective health, educational, and social interventions. There continues to be a need to develop and implement more effective screening and case finding for school aged children (4-16 years) with acquired and late onset hearing impairments that may negatively affect their behaviour and educational achievement.

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A memorable patient *A regular pain*

Ice cream and apple juice. They should not make a healthy 7 year old cry, should they? But she screamed. She had had an adenotonsillectomy that morning under the care of a senior colleague. Pethidine 25 mg had been given over 90 minutes ago. She screamed swallowing the "prn" paracetamol (500 mg dissolved in apple juice). "Prn" ibuprofen elixir (200 mg) caused the same response an hour later, but less so. That is, once the nurse had got the ibuprofen and convinced the girl to take it, and the drug had had time to work. Her father counted the hours until he could request more analgesia, trying to time its peak effect with meal times.

Why do we fail to apply existing knowledge and let children suffer? Pain is predictable after surgery. So why don't we time our analgesics to match? Pain prevention requires regular doses of analgesia, titrated to effect, given by the oral, rectal, or parenteral route. Rectal diclofenac and paracetamol can be given

peroperatively, avoiding the need for painful swallowing. Subsequent regular oral doses—such as ibuprofen 100 mg if no pain, 200 mg if pain—maximise analgesia while minimising side effects. "Prn analgesia" should consist of the extra, titratable rescue opioid analgesia.

My daughter's stoicism and forgiveness made her my most memorable patient.

Colm Lanigan *consultant anaesthetist, University Hospital Lewisham, London*

We welcome articles up to 600 words on topics such as *A memorable patient, A paper that changed my practice, My most unfortunate mistake*, or any other piece conveying instruction, pathos, or humour. If possible the article should be supplied on a disk. Permission is needed from the patient or a relative if an identifiable patient is referred to.