

ORIGINAL ARTICLE

Qualitative analysis of parents' experience with early detection of hearing loss

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Aims: To determine key themes from parents' comments on paths to diagnosis and intervention for their children with hearing loss, following introduction of at-risk neonatal hearing screening and modification of distraction test screening for infants not at-risk.

Methods: Parents of children born in 1993 in Victoria, Australia, who were eligible for screening via the Victorian Infant Hearing Screening Program and who were subsequently diagnosed with a permanent congenital hearing loss and fitted with hearing aids prior to the year 2000 were asked to complete a semi-structured questionnaire shortly after aid fitting. Two researchers independently analysed parent comments using the constant comparative method.

Results: Parents of 82 children (61%) replied to the questionnaire. Themes analysis revealed a generally positive response to neonatal ABR screening, with a mixed response to the distraction test; powerful emotions experienced by parents at diagnosis including denial and shock; frustration arising from delays in diagnosis, and communication difficulties with providers. Special difficulties testing children with other medical and developmental problems, confusion about tympanostomy tube insertion, and difficulty with wearing hearing aids were also reported. Some children had experienced problems in the school setting. Experience of post-diagnostic services was generally positive.

Conclusions: Parents need greater support both during the testing of screen failures and at the time of diagnosis. Providers need more training in how to communicate findings to parents, particularly at times when parents are experiencing strong emotions. Parents need more strategies to enable hearing aid wearing in very young children. Some children with additional medical, developmental, and behavioural problems need specialised approaches to testing.

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While there is growing consensus that the aim of practising evidence based medicine is sound, many aspects of health care delivery are difficult to study in randomised controlled trials.¹ The beliefs, experiences, and communication styles of patients and providers all influence the nature of clinical interactions.² Qualitative research methods provide a means of collecting and interpreting narrative or observational data about such interactions, leading to a deeper understanding of the process of health care delivery. Qualitative research has been well established in anthropology and sociology, yet its inclusion in mainstream medical research has been limited. This situation may be changing, with the National Health Services Centre for Reviews and Dissemination recently recommending consideration of the inclusion of qualitative research in systematic reviews of research on effectiveness.³ Understandably, the difficulty of assessing "quality" in qualitative research has led to reservations about the usefulness of this new approach and to debate on how to determine its validity and relevance.⁴⁻⁶ At worst, qualitative data can be dismissed as "anecdotes" which might be non-generalisable or even misleading. However, if performed with sufficient rigor and in a systematic, reflective way, qualitative studies can significantly enrich our knowledge of healthcare.⁴

It has long been known that most parents of children with congenital hearing loss would like their child's problem identified early.⁷⁻⁸ Prior to introduction of neonatal screening, previous studies by ourselves and others reported parents' frustrations at delays in the diagnostic process.⁷⁻⁹ Qualitative analysis of parents' comments prior to introduction of a two tiered Infant Hearing Screening Program in Victoria,

Australia identified denial in both parents and providers as a factor contributing to late diagnosis.⁹ Even following introduction of neonatal hearing screening in the UK, delays in diagnosis and intervention for children with permanent losses have been reported.¹⁰⁻¹¹ The reasons for these delays are difficult to study adequately in a purely quantitative manner. For example, two babies might each have failed their neonatal hearing screens, have profound losses, and subsequently have hearing aids fitted at age 9 months. In one case this might be due to the parents' decision to delay, while in the other there may have been system problems, such as lack of availability of aid fitting services. A qualitative approach allows for distinction between cases such as these, which quantitatively appear similar or even identical. The implications for programme operation are quite distinct in each case.

Qualitative inquiry of staff members has been used by one community paediatric audiology service in the UK to supplement information derived from audit and to involve and interest staff in the audit process.¹² Studies examining parents' perceptions of the screening and diagnostic processes are, however, few in number, and tend to concentrate on one or two aspects of the experience. One recent study involving a structured questionnaire identified four important features related to parent satisfaction with early detection of hearing loss: parent contact, allowing time to process complex information, provision of unbiased information, and counselling from a skilled empathetic audiologist.¹³ In another study empathetic listening was highlighted as a key component of counselling families with hearing loss.¹⁴

In this study, we performed a qualitative analysis of parents' written comments about their experiences with

screening, diagnosis, and intervention for their child's hearing loss. All children in the study had been eligible for screening by the Victorian Infant Hearing Screening Program. This approach was used to supplement existing quantitative data about the programme¹⁵ and to clarify reasons for delays in diagnosis not always apparent from quantitative analysis alone.

METHODS

In 1992, the Victorian Infant Hearing Screening Program was implemented for all infants born in the state of Victoria, Australia (population 4.5 million). Details of this programme and its evaluation have been reported in detail elsewhere.¹⁵ Briefly, all neonates with one or more identified risk factors for hearing loss were referred to an audiologist for auditory brain stem evoked response (ABR) screening. At age 7–9 months, infants were again screened by their maternal and child health nurse for the presence of risk factors and, if positive, were referred for audiological assessment. Maternal and child health nurses screened all infants without a risk factor by a modified form of distraction testing at age 7–9 months.

In 1993, 64 116 children were born in Victoria and survived the neonatal period, of whom 134 children were identified as having bilateral congenital hearing loss and were fitted with hearing aids by 31 December 1999. The parents of these 134 children were eligible to take part in this population based study.

Data were collected prospectively via a written parent questionnaire which was sent to parents of each of the 134 children shortly after aid fitting. If no reply was received within six weeks, a reminder letter and a second questionnaire were sent out. As most parents completed the questionnaires shortly after aid fitting, the process of screening and diagnosis that they were being asked to recall was a recent event. All data were held in confidence, and the study was approved by the ethics committees of six relevant major Victorian hospitals. For both responders and non-responders, data on date of birth, degree and type of hearing loss, dates of first appointment and aid fitting, and aetiology were available from Australian Hearing, the national hearing aid fitting and habilitation service.

The questionnaire asked detailed questions about the paths taken to diagnosis of hearing loss and asked for open-ended comments to the following questions:

- Please give as full a description as you can of what happened (when child's hearing loss was first suspected).
- Sometimes there are delays from when a child is first suspected of having a hearing loss to the time when they are fitted with hearing aids. Please write your experiences of this period of time.
- In your opinion, are there ways in which the system of detecting and supporting children with hearing loss could be improved?
- Are there any other comments you would like to make?

The parents' answers to these descriptive questions formed the basis of this qualitative analysis of the diagnostic process from the parents' perspective.

Qualitative analysis

Two researchers independently examined the data for themes. Two hundred and sixty one quotes from 82 parents formed the basis of the analysis. Initially, quotes were independently sorted into categories by the two researchers. Once all categories were identified, a search was made for underlying themes. The researchers then grouped individual themes into common themes, using the constant comparative

method of data analysis.¹⁶ Ten common themes were identified which form the basis of this report. These themes together with illustrative examples are explored in the results section. An exploration of responder bias was made by comparing responders and non-responders for severity of hearing loss (*t* test), and sex, diagnosis by age 6 months, and hearing aid fitting by age 12 months (χ^2 analysis).

Based on these findings, and in the light of the known outcomes from the Victorian Infant Hearing Screening Program, implications for service delivery are considered. A series of recommendations arising from the study are then discussed

RESULTS

Responses to questionnaire

Eighty two replies to the questionnaire were received (61% response). The mean age at diagnosis for the responders was significantly lower than for non-responders (see table 1). The responders did not differ significantly from the non-responders in degree of hearing loss or sex of child. However, responders were more likely to have been diagnosed by the age of 6 months and fitted with hearing aids by 1 year.

Ten principal themes emerged from the data. These were: experiences of the screening process, parent reactions to diagnosis, reasons for delays in diagnosis, experience with and qualities of providers, difficulties experienced by children with other medical and developmental problems, the placement of tympanostomy tubes (grommets), experiences of and difficulties with the wearing of hearing aids, school issues, experience of post-diagnostic services, and overall degrees of satisfaction with the service. Table 2 shows the number of parents mentioning each theme, together with illustrative quotes.

Themes

(1) Experiences of the screening process

These were divided into three sub-themes: at-risk identification, ABR screening, and distraction test screening.

At-risk identification

Difficulty with accurate risk factor recognition was an important sub-theme. In cases where parents themselves recognised that their child had a risk factor when the professionals overlooked it, there appeared to be an understandable loss of confidence in the system. In other cases the presence of a neonatal risk factor was completely missed by both parents and professionals. Sometimes this was in part due to the parents not realising that their child was at risk and being slow to act. Where risk factor recognition had led to diagnosis, parents expressed satisfaction with the at-risk identification system.

ABR screening

The overall degree of satisfaction with ABR screening appeared high. Parents often commented that they would not have suspected any hearing loss prior to failure on the ABR. One negative comment came from the parents of a child who passed an ABR screen but subsequently received hearing aids for a mild loss. The parents were distressed that they had not understood that the possibility of a mild loss had not been excluded on the first test.

Quote 1

"Parents should be given copies of results so that they can see what is actually occurring. The very first ABR [our son] had done, a mild hearing loss was reported; however we

Table 1 Demographics and degree of hearing loss in responders and non-responders

	Responders	Non-responders	p value
Number (%)	82 (61%)	52 (39%)	
Mean age (SD) in months at diagnosis	25.8 (20.9)	41.5	<0.01
Median age in months at diagnosis (IQR)	16.7 (8.9–44.3)	43.8 (18.3–61.6)	
Median age in months at questionnaire completion (IQR)	25.9 (14.6–3.7)	N/A	
Range of ages in months at diagnosis	0.9–69.9	4.0–72.2	
Mean age in months at aid fitting	29.3	48.7	<0.01
Range of ages in months at aid fitting	1.2–70.4	4.5–79.5	
Mean degree of hearing loss (dBHL)	58	49	0.1
Sex of child (%male)	56	62	0.33
% diagnosed by 6 months of age	19	5	0.033
% fitted with aids by 1 year	32	6	<0.01

were unaware of this until much later when we requested a copy of all results ... the service offered was extremely poor from the audiologist."

Distraction test

Regarding the distraction test, comments were very mixed and often negative. Where a failed screen had resulted in a

Table 2 Themes, sub-themes, and illustrative quotes

Themes and sub-themes	No. (%) respondents mentioning this theme (n = 82)	Illustrative quotes
Experiences of screening programme	42 (51%)	
At risk identification	15 (18%)	"There was a family history of hearing loss but we didn't think of it earlier"
ABR	10 (12%)	"We would never have suspected a hearing loss before ABR testing"
Distraction test	17 (21%)	"I would question the reliability of the health nurse testing procedure"
Parent reactions to diagnosis	14 (17%)	
Denial	7 (8%)	"As there was no family history in either of our families we found it a little unreal to think that two of our three children could have a hearing problem"
Shock/upset	7 (8%)	"It was more of a shock to me when the possibility of some sort of deafness was discussed"
Need for support	3 (4%)	"If all babies are to be tested routinely in hospital there had better be a lot of support for parents on the spot"
Empowerment	1 (1%)	"If (the support) continues this way I feel confident that I will be able to provide the best for my child"
Expectation	5 (6%)	"Because we already knew of the possibility of a hearing loss we were not as shocked as some other parents I have spoken to"
Delay in diagnosis	44 (53%)	
Difficulty with testing child	8 (10%)	"He was at times uncooperative and became easily bored"
Difficulty with test interpretation	9 (11%)	"The different types of tests gave many different results"
Need for prolonged repeat testing	12 (15%)	"He was tested at 8, 9, and 10–11 months. This was the frustrating time. At each test we were told he hadn't tested consistently ... wait another month"
Resource limitations	14 (5%)	"Major waiting lists for hearing tests are discouraging!"
Need for support during testing	4 (5%)	"This is a long period to wait ... not only for the child ... but for the parents who all of a sudden don't know how to communicate with their child. They feel lost ... and they feel their child is missing so much"
Other delays	7 (8%)	
Experience with providers	27 (33%)	
Lack of explanation to parents	11 (13%)	"More information on initial tests about how hearing works and what the results mean ... could be beneficial"
Professional qualities	11 (13%)	"Everyone has been very helpful and positive"
Knowledge base of providers	5 (6%)	"His paediatrician was adamant (at first) that he didn't have a hearing loss"
Children with other medical problems	11 (13%)	
Low priority given to possibility of sensory impairment	9 (11%)	"It was difficult to give the hearing problem much attention ... with other problems at the time"
Difficulty with testing in cases of developmental delay	2 (2%)	"... hard to assess her hearing loss due to developmental delay"
Grommets/tubes		
Need for insertion	16 (19%)	"Thinking back—everyone believed that grommets were the answer for all (his) problems"
Hearing aids	25 (30%)	
Difficulties wearing	12 (15%)	"Aids fitted ... child refuses to wear same"
Child's reaction	13 (16%)	"When his aids were fitted ... a truck went by and the look on his face as he heard it ... was amazing"
School issues	8 (10%)	
Need to repeat Grade	2 (2%)	"He didn't cope well at kinder and thus he did another year"
Triggered late diagnosis	6 (7%)	"Kinder teacher insisted he was deaf"
Post-diagnostic services	24 (29%)	
Need for support	2 (3%)	"Our parent advisor was excellent in many ways (with) parent support, e.g., what to expect"
Early intervention services	5 (6%)	"The hard work and support given to the children at the early intervention centre is amazing"
AH	17 (20%)	"I really think that the hearing centres are all fantastic!"
Overall satisfaction with experience	20 (24%)	"I think the system in general is very good"

rapid diagnosis, comments were mainly positive; however, in cases where the distraction test had been passed but a hearing loss requiring aids had subsequently been discovered, more criticisms and concerns regarding the effectiveness of distraction testing were expressed.

(2) Parent reactions to diagnosis

A number of parents commented on the powerful emotions they experienced when the diagnosis of hearing loss was made. As expected, denial, shock and upset were all expressed. Several parents mentioned the critical need for support at that time, with one parent commenting that good support had empowered her to feel she could provide well for her child despite his disability. Reaction to diagnosis was sometimes, but not always, less intense when the parents had been expecting the possibility of a hearing loss, usually due to the presence of a known risk factor. One mother expressed some ambivalent feelings about very early diagnosis resulting from ABR screening:

Quote 2

“Regarding very early diagnosis I have mixed feelings. My own experiences have shown me that when the news is good it is wonderful to hear very early (my third child had his ‘at risk’ screening test at 4 weeks of age). However when my daughter was diagnosed at 3 weeks of age I was devastated. I am glad that tests weren’t conclusive when she was first tested at 3 days of age because I don’t know how I could have coped in hospital by myself. I feel that if all babies are to be tested routinely in hospital there had better be a *lot* of support for parents on the spot.”

In this case aid fitting was also delayed until the baby’s mother felt the time was right:

“I wasn’t comfortable with my 3 week old baby who had a profound loss wearing aids. Rightly or wrongly this was my decision and I felt that both (audiology and early intervention services) were very sympathetic with my decision and stood by me.”

(3) Delays in diagnosis

Following the screening process, many parents experienced lengthy delays before a diagnosis of hearing loss was finally confirmed. Delays were thought by parents to be due to difficulties with testing individual children, difficulty with interpretation of test results obtained, the need for multiple repeat tests over prolonged periods of time, and resource limitations resulting in appointment delays. This was a time of great frustration for many parents, who described feelings of helplessness and anxiety. Again, parents emphasised the need for support at this time.

Quote 3

“There was always about 2–3 weeks between each test and they used to say ‘we should know better next time’ and next time would come around and still they didn’t know. I found this very hard. It wasn’t their fault but I still found it hard and nearly just forgot about the whole thing.”

(4) Experience with providers

Parents gave numerous examples of communication difficulties and misunderstandings with providers which negatively impacted their child’s care. Parents often felt that providers had not explained findings clearly enough to them. Where parents had had good experiences, they often mentioned personal qualities of the providers as being “helpful” and “positive”. Misleading or incorrect advice called into question the provider’s knowledge.

Quote 4

“Frustration—it has become increasingly clear to us that social skills and speech are very closely connected to being able to hear properly. Among all the health professionals we have seen (and there have been a lot) they did not lay it on the line just how essential this is. The ENT surgeon’s reaction was ‘but of course a hearing aid won’t fix the problem’ after we discussed it with him when the aid was first suggested by the audiologist. This was obviously not what we should have been told, as we interpreted his reaction as an aid being unnecessary. Result was—12 month delay before finally understanding gravity of problem and its impact (with help of audiologist) and referral to Australian Hearing.”

(5) Children with other medical problems

Children in this group had added challenges during the screening and diagnostic processes. Several parents commented that initially concern about hearing loss took a “back seat” to other medical and developmental difficulties and was not acted on until much later. Additional difficulties were also experienced in obtaining accurate audiological evaluations when the child had developmental delay. Some parents commented on the lack of rapport between child and tester, particularly where children exhibited challenging behaviours.

(6) Tympanostomy tubes

The insertion of tympanostomy tubes is included as a separate theme, as it was so commonly mentioned by parents as a time of confusion. Presence of middle ear fluid often appeared to result in uncertainty about the nature of the hearing loss, with tube insertion occurring during the assessment process. Provider difficulty with determining the nature of the hearing loss often resulted in incomplete communications to parents. Providers sometimes apparently missed the possibility of a permanent hearing loss, with subsequent shock to the parents when tubes did not solve the problem.

(7) Hearing aids

Parents often experienced great difficulty in getting their children to wear hearing aids.

Quote 5

“Being only 4 months when he got the aids it was very difficult to grab the moment he is awake to wear the aid and also he needs to be sitting up to avoid contact with carpet, back of chair etc, as the aids either slip out or whistle. We manage to have them in for 1–1.5 hours during his most wakeful period.”

Parents sometimes gave graphic descriptions of what happened when their child first experienced the wearing of

hearing aids, while other parents noted great developmental changes or improvements:

Quote 6

“(He) made an incredible progress in his speech development, once fitted with hearing aids. Also nearly all behavioural problems (frustration, temper tantrums) stopped, and he became happy, cheerful, and willing. His appetite also increased dramatically due to his feeling more secure about communication, I think.”

(8) School issues

Children experiencing very late diagnosis of mild and moderate losses had often struggled in the school system, requiring extra assistance and grade repetition. School personnel, such as kindergarten teachers and school nurses, had played an important role in identifying the possibility of a permanent hearing loss in a number of cases.

(9) Post-diagnostic services

Once a diagnosis of hearing loss was firmly established, satisfaction with the post-diagnostic services was generally positive. Both centre based early intervention teams and the home-visiting Parent Advisor service were seen as valuable sources of support. Australian Hearing, responsible for hearing aid fitting and monitoring, also received much praise.

(10) Overall satisfaction with the service

This varied with individual experience. Parents who had had a fairly straightforward screening and diagnostic experience had no negative comments and were very satisfied with the level of service they had received. When parents were dissatisfied, they tended to point out individual deficiencies with the system. Interestingly, no parent made any global negative comments about the overall process.

DISCUSSION

Principal findings

Qualitative analysis gave valuable insights into the operation of the Victorian Infant Hearing Screening Program, which were not apparent from quantitative analyses alone. Important themes emerged with implications for improvements in service delivery, most notably largely positive experience with ABR screening, relative lack of confidence with the distraction test, and difficulties for parents and providers with accurate risk factor identification. These results were consistent with quantitative reports of screen performance.¹⁵

Parents experienced very powerful emotions at the time of diagnosis including denial, shock and upset, with a great need for emotional support. Communication difficulties between parents and providers were often reported. Providers may have been attempting to give quite complex explanations about a child’s audiological status at times when parents were experiencing intense emotional reactions. Although the screening programme did develop a series of patient information leaflets and further parent information was available on intervention options, it is unclear from the present study how much these resources were utilised or how helpful they actually were. At the time of the study very little web based information was available for parents. Many parents experienced delays in the diagnostic process, becoming “stuck” in the system. Problems in distinguishing conductive from sensorineural losses, repeated inconclusive behavioural audiometry assessments, appointment delays and resource limitations all contributed to parents’ feelings of

frustration and lack of support. Support once a firm diagnosis was established appeared excellent.

For children with complex medical problems, hearing screening and diagnostic processes initially took a “back seat” to management of other conditions, while for children with developmental and behavioural problems accurate audiological evaluation was challenging. Problems with getting young children to wear hearing aids led to further frustrations and anxiety that the benefits of early detection might be reduced.

Comparison with other studies

Compared with our previous qualitative study prior to introduction of the Victorian Infant Hearing Screening Program, professional denial of hearing loss was a much less prominent theme, possibly reflecting the effects of a state-wide educational campaign during programme implementation. Comments on the screening process were generally more positive in the current study. However, difficulties confirming diagnoses and with achieving hearing aid fitting were still prominent themes, highlighting the need to address these issues to ensure overall programme success. Our findings support the concept that specialised training in counselling is needed for audiologists and other clinicians dealing with diagnosis of early childhood hearing loss.^{13 14} Our findings also support quantitative data on the need for specialised test batteries to confirm hearing loss in screen failures,¹¹ but suggest that these modifications are unlikely to be completely successful unless communication and support issues are also addressed.

Reflexivity and study limitations

As questionnaire responders were significantly more likely to have experienced earlier diagnosis and aid fitting than non-responders, their experience of screening and diagnosis may have been more positive, adding strength to their comments on suggested improvements. The parent questionnaire inquired predominantly about methods of improving the system of detection of children with hearing loss, hence may have invited more negative comments than positive ones. The parent comments used for analysis were all written. This is somewhat unusual in qualitative research, where narrative comments are usually either transcribed or abstracted. While this may have deterred respondents whose first language was not English, written comments may have been better thought out than verbal ones and are less open to selection bias.

The two researchers performing the qualitative analyses were female physicians and the research subjects were personally unknown to them. While inclusion of a second or third method of qualitative inquiry (e.g. focus group, in-depth interview) was beyond the scope of this study, we believe it would add strength to future studies. A more extensive analysis of taped interviews with parents would also have been desirable. The existence of published quantitative data on the same subject group¹⁵ did provide some comparative reference to ensure that the themes emerging were not incompatible with quantitative data.

Implications for clinicians and policymakers

At a time when introduction of universal neonatal hearing screening with a gradual phase out of the distraction test is planned in the UK, and being considered in Australia, these results serve as a reminder that adequate support and counselling must be available for parents during screening and diagnostic testing. Providers need enhanced training in communication skills, in delivering abnormal test results, and in identifying and dealing empathetically with likely parent reactions such as shock and denial. Programme planners need to ensure that providers are allocated sufficient

time with patients and parents to communicate effectively. Verbal communications about audiological findings need to be supplemented with written information using simpler language, diagrams, and clearer explanations of the implications of hearing loss for language development. Referrals to other information sources, e.g. websites would enable parents to access the information in their own time, and on more than one occasion.

Examples of existing web based resources include information on universal neonatal screening at www.unhs.org.uk and information on childhood deafness from the National Deaf Children's Society website at www.ndcs.org.uk. In Australia www.aussiedeafkids.com is a useful site for parents.

Difficulties inherent with risk factor identification will not necessarily disappear with the introduction of UNHS, as some babies passing their neonatal screens will need to be identified as at risk of later deteriorating or acquired losses and kept under close audiological surveillance.

Case tracking, preferably using electronic means, is essential to prevent children getting "lost" in the system. Resources for such tracking systems must be provided at the outset, together with adequately funded diagnostic and intervention services to ensure that screen failures move rapidly through the system.

Where behavioural testing of older infants is inconclusive on more than one occasion, use of electrophysiological tests such as ABR or steady state evoked potentials (SSEP) may be needed. Protocols including early use of bone conduction studies may benefit cases where a conductive component to the loss is suspected. Checklists for use at hospital and community appointments might help prompt diligence to ensure that screening and appropriate diagnostic hearing tests have been undertaken, especially in cases where the child has other medical problems. More research into hearing aid design for young children, and behavioural interventions to maximise use are needed.

Conclusions

Qualitative enquiry in to the process of detection of hearing loss provided a valuable adjunct to quantitative research on the same study cohort. Reaching beyond numerical analyses, qualitative studies allow for expression of parents' thoughts, feelings, and experiences. At a time when the future direction of community paediatrics is being debated, and calls are increasing for partnership with and inclusion of parents in medical decision making,¹⁷ this form of enquiry provides a tool for listening collectively to parents' insights. As universal neonatal hearing screening programmes become established, inclusion of qualitative research in programme evaluation and application of the findings to future programme planning and development will enable providers to better

meet the needs of children with hearing loss and to adequately support and inform parents.

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