

EAR DISEASE AND ABORIGINAL FAMILIES

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The high incidence of middle ear disease in Aboriginal communities contributes to massive levels of conductive hearing loss among Aboriginal children. It has been estimated that, on average, Aboriginal children have middle ear disease for more than two and a half years during their childhood. The equivalent figure for non-Aboriginal children is three months (OATSIH, 2001). Although middle ear disease is usually considered a health problem, it also contributes to poor social and emotional outcomes. The West Australian Aboriginal Child Health Survey (WAACHS) found significantly poorer social and emotional wellbeing for children who had 'runny ears' (caused by perforation of the ear drum) than other Aboriginal children (Zubrick et al., 2005). Childhood hearing loss has also been found to contribute significantly to learning and behavioural problems at school (Howard, 2004). Aboriginal children with conductive hearing loss were found to tease other children more, peers often rejected them socially and they are more disruptive in class than other students (Howard, 2005).

We know little about that effect of conductive hearing loss can have on family life. There is some evidence, from studies of non-Aboriginal children that conductive hearing loss can influence family life. Children with conductive hearing loss may instigate interactions less often and be less responsive to parents (Roberts et al., 1995), so that there is a diminished quantity and quality of social interaction between children and caregivers (Hoff-Ginsberg, 1990; Vibbert & Bornstein, 1989). Western mothers with a child who had experienced chronic middle ear disease were more likely to be depressed and feel that they were less adequate as parents than other mothers (Forgays et al., 1992). Some non-Aboriginal Australian mothers also reported that they found it more difficult to feel close to their child with conductive hearing loss (Dorothy Moore personal communication 1992). It should be remembered that these studies were carried out in communities where far fewer children are affected by less severe middle ear disease than in Aboriginal communities. Despite hearing loss being endemic among Aboriginal children there have been no formal studies of the family effects of Aboriginal children's hearing loss.

Aboriginal parenting styles that use more intensive and visual communication strategies help to compensate for hearing loss related communication problems (Jacobs, 2005). However, the early and persistent hearing losses experienced by so many Aboriginal children are likely to adversely impact on child/family relationships. In relative terms, far more Aboriginal children experience earlier, more severe incidents of middle ear disease, more often than do most non-Aboriginal children (Boswell et al 1994).

The proposition that conductive hearing loss has an effect on family life was supported by interviews carried out with parents and health workers in this study. Hearing loss, especially mild to moderate hearing loss, is most often not identified. Since it is not

known that children have hearing loss, communications and social problems associated with the hearing loss are often seen simply as 'bad behaviour'. It is only when parents or health workers are informed through identification of ear disease or hearing tests that they have an opportunity to better understand the social and behavioural problems related to current hearing loss.

If families are aware of their children's hearing loss they have the most direct experience of the ways in which conductive hearing loss can affect family life. Five Aboriginal mothers were interviewed in this study. The authors also interviewed three Aboriginal Health Workers (AHW's) and two nurses working in Aboriginal communities. Aboriginal Health Workers who live in small remote communities treat children with middle ear disease while also talking to their parents and observing the children in the community. Community nurses' observations are mostly based on families attending the health centre. The observations made by parents, AHWs and nurses were consistent with each other and support the proposition that conductive hearing loss can have a major impact on family life in the ways that are described below.

BEING FLOGGED

It was reported that children who have difficulties with communication because of hearing loss are often punished physically.

'Half the kids get floggings because they (the parents) think they're (the children) ignoring them. I see parents giving kids with hearing loss a flogging when they (the children) have not understood; I see that all the time, everywhere... I think half the kids (with hearing loss) get hidings sometimes.' (Aboriginal Health Worker)

'Sometimes it is they (the children) don't show any respect to old people and they get really upset with them and they get hidings from old people.' (Aboriginal Health Worker)

BULLY OTHERS

Children with hearing loss sometimes receive 'floggings' from their family, but children with hearing loss were also observed to 'bully' their parents.

'They are cheeky...you see a kid (who has middle ear disease) throwing rocks at Mum and swearing and demanding something, and usually most times they will give it to them to shut them up.' (Aboriginal Health Worker)

'I have noticed that it is the kids with chronic ear problems who are the ones you sometimes see hitting their family when they are in the waiting room.' (Remote Area Nurse)

CAN'T HANDLE THEM

Other people reported that family members had limited contact with others because of communication and behaviour problems of their children with hearing loss.

'My parents say that they can't handle them (the children) so they don't want to baby sit them because they (the children) won't listen to them. It is hard because there is no-one else I can leave them with.' (Mother)

This parent faced her children's problems related to hearing loss by herself. Other parents described how challenging this could be.

HARD TO MAKE HIM UNDERSTAND

A mother, who has hearing loss, described the challenges she faced when communicating with her son, who also has hearing loss.

'With my son, when I used to get angry, if I get angry with him, he's probably a bit shitty with me and doesn't want to listen...my son used to be very strong, you know - probably not listening to what I'm saying but still trying to have his say, keep on going and not listening. It used to be hard to make him understand. It took me a while. He used to run off, take off and don't listen. Keep doing it, keep doing it. It was really hard.' (Mother)

DEPRESSED AND FRUSTRATED

One mother, also a health worker, realized her daughter might have hearing problems after she participated in training on the social problems that can result from hearing difficulties. Hearing tests later confirmed that her child had hearing problems.

'At the workshop it clicked, the patterns of behaviour and the withdrawal that you described. It was a relief to know. ...I (earlier) felt depressed and frustrated because I didn't know what was going on. I was blaming myself. I thought it was my fault and I was a bad mother. I felt like I was letting her down. I was trying to figure out what to do. The behaviour problem came at school. They never suggested anything and it was depressing not knowing what to do...but it was getting me down and it was the stress levels. I was growling her and yelling. I was pushing her away because I didn't know how to deal with it. It made us grow apart. I did not want to be around her. I didn't want to deal with it, I didn't know how to deal with it. It really stresses me. Other people (people in the family) scatter coz I am going off my head yelling at her.' (Mother)

These comments suggest a process whereby her child's hearing related social problems led to this parent blaming herself and withdrawing from her child. This type of response, also suggested in research with non-Aboriginal parents (Haggard and Hughes, 1991), is likely to lead to the child's social problems becoming even greater. Many Aboriginal families are likely to be caught in a cycle involving increasing social problems among children and decreasing social and emotional well being among their carers. Breaking this cycle involves identifying children's hearing loss and informing families of the predictable social outcomes of hearing loss and how they can be best managed. There are family information resources available on this topic at www.eartroubles.com.

MARRIAGE AND WORK

Support from families can be hugely important in helping children to cope, but this can involve significant costs for the family. The following comments come from an interview with a mother whose daughter had moderate levels of hearing loss in both ears.

She said that she needed to help her daughter a lot while she was growing up. Each afternoon she would have to talk to her daughter about what happened at school. Her daughter would often get very angry with the other children and she would need to talk to her to calm her down and help her to understand what had happened. She was often called to the school because her daughter had been fighting with other children. This mother said that she thought one of the main reasons her husband had left the family was that he felt she put too much time and effort into support for her daughter and did not have enough time for him. She said she had only started working again after her daughter went interstate to a school for children with hearing loss. She had time to work then, when before that too much time was taken up supporting her daughter.

The level of social support provided by this mother helped her daughter to cope with the difficult social situations at school but at considerable expense to her own ability to work and to her marriage.

PROBLEMS AT SCHOOL

Health workers confirmed that the children they were treating for ear disease had problems at school.

'All of the kids with that ear problem, they're fighting or bullying the other kids (at school). (Aboriginal Health Worker)

'When they had the school play you see all the kids who aren't singing and doing what the class are doing, and they're all the ones on our list (to check ear disease) and we review them weekly, and it was freaky to see that, yes... not doing anything that the class is doing, and then looking around like they're not really sure what's going on...I've seen that at assembly when they present things and when they do their little plays and dances. The ones with that (ear disease) are usually just standing there holding something, like they give them the banner thing to hold or something where they don't have to do much... the other ones are in the play, (but for them) no singing, no dancing, no movement, just standing there looking at the crowd. It's like - you can tell they're missing out on a lot. (Aboriginal Health Worker)

DRINKING AND FOOD

Aboriginal health workers noticed that children with consistent ear health problems often came from families that had other problems.

'Those kids with lots of hearing problems come from families that are doing a lot of drinking... a lot of the time the parents are leaving and they send their mum to look after

them. A lot of the time it's the food too. They're not getting good food. When there is no-one looking after them properly it (the infection) just stays there and never goes away, especially the ones with young mums, like single parent mums and they're young, their friends are having fun and they leave their kid with grandma and grandma might do this way, or drinking or something, and then she might leave it with mum's sister or something. The kids go everywhere. Up and down the community with this family, that family and from community to community, and different people. They can get sent here, there or anywhere.' (Aboriginal Health Worker)

DISCUSSION

It is clear from these comments that hearing loss from middle ear disease can have important influences on a child's relationships within a family and at school. Family members are likely to conclude that children who do not understand what has been said are ignoring them deliberately and they may physically punish them for doing so. Some children are very demanding and even 'hit out' at their parents. These observations are consistent with behaviour that has been observed in schools. The evidence suggests that many Aboriginal children who are have behaviour problems at school and at home are affected by hearing difficulties.

Teachers usually view responses shaped by hearing related communications difficulties as behavioural problems (Howard, 2004). This can undermine the relationship between a child and their teacher(s); a relationship that is a key determinant of a child's educational opportunities (Malin, 1990). Research in schools also indicates that hearing loss adversely affects a child's relationships with its peers when that child teases others to an excessive degree or attempts to use physical coercion to get what they want (Howard, 2005).

A child's relationship with his/her family is of even greater importance than the relationship with its teachers and peers. For a child, family relationships form the basis of social and emotional well being and long term social development. The child's web of social relationships is critical for individual, family and community well being (Eckersley, 2004). However, it is clear that the listening/hearing problems described in this article have the capacity to significantly disrupt family life, impact on community functioning and damage a child's social and emotional well-being. It would also appear that for many children, the recurrence and persistence of ear disease may be related to family alcohol consumption and nutrition.

So many Aboriginal children experience so much middle ear disease that there are heavy demands on Aboriginal families for support and nurturance. In many remote Aboriginal communities fewer than 10% of children have normal hearing (Morris et al., 2005). It is likely that this huge prevalence of hearing loss contributes to many individual, family and community problems. Take for example petrol sniffing; the NT coroners report on the death of an Aboriginal child who had been sniffing petrol for many years commented "*Health worker notes from his Mutitjulu file and his Alice Springs file record that he was very quiet, uncommunicative and difficult to get a history from. Lack of English, and*

symptoms from his chronic ear infections were no doubt contributors to this.” (Cavanagh, 2005). This child’s difficulties in communication probably contributed to the social and emotional problems associated with petrol sniffing as well as limiting his access to health care. Anne Lowell when researching the educational effects of hearing loss at Galawinku noted that many children with hearing loss were among the group of children habitually sniffing petrol (Lowell 1994).

Hearing loss is such an invisible handicap that few are in a position to observe associations with social problems in Aboriginal communities. These can include parents who become aware of their children’s hearing loss, health workers carrying out middle ear disease health programs, researchers investigating educational aspects of hearing loss or occasionally a coroner seeking to understand an untimely death. There is a need for more formal research into this area. Over the years there has been research and program support in the medical aspects of hearing loss but almost none into the social, emotional, family, educational and community effects. However, the limited progress in treating ear disease (Morris et al., 2005) means that we must begin to focus on understanding and addressing the social consequences of ear disease. The observations of parents and health workers described above, though few in number, is a wake up call to consider more seriously how this invisible condition contributes to Aboriginal family and community problems. .

There is an urgent need for research and programs to support families as they deal with the family effects of conductive hearing loss as well as for school and community based programs for the many Aboriginal children and adults who experience hearing loss. Further, the staff of programs that seek to address such areas of substance abuse or family violence should be trained in effective communication strategies for people with hearing loss. For too long hearing has been an ‘invisible’ contributor to many areas of Aboriginal disadvantage. It is time to investigate, develop understanding and act.

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