

Presentations at BACDA Study Day

"Middle Ear Problems"

Diagnosis and Management of Childhood Otitis Media in Primary Care - A National Clinical Guideline; SIGN

Professor George Browning

Professor Browning will be discussing in detail evidence to support the following SIGN guidelines:

- Primary Care personnel should have an increased awareness of the possibility of the presence of otitis media with effusion (OME) in asymptomatic children, particularly those in day care, those with older siblings and those with parents who smoke as well as in those who present with hearing or behavioural problems. Boys are more likely to be affected than girls and OME is more prevalent in the first than second year of life.
- In most situations, the GP will have to depend on history and otoscopy for diagnosing otitis media.
- Children diagnosed with uncomplicated acute otitis media should not routinely be prescribed antibiotics.
- Delayed antibiotic treatment is an alternative approach, which can be applied in general practice
- Children with acute otitis media should not be prescribed decongestants or antihistamines.
- Despite the lack of a large volume of evidence, it seems sensible to recommend that parents give paracetamol while ensuring that they are aware of the potential danger of overuse.
- Insertion of oils should not be prescribed for reducing pain in children with acute otitis media.
- Children with otitis media with effusion (OME) should not be treated with antibiotics.
- Decongestants, antihistamines or mucolytics should not be used in the management of otitis media with effusion.
- There is no evidence to support the recommendation of steroid therapy in the management of children with otitis media with effusion.
- Autoinflation may be of some benefit in the management of children with otitis media with effusion.
- Children under three years of age with persistent otitis media with effusion and typical hearing problems, but no language development or behavioural problems, can be safely managed with watchful waiting.
- Children with otitis media with effusion over three years of age or with language or behavioural problems should be referred to a specialist for assessment.
- The speaker should be facing the child. It is important to get the child's attention before starting to talk. Background noise should be reduced as much as possible and speech should be clear with normal rhythm and volume.
- Parents with children with otitis media with effusion should be advised to refrain from smoking.
- Parents should be advised that breast-feeding may reduce the risk of their child developing otitis media with effusion.
- Grommet insertion is not a contra-indication to swimming.

What Colleagues Think of Long Term Ventilation Tubes in the Management of Persistent OME

Dr. Ansar Ahmmed

The presentation is based on a postal survey looking into the current clinical practice amongst Consultant Otolaryngologists in the U.K., in cases of recurrence of otitis media with effusion (OME) after extrusion of short-term ventilation tubes.

Of the 319 respondents 47.9% routinely, 9.7% sometimes and 41.3% never use long-term tubes. Of the Otolaryngologists who used long-term tympanostomy tubes, 83.4% used them to improve hearing, 59.8% to prevent middle ear complications, while 47.5% to prevent recurrent otalgia and acute otitis media. Of the colleagues who did not use long-term tubes, 77.3% believed that long-term tubes caused more complications than benefit, 29.4% thought that long-term tubes did not significantly reduce the risk of middle ear complications, and 27.6% had the opinion that long-term tubes did not restore the changes in the middle ear and tympanic membrane that had already taken place.

Amongst the 319 respondents, 15 (4.70%) routinely, 146 (45.77%) sometimes, while 158 (49.53%) either never or very rarely recommended hearing aids. Hearing aids and ventilation tubes were both suggested as equally good options by some consultants but they preferred surgery for a number of reasons.

There are inconsistencies in practice and some of the reasons for re-inserting ventilation tubes are not evidence based. A hearing aid is a non-invasive option and this survey shows a need for a randomised control trial of hearing aids and ventilation tubes in the management of persistent and recurrent OME.

Children's Views on Hearing Aid Use in Otitis Media with Effusion

Annabel Dodds

Objective -

To determine children's views on hearing aid provision for recurrent persisting Otitis Media with Effusion (OME).

Method -

Since 1998 children with recurrent persisting OME with hearing loss have been offered hearing aid(s) as oppose to further surgery. Following hearing aid fitting a questionnaire is sent to the children for completion and in this paper the results of the returned questionnaires are presented.

Results -

The majority of the children used their hearing aids for school, in the house and when watching television either all the time or most of the time. Previous surgery ranged from none (due to medical condition) to a maximum of 4 sets of ventilation tubes. Self consciousness was reported in a number of children especially when a second aid was fitted but despite this the majority of children said they preferred wearing a hearing aid to further surgery.

Conclusion -

Hearing aid provision is an acceptable alternative to surgery for persisting OME providing children are selected carefully.

Key Words - Otitis Media; Hearing aids; Children

TARGET Study results - implications for intervention policy and service structures

Mark Haggard for MRC Multi-centre Otitis Media Study Group

Randomised trials are the only way to unbiased the allocation to treatments, hence to accurately quantify the benefit of any proposed treatment programme in the future. The proximal and short-term therapeutic effects of ventilation tubes (VTs) and adenoidectomy for OME have been documented by past trials, but the information on cost-effectiveness for parentally valued outcomes falls short of an evidence base for general policy or specific intervention criteria. From 1994 to 1998 children were recruited into TARGET, the UK national cost-effectiveness trial; 376 were randomised and results are now emerging from the 2-year follow-up. Proper psychometric development of a coherent set of outcome measures has been successful and the major fallacies in the statistical reasoning of much of the medical literature have been avoided. This enables conclusions to be drawn for the 1-year and 2 year period following randomised intervention. Of the qualifying children (i.e. those with ≥ 20 dB HL, twice 3 months apart), adenoidectomy emerges as seriously attractive for a fair percentage, the exact optimum percentage yet to be specified on health-economic grounds. Sufficient dimensions on which the intervention criteria can be specified are now known, making it possible to rectify the past disregard for such criteria. Ventilation tubes would not be denied to the adenoidectomised (on the basis of cost effectiveness at the margin) as short-term tubes have low risk. Results show that they should also not be denied to the qualifiers not receiving adenoidectomy. The implied programme would be less costly but more effective than current practice provided that whimsical variation in practice can be contained. Policies for selection and watchful waiting are now up for re-examination and for proper specification.

'A VISIT TO THE HEARING CLINIC'

Adrian Dighe

What do parents tell young children by way of preparation for a visit to a community hearing clinic? The author had overheard comments made to children by parents and carers either on their way in to the clinic or as they were leaving that indicated a child's performance at the assessment might be improved by better awareness of what was expected.

Fifty consecutive parents were asked what they told their child about the clinic visit, what they expected to

happen in clinic and whether anyone had explained the assessment procedure. Virtually all parents would like more information to prepare both themselves and their children for the visit, the great majority having been given no information by the referrer.

The author developed a proposal for development of parent and child information which was selected for funding, Two booklets were designed, each page describing some aspect of the clinic assessment process and accompanied by an illustration by a well know children's illustrator. In the booklet for older children clinic activity is presented as a story to be read by an adult with pictures for the child to colour in. This booklet describes the assessment in terms of 'hearing games' that the child will be asked to play. The booklet for babies is addressed to adults and explains why babies are referred to hearing clinics, how hearing will be checked, and how parents can contribute to the assessment process. Both booklets are written in a clear child friendly typescript and have won the crystal mark from the Plain English Campaign for clarity.

A video has also been made showing three children of different ages attending for assessment. The video is available to borrow from health visitors and local public libraries.

A copy of the relevant booklet is sent with the appointment letter and a flyer about the video is included. Booklets fit into regular DL size envelopes and do not add to postage costs.

The authors have observed that many more children seem to enjoy their visit. Exclamations such as 'mummy here are the men' (referring to the men in a boat game) or 'I saw this on the video' are regularly heard. Informal evidence suggests the project has been a great success and contributes to a family friendly service. The material received very favourable reviews in the April edition of BSA News Magazine.

A recent face to face survey of 100 new patients who had received the booklets has been conducted. Parents indicate that the booklets are helpful, easy to understand and that illustrations help. Over 50% of eligible children look at the booklet with an adult, although very few colour in the pictures. Parents and carers found the information closely matched their clinic experience and the vast majority consider the information helps reduce anxiety about the clinic visit. There were very few suggestions for improving or altering the information presented in the booklets. Few families watch the video perhaps indicating problems with access or knowledge of availability.

For more information contact the author by phone 01903 286719 or e-mail <adrian.dighe@wpc-tr.sthames.nhs.uk>

The Colorado Newborn Hearing Screening Project, 1992-1999: On the Threshold of Effective Population-Based Universal Newborn Hearing Screening Albert L. Mehl and Vickie Thomson

Objective.

Although previous studies have documented the feasibility and benefits of universal newborn hearing screening in selected hospitals, none have reviewed the effectiveness of regionally mandated participation of large numbers of hospitals with variable levels of motivation to succeed. The purpose of this study was to measure hospital participation and overall screening success in a statewide program for universal newborn hearing screening and to track improvements in program establishment and outpatient follow-up over time.

Methods.

Four Colorado hospitals began voluntarily performing hearing screening before hospital discharge on all newborns in 1992. By 1996, 26 Colorado hospitals were participating in universal newborn hearing screening. The publication of screening results from these early years served as a catalyst for legislation requiring increased hospital participation in establishing universal screening programs. Data systems were subsequently developed to improve statistical tracking and follow-up.

Eight years' worth of cumulative study data as well as the results from calendar year 1999 (the year of greatest hospital participation) were reviewed for collective measures of successful screening and follow-up. Three hospitals did not initiate newborn hearing screening programs until after the study period ended in 1999. Of the 57 hospitals that were screening newborns in 1999, the chosen method of screening at 52 hospitals was automated auditory brainstem response testing; 3 hospitals used otoacoustic emission testing, and the remaining 2 hospitals used 2-stage screening. Hearing loss was defined as a threshold of 35 decibels or greater in 1 or both ears at the time of confirmatory testing.

Results.

During the full 8-year study period, 1992 to 1999, 148,240 newborns were screened. A total of 291 infants who were born during the study period received a diagnosis of congenital hearing loss. In this cohort of 291 children, the cumulative frequency of bilateral hearing loss was 71% (range: 48%-94% by calendar year), the frequency of sensorineural hearing loss was 82% (range: 67%-88%), and the frequency of

1 or more risk factors was 47% (range: 37%-61%). During calendar year 1999, a total of 63,590 births were recorded at 60 birthing hospitals in Colorado. The families of 263 (0.4%) of these newborns refused newborn hearing screening. Of the remaining 63,327 newborns, 87% (55,324 infants) were screened for hearing acuity before hospital discharge, a far greater percentage than the 19% of all newborns screened during the first 5 years of voluntary hospital participation, and approaching the American Academy of Pediatrics's recommendation of 95% of newborns completing hospital-based testing in a successful screening program.

As a result of this statewide hearing screening program, congenital hearing loss was diagnosed in 86 Colorado newborns during 1999, representing an occurrence rate of approximately 1 affected child in every 650 newborns. In this group of 86 infants, 59 had bilateral sensorineural hearing loss, 17 had unilateral sensorineural hearing loss, 4 had bilateral conductive hearing loss, and 6 had unilateral conductive hearing loss. Mild hearing loss was present in 6 infants, moderate hearing loss was present in 42 infants, severe hearing loss was present in 33 infants, and profound hearing loss was present in the remaining 5 infants. Only 32 of the 86 affected newborns in 1999 had 1 or more risk factors for hearing loss subsequently identified. After failing an initial hospital-based screening at 1 of the 57 participating hospitals in 1999, 2.3% of infants screened (1283 newborns) were referred for follow-up testing, easily exceeding the standard of <4% recommended by the American Academy of Pediatrics. Similarly, the false-positive rate of 2.2% during 1999 exceeded the recommended standard of <3%.

Of the infants who failed their initial screening, 76% (978 infants) had documented follow-up testing to confirm or exclude congenital hearing loss, a percentage significantly improved from a follow-up rate of 48% during the first 5 years of screening, although not yet achieving the standard of 95% recommended by the American Academy of Pediatrics. Nine participating hospitals, however, were able to document appropriate follow-up for 95% or more of the infants who failed their initial screening tests. The median age of diagnosis of congenital hearing loss during 1999 was 2.1 months; 71% of affected infants were identified by 3 months of age (the recommended standard for age of diagnosis),

and 92% of affected newborns were identified by 5 months of age. Measures of screening success were compared for large, mid-sized, and small hospitals. Increasing hospital size, as measured by the number of births per year, was associated with an increasing percentage of newborns who were successfully screened. It was notable that smaller hospital size was associated with increased referral rates for follow-up testing, whereas larger hospital size was associated with the highest recapture rate for follow-up testing.

Conclusions.

Universal screening for congenital hearing loss is demonstrated to be feasible in a large regional effort of legislatively mandated participation. The success

of such an endeavor is dependent on educational efforts for community professionals, commitment on the part of program planners, and data systems that more accurately track and recall infants who fail initial hospital-based screening.

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Otitis Media with Effusion and Atopy in children.

Dr D Umapathy, Dr GK Scadding, Dr R Alles.

ABSTRACT

Objective:

To evaluate the association between symptoms suggestive of otitis media with effusion (OME) and those of atopic disorders as reported by school children within the community.

Methodology:

A questionnaire based study with domains for ear, nose, and chest symptoms. A weighted scoring system was developed for each of these symptoms; 1-5 suggesting a possible diagnosis, and ≥ 6 indicating a strong likelihood.

Subjects and Setting:

332 schoolchildren aged 5 to 6.5 years from 11 Infant and Preparatory schools in the East Berkshire District.

Main outcome measures:

Frequencies of weighted symptom scores (0, 1-5, ≥ 6) for ear, nose, and chest symptoms, and for treatment of OME, asthma, and eczema. Correlation between

ear, nose, and chest symptom scores.

Results:

Ear, nose, and chest symptom scores (1-5, ≥ 6) suggestive of OME, allergic rhinitis, and asthma were reported by 32.8%, 36.6%, and 24% children respectively. Correlation between ear scores and nose or chest scores was very significant ($p=0.0000$) as was nose and chest scores ($p=0.00001$). Correlation between ear scores and a family history of asthma was statistically significant, but not for other atopic manifestations. No association was found between scores suggestive of OME and a history of eczema, urticaria, food or drug allergies.

Conclusion:

There is a notable connection between symptom scores suggestive of OME and those suggestive of respiratory tract atopic disorders in children. It is therefore important to inquire about such symptoms as

THE BACDA PRIZE

A NEEDS ASSESSMENT SCALE FOR FAMILIES WITH HEARING-IMPAIRED CHILDREN

Dr Jane Dalzell

Introduction

There is much current interest in the development of skills and technology for diagnosis, assessment and management of hearing loss in children. Hearing services are undergoing extensive modernisation processes centred on the implementation of universal neonatal hearing screening and provision of digital hearing aids. Research continues to provide evidence for the significant impact that hearing loss has on a child's development and consequently our understanding of the child's needs is becoming clearer. These needs are traditionally met by a combination of health, education and social services and are directed from the professional perspective.

But how does a child's hearing impairment impact the family? What are the family's expectations? What are the family's needs to provide the most favourable environment for their child's development? Studies of families who have children with a range of different disabilities have shown that the family's needs are unequivocally linked with the child's, and the importance of addressing family needs has been clearly recognised (Ayer, 1984). Indeed it has not only aroused professional interest but also has become a political issue with directives from the Department of Health over the last twenty years or so (DHSS, 1976, DoH, 1998).

The Shorter Oxford English Dictionary defines a need as "something that is desired or lacking". It can imply both requirement and inadequacy in the same instant.

When considering *family* needs the definition of need is extended to imply requirement for a particular purpose or goal. Needs vary with time, place and person and may be unique. On the other hand, needs perceived by one individual or group may differ from those perceived by another observer. So how can one measure such a changeable and individual entity? How can one identify family needs in a way that is both practical and meaningful to families and service providers?

The Family Needs Survey

The Family Needs Survey is a verified assessment tool for identifying needs from families who have children with a variety of disabilities (Sexton *et al.*, 1992, Bailey *et al.*, 1992, Bailey and Blasco, 1990). In the USA it has proved to be a valuable component, either in modified or original form, of the family-centred process used in State intervention programs and has been established for example, in Colorado (Stredler Brown and Yoshinaga-Itano, 1994) for several years.

The Family Needs Survey was designed by Bailey and Simeonsson (1988) to be a practical instrument identifying specific family needs and parent priorities for a service provision. They based the content and format of the survey on comprehensive literature review, research data, extensive discussion with professionals working with families and their own personal clinical experience.

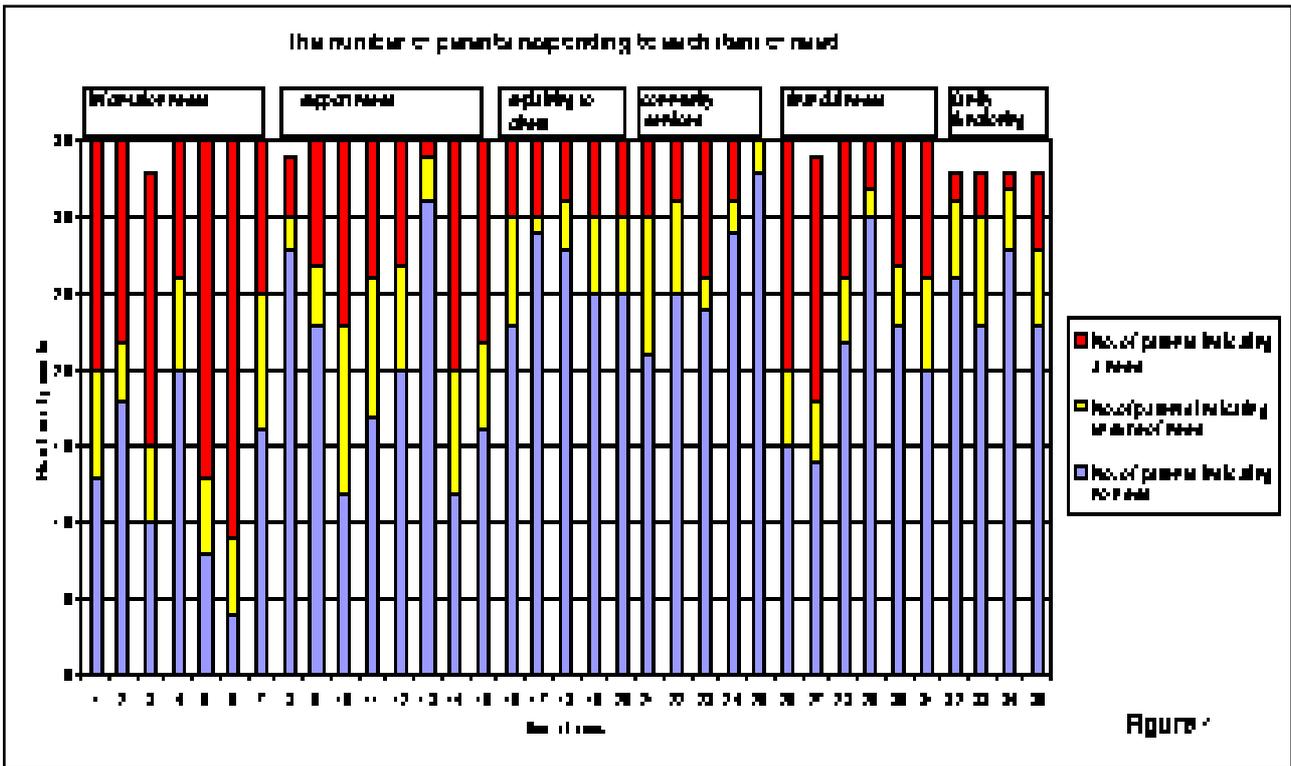
It has 35 items divided into six categories of need: information, support, explaining to others, community services, financial needs and family functioning. Each item is responded to in one of three ways indicating: - a definite need, unsure of need and definitely no need. It is intended for the survey of parents, but it may be used with other family members. A needs profile for each family can be obtained as shown in figure 1.

With growing recognition in the UK of the importance of involving families in intervention programs for their children as part of a Family-Friendly Hearing Service, (Baguley *et al.*, 1999), consideration was given for a study to explore the identification and quantification of family needs.

A Family Needs Survey in a local District

A pilot study was conducted using the Family Needs Survey in the District of Chester and Ellesmere Port. The aim of the study was to identify current functional needs in families who have children with permanent hearing impairment and to evaluate the assessment scale in this area (Dalzell, 2000). Twenty families (35

ADD9EMS



parents, including five single parents) with hearing-impaired children completed the survey and 28 parents were interviewed afterwards. All the children (age range: 0-11 years) had a sensorineural hearing loss which varied in degree from mild to profound. Some of the children had additional developmental difficulties associated with prematurity or genetic conditions.

There was great variety in the number and item of needs indicated by parents. The most reported needs were in "information" and "support" categories, categories in which a service provision response would be practical (figure 2).

The most reported needs from parents were for information about future services available to their child (indicated by 74% of parents) and for information about present services (63% of parents). Fifty-one percent of parents indicated a need for information about how to teach their child and 43% for information about their child's condition. Also highly ranked were support needs for reading material about parents who have a similar child and this was identified by 43% of parents.

All seven items of need for information in the Family Needs Survey were ranked highly by parents. Financial and support needs varied in ranking, needs

Chart showing the number of need indications (%) in each need category given by 15 mothers and 15 fathers

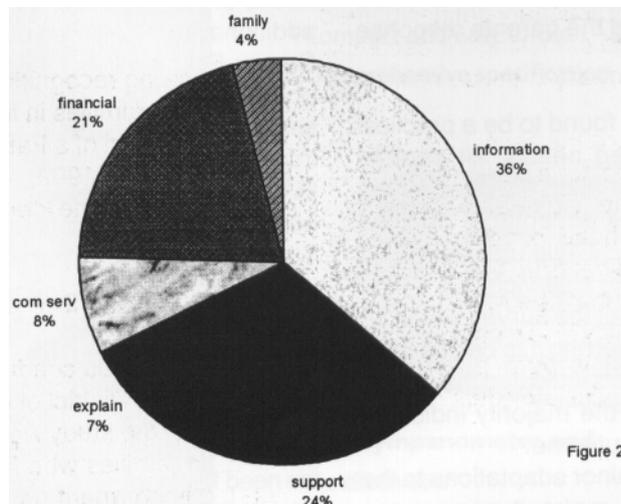
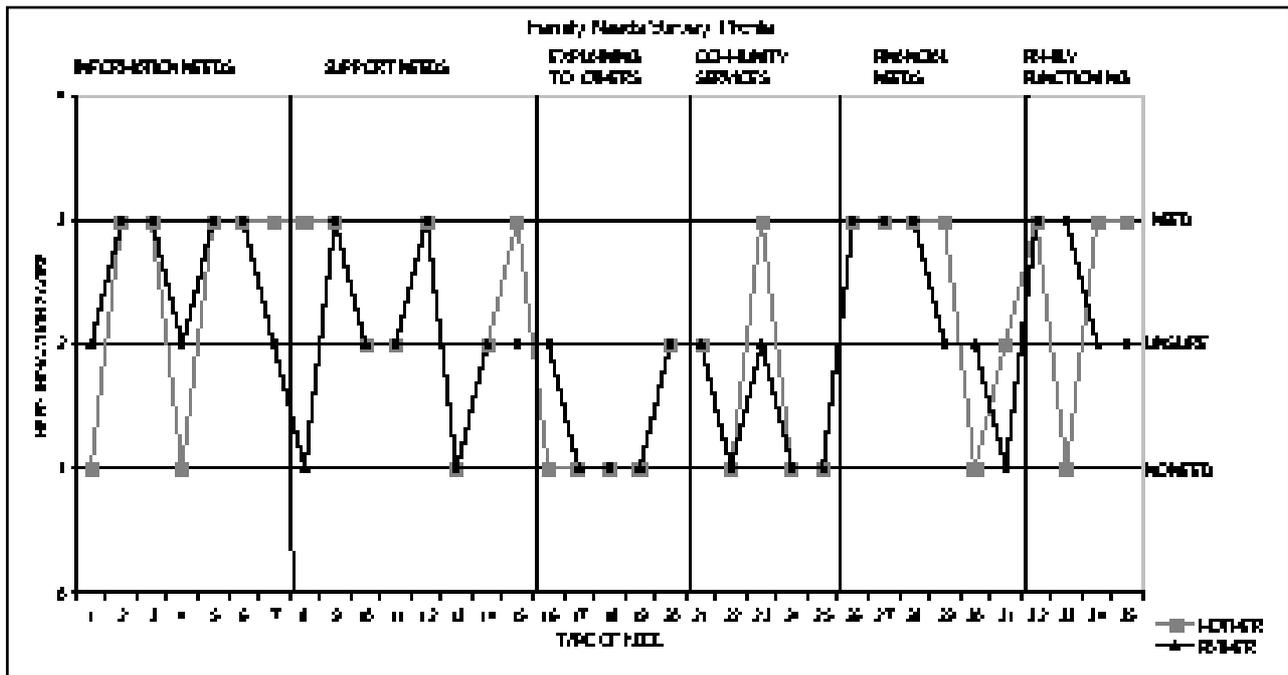


Figure 3



for community services and advice on explaining to others ranked in the lower range and family functioning needs ranked lowest.

Figure 3 shows the distribution of needs, unsure of needs and no needs for the 35 parents responding to each item. Although some parents did not respond to every item it can be seen from the chart that the majority of need indications lie in the categories of need for information, support and finance.

What did families with hearing-impaired children think of the Family Needs Survey?

Twenty-eight parents were interviewed and their answers coded to obtain a chart showing the parents response to each question (figure 4).

The Family Needs Survey was found to be a practical measure of parents expressed needs. All parents indicated that sharing the information provided by the survey with professionals was acceptable and the majority indicated they would find it helpful in identifying what their family might need from a service.

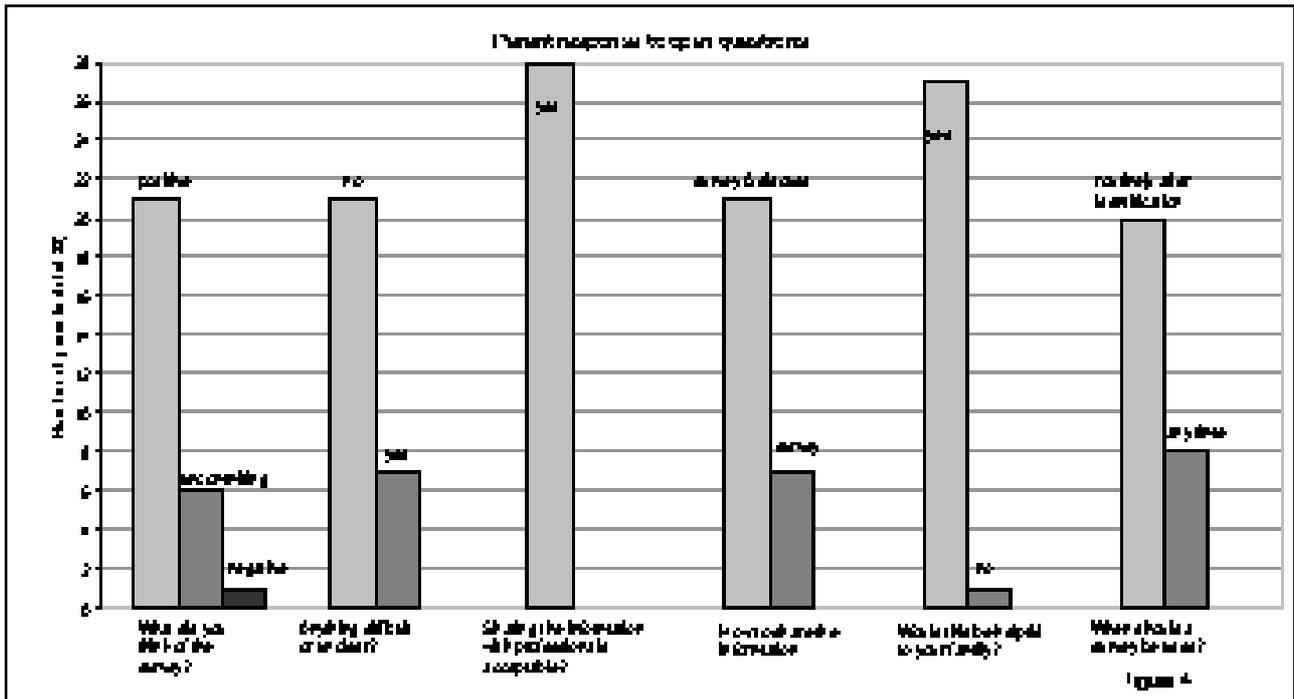
All parents indicated that they felt the survey would be helpful at some stage, most preferring it to be available routinely after diagnosis. All parents indicated they would like to complete a survey and the majority indicated they would like to discuss the outcome.

Some parents suggested that minor adaptations to the Family Needs Survey might make it even more acceptable. Suggested modifications included the

addition of a fourth column indicating that the parent would "like to discuss the item" and changing the words "definitely" and "need" to "would like information on.... etc." with yes/no/not sure responses are some modifications suggested. Interestingly, similar modifications exist in an adapted Family Needs Survey by DeConde Johnson that is used as part of the FAMILY assessment in the CHIP program (Stredler Brown and Yoshinaga-Itano, 1994).

Does the Family Needs Survey identify the needs of families who have hearing-impaired children?

Families were requested to indicate their five greatest needs at the end of the survey in order to highlight any additional items of need not listed in the Family Needs Survey. Four families found this the most difficult part to complete but 14 families were able to complete this section. Fifteen parents prioritised at least one need that was described in the Family Needs Survey. Over 60% of the greatest needs listed were items of need or need category described in the Family Needs Survey. Six needs were listed that related specifically to hearing-impaired children, as follows: - information about how deaf children grow and develop, reading material about deafness, meeting children with hearing aids, investigation of cause, accurate assessment of hearing ability and monitoring, information about new technology and hearing aids. Twelve out of eighteen parents listed the need for financial support/security. There were eleven information needs listed and these included information about education, services for the



future, how deaf children grow and develop, how to help/teach the child and about new technology. Support needs were also listed and two parents listed meeting with other families who have a child with similar difficulties. The greatest need for one family was the availability of an English language interpreter.

Implications of using a Family Needs Survey

The use of a survey such as the Family Needs Survey creates the expectation that professionals will respond to an identified need (Bailey and Blasco, 1990). In this respect, if families are questioned about their needs it becomes obligatory for there to be appropriate service availability according to their answers. This is an important consideration and clear response pathways should be established within a service for any need identified, before any widespread application of a survey. In this way such an instrument might fulfil its practical purpose and satisfy development of a collaborative partnership between professionals and parents.

In the UK, the assessment of skills and deficits of a hearing impaired child have provided the basis for planning services for children nationally; the functional assessment of *family needs* is not usually considered. With the increasing evidence for the benefits of both early diagnosis of hearing impairment and early intervention for families using an individualised family-focused program, the application of a needs assessment tool is a serious consideration that facilitates effective service development (Bailey et al., 1989, Baguley et al., 1999)

A modified Family Needs Survey

As a consequence of this pilot study, a new modified survey has been developed for potential family need identification in the UK (appendix 1). It is based on the Family Needs Survey, with some modifications already made by DeConde Johnson and giving consideration to parents' views obtained in the pilot UK Family Needs Survey study. It is an adapted scale in which an attempt is made to merge the principle structure of the Bailey and Simeonsson assessment scale with the specialisation of the DeConde Johnson version set in context for a local application.

As long ago as 1976, the DHSS Court Report identified the principle that the family should play a key role in the development of children with disabilities. Assessing the needs of those families is a complex and challenging process, and the involvement of the family has considerable practical implications. Today we are experiencing a broad cultural change of attitude and there is crystallisation of a number of ideas, which embrace the development of a partnership between professionals (health, education and social services), and families. As with any partnership, there is promise of much to be learned from each other.

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ADDENDUMS

List of items in a modified family needs survey. Responses indicate: no/not sure/ yes information/yes discuss.

INFORMATION

1. I would like more information about how I can help my child develop communication skills
2. I would like more information about how to handle my child's behaviour.
3. I would like more information about how to teach my child.
4. I would like more information on how to play with or talk to my child.
5. I would like more information on the services that are presently available for my child.
6. I would like more information about the services that my child might receive in the future.
7. I would like more information about how children grow and develop.
8. I would like more information about reading material, videos, local and national organisations and resources about hearing loss
9. I would like more information about hearing aids
10. I would like information about educational options for my child.

SUPPORT

11. I would like to talk with someone in my family or a friend about my concerns
12. I would like more help for our family to accept the hearing loss
13. I would like information about parent support groups
14. I would like more time for myself
15. I would like to meet with other parents who have a child with hearing loss
16. I would like to meet with adults who have hearing loss
17. I would like advice on how to explain my child's hearing problems to siblings, friends, family or others.

COMMUNITY SERVICES

18. I would like help locating babysitters for my child
19. I would like help locating daycare or nursery/preschool for my child
20. I would like help locating a GP, Specialist or Dentist
21. I would like help with transportation

FINANCIAL

22. I would like help paying for special equipment for my child
23. I would like help paying for child care/respite care
24. I would like help paying for food, housing, clothing or transportation
25. I would like advice or help in getting a job
26. I would like details about which benefits can be claimed

OTHER

27. Please indicate if there is any other information you would like to have or discuss.

Adapted with permission from Bailey and Simeonsson by Jane Dalzell, CHCD University of Manchester. Bailey, D. B. and Simeonsson, R. J. (1988), *Family Assessment in Early Intervention*, Columbus, Ohio. Merrill Publishing Company

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