ORIGINAL ARTICLE

Parents' Awareness and Knowledge of the Special Needs of Their Hearing-Impaired Child

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Summary

We surveyed parents of school-aged hearing impaired children to investigate their awareness and knowledge of the special needs of their child, especially in the area of the usage of hearing aids and methods of communication. Questionnaires were distributed to parents of hearing impaired children at 13 special schools for the deaf in Malaysia. Out of 1,267 questionnaires given out, 787 (62.1%) were completed and returned. Results of the survey indicated the majority of parents (68.6%) suspected hearing loss late, that is after their child's first birthday, and there was a significant time lag before the suspicion was confirmed. Over 82.8% of the children were diagnosed only after 1 year of age, with 41.3% being diagnosed after 3 years of age. Hearing aids were fitted late (mean = 5.32 years; SD =2.66). Hearing aid ownership was influenced by the factors of socio-economic level and ethnic group ($p< 0.01$) whereas knowledge of use and proper care of the aids was influenced by socio-economic level ($p< 0.01$). Communication methods were generally inappropriate with 41.3% of the mothers and 48.5% of the fathers reporting ignorance of Bahasa Malaysia Kod Tangan, the sign language that is commonly used by their children. The parents' choice of communication method was not significantly influenced by socio-economic level or ethnic group. The study revealed the present inadequate state of services available for the rehabilitation of children with congenital hearing impairment.

Key Words: Parent awareness, School children, Congenital hearing impairment, hearing aid

Introduction

The outcome of rehabilitation of congenitally hearing impaired children depends on many factors. Some of these factors such as the degree and aetiology of hearing loss, the commitment of parents as well as the availability of financial resources are beyond the control of professionals working with these clients. However, many other determining factors are within their responsibility and include the provision of information and counselling to the parents on the impact and management of hearing loss, proper hearing aid fitting, periodic monitoring of hearing aid functions and early communication intervention. If parents are to contribute to the success of any intervention program, they need adequate knowledge that helps them to accept their child's hearing loss and assume responsibility for ensuring consistent and effective use of amplification devices. Indeed, the success of any intervention programme requires not only the support and commitment of related professionals, but the informed involvement of parents[1,2].

Other factors which highly influence the results of an intervention programme are the age of identification and intervention. Recognising the importance of these factors, the statement by The Joint Committee on Infant Hearing 1982[3] suggested that hearing impairment of congenital deaf infants be detected and intervention initiated before 6 months of age. However, many studies done in various parts of the world generally reveal unsatisfactory findings[4,5,6,7,8]. For instance, a study done by Meadow-Orlans et al[5] in the United States which sampled congenital hearing impaired children born between 1989 to 1990, found that children with mild to moderate hearing loss had a mean age of diagnosis of 28.6 months while children with severe to profound hearing loss had a mean age of diagnosis of 14.5 months. A study done locally in 1992 found the mean age of diagnosis was 48 months, and the mean period of lapse between the date of the diagnosis and the date of hearing aid fitting was 4 months [9]. A subsequent local study carried out in 1997 did not report much improvement in the mean age of diagnosis. That study reported a mean age of diagnosis of 45.1 months with the age of diagnosis ranging between 2 to 122 months[10] .

A possible contributory cause to this general delay in diagnosis is the fact that hearing impairment is a concealed handicap and thus hard to detect. It is noteworthy to mention that in a few hospitals in Malaysia, collaborations between paediatricians and audiologists have enabled high-risk infants to be screened for hearing loss early. However, in the majority of cases, hearing impairment in children is first noted by the parents following a failure in acquiring speech and this prompts them to seek medical advice much later. Paediatricians and Ear Nose and Throat doctors refer the child to an audiologist for diagnosis of the specific nature of the hearing impairment and subsequent management. In Malaysia, however, there are currently only two centres that provide professional audiological services. Therefore in the majority of cases, parents go to untrained hearing aid dealers or audiometric technicians for the fitting and subsequent management of the hearing aids. It is thus very possible that parents do not receive adequate information on proper hearing aid fitting, and the role of the hearing aid in the hearing and speech rehabilitation of their child.

Together with the proper and early fitting of hearing aids, early communication intervention is crucial for hearing-impaired children especially those with severe and profound hearing loss. They are at-risk to develop language disorders because of their lack of ability to listen to speech. They need to learn to listen through using any residual hearing left which has been amplified by a hearing aid. Indeed, children with congenital severe-to-profound hearing loss will not develop adequate language without intensive language stimulation.

Government sponsored intervention programmes for the hearing impaired were first initiated by the Ministry of Education in 1954 with the setting up of the Federation School for the Deaf in Penang, while total communication was established as the primary communication mode since 1977. A few pre-school programmes, usually run by nongovernment organisations, are also available but accessible to only a very small group of children. For the majority, communication intervention services begin at the age of five or six years, which is the age of formal school enrolment.

It is thus very possible that a hearing impaired child may not receive any special intervention for developing communication and language skills until the age of five or six years, an age which is very far from that recommended by the Joint Committee on Hearing. Without professional collaboration and support, parents may experience great difficulties in understanding best ways to help facilitate language in their child.

A review of the literature reveals that only few local studies have been done in this field[9,10,11] . This present study was thus conducted to find out whether parents of children with congenital hearing impairment, in Malaysia, know about their child's special needs, especially in the areas of early detection of hearing impairment, successful and consistent hearing aid usage, and the early facilitation of communication. This study will provide useful information towards improving services for the congenital hearing impaired child in this country.

Materials and Methods

Subjects

The survey was carried out as part of a study done at 13 special schools for the Deaf in 13 different states in Malaysia in 1994 and 1995, where a sample of parents of hearing impaired children was obtained. The selection of sample schools was made using stratified random sampling.

Questionnaire

A questionnaire was developed and used in this survey. The questionnaire contained items inquiring about the parents' socio-economic profile (i.e., race, educational level and occupation), age of child when hearing impairment was suspected and confirmed, age of hearing aid fitting as well as consistency of hearing aid usage. Questions on the maintenance of the hearing aids i.e. the frequency of servicing and whether hearing aids were functioning well were also asked. The communication method commonly used with the child, the families' perception of their skill in BMKT and whether they had received formal training in this communication method were also investigated in this questionnaire. The questionnaire forms included fill-in-the blanks, five point rating scales and Yes/No answers.

Procedure

The questionnaire, which included an introductory note, stating the aims of the survey, was distributed to all the parents of the selected schools through their children. They were collected again one week after being distributed. The information gathered was compiled and analysed using a statistical software program. Tabulations, cross tabulations and statistical analysis were obtained for the age of suspicion and diagnosis of hearing loss, the hearing aid profile of the children and the preferred mode of communication used by the family with other variables. Variables selected were ethnic groups, socio-economic status and residential status.

Results

Description of Survey Respondents

Parent Characteristics

A total of 1267 questionnaires were sent out, and 787 were completed appropriately and returned giving a response rate of 62.1 %. The ethnic composition of this study group were 455 (57.8%) Malays, 244 (31.0%) Chinese, 50 (6.4%) Indians whilst the remaining 4.8% were of other races mainly of Punjabi and Eurasian descent. The ages of the parent respondents ranged from 24 to 60 years for the mothers (M = 36.9; SD = 5.94) and from 26 to 73 years for the fathers (M = 41.23; SD = 6.62) at the time of this study. All parents had received education at least at primary school level. About 39% of the mothers and 49 % of the fathers were graduates of secondary schools while the percentages of mothers and fathers who had either diploma or degrees were 4.2% and 8.1% respectively.

39.3% of Malay parents, 30.5% of Chinese, 34.2 % of Indians and 58.2% of parents in the others category did not return the questionnaire. There were also differences in response rates according to residential states. Perak, the Federal Territory and Selangor had the best response rates that is 91.3%, 85.8%, and 80.6% respectively, while Penang and Sabah had the lowest response rates that is 43.7% and 42.5% respectively. The response rates for these states were particularly poor as they were fully residential schools so it was more difficult to pass on and then collect the questionnaires from the parents.

Child Characteristics

All the children of the parent respondents in this study group had congenital hearing impairment. The age range of the children in the sample group was from 4 to 15 years. The majority of them (86.7%) had profound hearing impairment, 10.5% of them had severe losses, while in 2.8 % their hearing loss was either mild or moderate. All the schools included in this study used total communication (Bahasa Malaysia Kod Tangan (BMKT) and speech) as the mode of communication.

Suspicion and diagnosis of hearing impairment

The majority of the parents in this study group suspected the child to have hearing problems, well before the diagnosis was confirmed. In 31.4% of the cases, the parents suspected hearing problems before the child was one year old, in 52% of the cases this first occurred between the age of 1 to 3 years old, while in the remaining 16.6% this was noted only after 3 years. By contrast, information on the age of confirmation of diagnosis revealed that only 17.2% of these children had their hearing loss confirmed before one year of age. In 41.5% of the cases hearing loss was confirmed between 1 to 3 years and in 41.3% diagnosis was not confirmed until the child was more than 3 years old. Figure 1 shows the age of suspicion and the age of diagnosis of hearing loss in this study group. By examining this figure it is obvious that there was a delay in confirming the diagnosis in a large percentage of these children.

Fitting of hearing aid

Only 59.8% of parent respondents indicated that their child had been fitted with hearing aids. Of these children, the ages when hearing aids were fitted ranged from 7 months to 15 years (mean = 5.32 years; SD =2.66). The majority of these children (78.7%) had their hearing aids fitted after the age of 3 years, in 18.1% of them hearing aids were fitted between the age of 1 to 3 years while in the remaining 3.2% hearing aid fitting was done before the age of 1 year old.

In the majority (68.9 %) of children who were fitted with hearing aids, the parents bought the aids using personal funds, while the rest had assistance from the Public Welfare Department (15.1%), their employer (6.1%), or other sources (9.9 %). It is important to note that of those children who were not fitted with hearing aids, the most frequent reason for not owning hearing aids (54.4%) was because parents could not afford the cost of the aids.

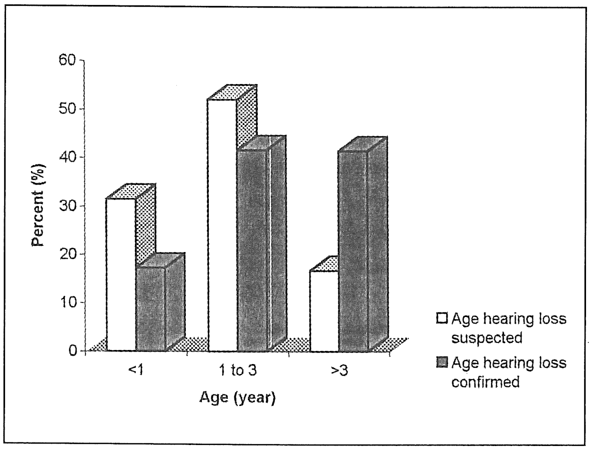

Fig. 1: The ages when hearing loss was suspected and confirmed (N=787)

Registration of Child with the Public Welfare Department

In this country registration of handicapped individuals is made through voluntary registration at the Public Welfare department. This survey found that only 47.8% of the parent respondents had registered their child with the Public Welfare Department. The majority of parents who had not registered their child (79.3%) noted that they were not aware of this requirement.

Hearing aid usage and maintenance

Hearing impaired children need to wear their hearing aids at all waking hours to ensure optimum benefits from its use. This study, however, showed that only 17.1% of the children who owned hearing aids wore them all the time, 57.1 % wore their aids either only at home or only at school and a significant proportion of them (25.8%) totally rejected their hearing aids.

Another crucial factor which influences successful use of amplification is appropriate maintenance of hearing aids. To ensure that the hearing aid is functioning well, it needs to be serviced at regular time intervals. One of the questions posed to the parents was on how frequently they sent the hearing aids for servicing. Many of the parent respondents did not give proper attention to this matter. Of the 429 parents that answered this question, 50.2 % had never sent the hearing aid for servicing, since it was purchased, while 17.9 % of them have not serviced it for over a year. Only 31.9 % of the respondents had serviced the hearing aid recently, in less than a year.

Communication methods used with hearing impaired child

For individuals with hearing impairment, especially those with severe to profound hearing impairment and who do not wear appropriate hearing aids, understanding and communicating with speech is very difficult. These children need to learn total communication, that is using a sign language with any speech they may have acquired. Since the communication method that is used in the Malaysian schools is BMKT, it is recommended that family members learn this language so they can communicate more effectively with their child.

This survey, however, indicated that 41.3 % of the mothers, and 48.5% of the fathers did not know BMKT. It is even more alarming to note that of those that know BMKT, only 1.8% of the fathers and 3.9% of the mothers considered themselves proficient while the remainder rated their proficiency in BMKT as moderate. Although lessons for parents were conducted in almost all schools included in this study, only 21.7% of fathers and 32.0% of the mothers attended such classes.

This poor competence in BMKT and lack of awareness of the special communication needs of the child were further reflected in the mode of communication that the parent respondents used with the child. More than half of them (52.1%) reported that they communicated with their children using speech and rudimentary gestures, while only 39.7% used total communication. About 8% of parents used only speech, with an alarming 59% of these children being profoundly deaf and without hearing aids.

Diagnosis of deafness and subsequent rehabilitation compared with ethnicity

The variables listed below were compared against the three major ethnic groups to see if there were differences. A higher percentage of the Chinese group (24.8%) had the child's hearing loss confirmed before the age of 1 year as compared to 14.9% of Indians and 12.7% of Malays respectively. This difference was significant. (χ^2 = 32.06,p< 0.01). Computation of hearing aid ownership against the three ethnic groups showed that the Chinese group had the highest percentage of ownership (73.4%), followed by Indians (56%) and Malays (52.9%) and again these differences were significant. (χ^2 = 27.83, p < 0.01).

However, when the age of hearing aid fitting, servicing of the aids, and hearing aid use among those who own aids, were computed against the ethnic groups, no significant difference was noted. The groups also did not differ in terms of the communication method of choice and the parents' proficiency in BMKT.

Diagnosis of deafness and subsequent rehabilitation compared with socio-economic level

Father's educational level was used as an indicator of socio-economic standing. Based on the father's educational level, the parent respondents were divided into 3 categories; i.e. fathers who had primary education, fathers who had secondary education and fathers who had tertiary education. The groups differed significantly with respect to the age of confirmation of diagnosis (χ^2 = 25.71, p< 0.01). A greater percentage of children of tertiary level fathers (24.2%), were confirmed to have hearing loss before 1 year of age compared to children of primary-level fathers (18.2%) and secondary-level fathers (15.2%). In contrast late confirmation was most prevalent in children of primary-level fathers, with 46.4% of them having the diagnosis confirmed after the age of 3 years as compared to 40.4% and 20.9% of children of secondary-level and tertiary-level fathers respectively.

To see if the three socio-economic groups differ in terms of their rehabilitation efforts; hearing aid possession, age of hearing aid fitting and frequency of servicing aids were separately compared with socio-economic groups. There was a very significant difference noted with respect to ownership of hearing aids (χ^2 = 47.18, p< 0.01) with about 84% of the children of tertiary-level fathers owning hearing aids as compared with 66.1% and 46.0% of children of secondary-level and primary-level fathers respectively. There was also a significant difference between the groups in terms of the age when the hearing aid was fitted (χ^2 = 61.62, p< 0.01) with age of fitting above 3 years old occurring in 50.0% of the children of tertiary-level fathers as compared with 86.4 % and 80.6% of children of secondary-level fathers and primary-level fathers respectively. In terms of the servicing of hearing aids, it is found that children of primary-level (72.2%), and secondary-level fathers (70.5%) are more likely not to service the hearing aid regularly or not at all as compared with children of tertiary-level fathers (49%) (χ^2 = 21.01, p<0.01).

We expected the more educated parents to have a better understanding of the special communication needs of their hearing impaired child. This survey, however, revealed that the 3 groups of parents had an equally low proficiency in BMKT. There was no significant difference noted in the choice of communication method used with their hearing impaired child.

Hearing aid usage compared with residential states

The proportion of children with hearing aids varied greatly across the states in Malaysia. A significantly higher percentage of children in the Federal Territory (83%), Selangor (67%) and Perak (65%) owned hearing aids, while the state with the lowest number of children owning hearing aids was Kelantan (28%) (see Table I). The percentage of regular hearing-aid users varied across states with the Federal Territory (26%) and Perak (29%) recording the highest percentage of regular hearing aid users, and Kelantan (0.0%) recording the lowest percentage. Table I also shows how the regular servicing of hearing aids varies across states, with a significantly higher percentage of parents in the Federal Territory (54%), and Negeri Sembilan (62%) servicing the hearing aids regularly as compared to very low percentages of parents from the states of Sabah (5%), and Terengganu (5%).

Table I
Ownership of hearing aids, usage of hearing aids and servicing of hearing aids by residential state

State	Ownership of hearing aids (% rounded)	Regular hearing aids usage (% rounded)	Regular servicing of hearing aids (% rounded)
Federal Territory	83	26	54
Selangor	67	16	32
Perak	65	29	39
Melaka	59	21	22
Negeri Sembilan	49	26	62
Penang	36	5	15
Johor	72	15	29
Pahang	60	16	27
Terengganu	53	12	5
Kelantan	28	0	11
Perlis	54	5	12
Sabah	46	7	5
Sarawak	61	12	33

Discussion

Although effort was made by the research team to ensure that all questionnaires were returned, the low response rate; i.e. 62.1 % is one of the limitations of this study. It thus cannot be assumed that the data presented here is that of a random sample. Firstly one of the prerequisites for doing the questionnaire is the ability to read and write Bahasa Malaysia. Hence it does not adequately represent persons with low Bahasa Malaysia literacy skills. The data may also be biased in favour of parent respondents who are more actively involved with their child, and thus are willing to spend time to complete the questionnaire. Further, there was a higher percentage rate of non-compliance among parent respondents who were in the others ethnic group (58.2%), as compared to those in the Malay, Chinese, and Indian ethnic groups. Thus the study does not adequately represent the viewpoints of marginal communities in Malaysia (i.e. Punjabi's, Eurasian's etc.). The data is also biased in terms of geographic location with some states having extremely low rates of parental respondents. In particular, the states of Penang, Sabah, Kelantan, and Negeri Sembilan have less than a 50% response rate and there is no data on the state of Kedah. The study is also biased towards parents of children with severe and profound hearing losses, since they constitute 97.2% of the sample. Despite these limitations, one can still make some interesting observations on the study.

This study concurs with the previous studies done by Mukari et al [9] and Ariffin [10] on the late diagnosis of hearing loss. One of the factors contributing to this is the lack of public awareness about congenital hearing impairment; the majority of parents (68.6%) were unaware and did not suspect hearing loss until their child was over one year old which is the average age when a child begins to talk. The time that parents of this study had to wait before the diagnosis was confirmed was lengthy. This can be attributed to the lack of medical services, especially in the rural areas. Because late diagnosis has a bearing on when early intervention services begin, this finding is of grave concern.

The majority of the parents of this study appeared to lack adequate information on the proper management of their child's hearing impairment. Only 59.8 % of the children in the study had been fitted with hearing aids, further only 17.1% of them wore the hearing aids consistently. The late fitting of hearing aids with the average age of hearing aid fitting being 5.32 years would be one factor contributing to this rejection of hearing aids by the children of this study. Ling[1] states that early fitting is a factor contributing towards early acceptance of hearing aids, while Simser[2] has underlined that verbal language development occurs more easily, among children detected and fitted with appropriate hearing aids before three years. Similarly, the study conducted by Clerke & Howarth[12] attributed late fitting of hearing aids to the poor acceptance of hearing aids and the subsequent poor development of verbal language among children in Canada. Another factor contributing to the above results would be the improper fitting of the hearing aids done by untrained hearing aid dealers. Finally, the findings from this study, such as the lack of regular servicing of the hearing aids by many parents and their lack of insistence that their child wears the hearing aid at all times, mirrors their lack of knowledge on good practices necessary for their child's aural rehabilitation. This is so pervasive in the results that it would be fair to say that it is caused by inadequate professional support in this area.

Parents also displayed a lack of knowledge about communication methods suitable to be used with their child. About 5% of the parent respondents reported they used speech alone to communicate with their profoundly hearing impaired child who was not wearing any hearing aids. This would make it virtually impossible for their child to understand them, except through body language or knowledge of context. Only 38% of parents sampled used a recognised standard language such as BMKT in their communications with their children, the rest communicate using rudimentary gestures and signs. As high as 41.3% of mothers and 48.5% of fathers do not know BMKT and at least three quarters have not attended the classes held for parents offered at the schools. All these indicate that parents seem to be grossly unaware of how they can contribute to their child's communication development, and perhaps have delegated this role to the school. This is all the more likely to happen given that communication intervention begins late and in a formal school setting. To overcome this problem, interventionists need to recognise that communication intervention must begin early and in collaboration with parents.

Information about age of diagnosis, hearing aid possession and management, and communication methods were compared against the factors of ethnicity, economic status and location. It must be noted that in Malaysia the factors of ethnicity, economic status and location are never totally independent from each other. For instance, the significant differences in the ages of diagnosis of deafness and the ownership of hearing aids between ethnic groups may be attributed to the different economic or occupational status of the parents. Given these limitations, a few points of interest can still be discussed.

In terms of location, it was found that the Federal Territory had a relatively high percentage of parents with children who owned hearing aids, used them consistently and had them serviced regularly. This is not a surprising finding, as there are both audiological services and hearing aid dealers located in the Federal Territory, allowing the parents easier access to the services they need. It would appear that with proper professional support, parents are capable of playing key roles in their child's aural rehabilitation. A more detailed statistical analysis of the results, which is beyond the scope of this study, would be needed to confirm that location is indeed a significant variable.

Father's socio-economic level appears to be a significant variable contributing to a child's ownership of hearing aids and the proper maintenance of the hearing aids. This can be attributed to the fact that individual hearing aids are expensive, and poorer parents may not have the funds to purchase this for their child. Many of the poorer parents may not be aware that they can apply for funds from the Public Welfare department. Indeed, only 47.8% of all the parents have registered their child with the Public Welfare department and this statistic may point to a general level of awareness that parents have on the options available to them. Further the subsequent maintenance of the hearing aid requires time and effort, and parents with a higher economic level may be in a better position to contribute to the above. As with the previous finding, it must be noted that the factors of ethnicity and location may be confounders in the above result.

What is surprising, however, is that there appears to be no significant difference between the different socio-economic groups, in the communication method used with the child. The results indicate that even parents who are potentially in a position to have better access to special intervention services are communicating with their child inappropriately. This points again to a pervasive sense that most parents have not received adequate support and counselling from professionals in this matter.

Two major factors may contribute to the parents' lack of awareness. One is the general lack of public awareness that exists in this country about the early signs of congenital hearing loss and its subsequent management. The other is the lack of appropriate support services, including medical, audiological and other early intervention services for children with congenital hearing impairment.

Conclusion

This study revealed the unsatisfactory level of parental knowledge and awareness of the special needs of the hearing impaired children attending special schools for the deaf in Malaysia in 1994/1995. This lack of knowledge can be related to factors such as location from and availability of support services, ethnicity, educational status, the availability of financial resources, and perhaps individual levels of commitment of the parent. However, the fact that the overwhelming majority of parents do not have knowledge of proper rehabilitation procedures points to a general lack of public awareness about congenital hearing impairment and a dire lack of relevant support professionals to aid parents in their rehabilitation efforts.

The delay in confirmation of diagnosis of these children due to the lack of medical services especially in the rural areas, is of grave concern. Due to this delay, the provision of early intervention services is delayed.

It is thus crucial that a national programme on deafness be implemented so that we can provide our congenital hearing impaired children in Malaysia, a better opportunity to develop to the best of their potential. The reason being, early intervention can minimise the handicapping and negative aspects of congenital hearing impairment and offer these children a chance to become a more integrated part of our community.

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