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Post-Fitting Issues: A Need for Parent Counseling and Instruction

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The success of hearing aid fittings on children and infants (children hereafter unless specified as infants) is dependent on multiple and interrelated factors. Although the factors that contribute to positive use of hearing aids in children have not been fully mapped, they likely differ across children as well as in their relative contributions for individual children. Success clearly is dependent on the appropriate selection and setting of the hearing aids. It also is likely influenced by the inherent characteristics of the children, many of which are not readily captured by the assessment tools or paradigms typically used in audiology clinics. Nonetheless, the acceptance and effective use of hearing aids by pediatric patients may have as much to do with the involvement of the audiologist with the family and child throughout the (re)habilitation process, as the acoustic properties of the hearing aids.

For example, the audiologist's ability to counsel and instruct parents may determine whether a child's hearing aids are worn consistently and functioning at any given time (Elfenbein, 1994). Studies that have looked at the status of hearing aids on pediatric patients have found that, depending on the performance criteria, 27 to 92% of hearing aids used by children are not functioning properly (See Elfenbein et al, 1988). Given the assumption that there is a direct connection between parent training and counseling, and hearing-aid monitoring, these data suggest that post-fitting services have been inadequate for many children and their families. The implication is that the establishment of successful amplification is a long-term process that must go beyond the determination and meeting of acoustic targets. Additional implications are that audiologists must develop and use good counseling and instructional skills and become an integral part of the total (re)habilitation process which not only focuses on the child, but the child's family and their social support-network. Audiologists must develop individual goals for their patients and assist parents and children in establishing their own goals for treatment, and in so doing consider the factors that impinge upon a child and family after they leave the audiology clinic. That is, audiologists need to extend their influence and involvement beyond the audiology clinic doors.

PARENT COUNSELING AND INSTRUCTION

Increased Stress Levels

A relatively consistent finding in the literature is that hearing loss in children substantively increases stress levels in normal-hearing families, and that this increased stress can have deleterious effects on parent-child interactions and the total (re)habilitative process (Quittner, 1991; MacTurk et al, 1993; Meadow-Orlans, 1995). It puts children with hearing loss at risk for attachment problems and has implications for emotional, cognitive, and linguistic development, as well as stability of the family (Adams and Tidwell, 1989; MacTurk et al, 1993). Counseling and instruction appear to reduce the stress that is associated with having a special-needs or high-risk child (Crockenberg, 1981; Crnic et al, 1983; Feiring et al, 1987). Specific to hearing-impairment, Greenberg (1983) and Greenberg et al (1984) found that parents of young children with hearing loss who received counseling tended to interact with their children more normally than did parents who did not receive counseling. Their interactions tended to include more praise and

touching. There were more displays of enjoyment and their communications were more complex and associated with decreased directiveness. In contrast, Adams and Tidwell (1989) evaluated the effectiveness of a self-instructional program and found that it did not successfully reduce parental stress or child behavior-problems secondary to hearing loss, suggesting a possible need for direct professional involvement.

Providing Support

As part of the counseling process, it is important that audiologists provide an accepting and supportive environment. Meadow-Orlans and Steinberg (1993) found that hearing mothers of infants with hearing loss tend to consider the professionals with whom they deal as major sources of support. Further, a single professional can have a pronounced effect on mothers' perceptions of support, as the support networks of many mothers of infants with hearing loss tend to be more restricted than those of mothers of hearing infants, particularly if they have limited financial means and education (Greenberg, 1983; Quittner, 1991). Meadow-Orlans and Steinberg (1993) studied twenty mother-infant dyads and found that the effects of support are additive over time and across sources. They found reduced levels of stress when the mothers believed that they were well supported. Those mothers who reported lower levels of stress interacted more normally with their infants than did mothers who were experiencing higher stress levels.

MacTurk et al (1993) similarly found that levels of support influenced maternal sensitivity and nurturing, and that support levels found at nine months of age predicted the effectiveness of mother-infant interactions at eighteen months, which in turn related to linguistic competence. Work by Spencer (1993) also targeted the need for providing parental support. She found that mothers who received support from professionals and family members for using sign with their children were more likely to be consistent and fluent signers than mothers who received no or limited support.

Differences Between Fathers and Mothers

It is important to realize that stress may manifest itself differently for different members of a family. Although fathers and mothers report similar overall levels of stress as a consequence of having a child with hearing loss, on specific issues they tend to report somewhat disparate levels of stress (Brand and Coetzer, 1994; Meadow-Orlans, 1995). Fathers are more likely than mothers to experience stress as a consequence of their children's acceptability and the degree to which the child demands emotional and physical resources. Fathers also tend to deny a need to learn about hearing impairment and are less inclined than mothers to develop constructive coping strategies in response to their stress (Leigh, 1987). As a result, fathers may be less inclined to become involved in the counseling and (re)habilitation process, although counseling has been found to improve fathers' attitudes, feelings, and knowledge of their children's hearing impairment (Crowley et al, 1982). Counseling and instruction also result in more active involvement of fathers with their children.

Mothers, on the other hand, tend to be more concerned about the effects of the hearing loss on themselves, their families, and their personal relationships (Brand and Coetzer, 1994; Meadow-Orlans, 1995). They complain more than fathers of reduced free time and inadequate support from their spouses. They tend to assume more childcare responsibilities than fathers and are more inclined to be actively involved in (re)habilitation-related activities such as sign language and communication classes (Hadadian and Rose, 1991). Moreover, mothers are more inclined than fathers to experience depression in response to their child's hearing loss (Prior et al, 1988; Meadow-Orlans, 1995). As maternal depression has implications for emotional availability and effective interactions between mothers and children, it places children with hearing loss further at risk for emotional, communication and cognitive difficulties (Field et al, 1988; Cohn et al, 1990). For example, Redding et al (1990) found that hearing infants with even mildly depressed mothers tended to limit their stimulation and environmental exploration. The differences in perceived stress and parents responses to it, as well as the potential reactions that may occur with siblings, speak to the need for individualizing the counseling process and including the entire family whenever possible (Israelite, 1985). The implication is that audiologists should look at the individual differences within each family and try to address each member's needs.

Providing Information

As part of the counseling process, parents need and want information (Bernstein and Barta, 1988).

However, the style and manner with which the information is provided may be critical to its acceptance and integration by the parents. When providing information and feedback to parents it is important that it be done in an empathetic and supportive manner. Although empirical data are limited on the interactive style of audiologists, they have been described in numerous articles as being directive in their manner, and narrowly child rather than family-focused (Matkin, 1988; Elfenbein, 1994). They also have been described as providing insufficient emotional support for families of children with hearing loss. Elfenbein (1994) went so far as to say that the manner in which audiologists interact with parents probably contributes to the poor hearing-aid monitoring practices that have been so consistently observed with pediatric hearing-aid users.

Along with an empathetic style, Able-Boone et al (1990) indicated that parents of children with special needs should be allowed the opportunity to inform professionals of their needs and wants as well as those of their children. They suggested using an open-ended questioning style to promote parental input into the (re)habilitative process. Further, parents should be allowed to express feelings along with more concrete information and questions. They also should be given sufficient opportunity to inform professionals of what they want and need to know. Again, an open-ended approach can be employed but a worthwhile structured approach is to use a needs-assessment questionnaire. A good example of that is the Family Needs Assessment Questionnaire by Diefendorf et al (1996). This questionnaire provides common questions within specific categories that parents often have about their child's (re)habilitation such as hearing aids, behavioral management, and the development of listening skills. It provides a consistent framework and allows those parents who are just beginning the process a way to formulate questions. However, with both the open-ended style and more structured approaches, audiologists should be aware that the informational needs of parents change over time as does the specificity with which information is desired (Bernstein and Barta, 1988). Therefore, it is advantageous to offer multiple opportunities and avenues for parents to seek information over time.

It also is important to note that many parents acquire and use information more easily if it is presented in multiple forms. For example, providing written along with verbal instructions allows parents a backup if they do not remember or did not correctly process the verbal information that was presented to them. It also allows them more time to consider the implications of the information and to review it as needed. The video recording of counseling and instructional sessions for parents to view at a later time may be helpful for some parents as might interactive computer and standardized video and audio-recorded instructions (Sweetow and Barrager, 1980; Elfenbein, 1994).

Establishing Goals

As part of the counseling process, establishing goals appears to facilitate inclusion into the (re)habilitation process for both the audiologist as well as the child and the family. In addition, it appears to help parents proceed through the grieving process (Kampfe, 1989). Goals further provide a benchmark for judging changes in performance, and as a consequence, provide a road map for the provision of support, reinforcement, and the modifications of treatments and objectives. When developing goals for children, audiologists are advised to generate them in concert with the parents, children and other involved (re)habilitation specialists. As indicated previously, the goals should target issues beyond the acoustic characteristics of the hearing aids and should relate to the function of the entire child and family within their environment. To develop and attain such goals requires open communication with the family and other involved (re)habilitation specialists. Further, if discussed openly, the development of goals exposes the working assumptions of all the involved people and reduces the likelihood of long-term conflict. At times there may be conflict within and between the goals of the audiologist and the parents. There also may be a lack of compatibility with the other involved professionals. However, as more information is obtained about a child, the various goals are more likely to become similar or complementary if the lines of communication remain open.

Beyond the Audiology Clinic Doors

In order to best serve parents of children with hearing loss, time should be devoted to knowing available resources and making appropriate referrals. In some areas of the country the process of making referrals is straightforward while in other areas it can become highly complicated and politi-

cized, which in turn can result in inadequate service delivery. In interviews with parents of special-needs children, Able-Boone et al (1990) found that 69% of the parents reported having difficulty locating services. As a consequence, these parents needlessly experienced substantive amounts of anger and frustration. Making the situation more grim is that these parents had case managers who were responsible for assisting the parents in securing appropriate services. Therefore, it is likely that families who do not have the help of a case manager experience great difficulty in obtaining appropriate (re)habilitation services for their children. When parents of children with hearing loss are under-served they often direct their frustration toward professionals such as physicians and audiologists (Gregory, 1976). In addition, families experience increased stress and breakdown in mother-infant interactions if the delay between identification and services is long (Meadow-Orlans and Steinberg, 1994).

Once children are connected with a case manager and are in the initial stages of receiving services, it is important that the audiologists play an active role in the development of their treatment and educational plans whenever feasible and appropriate. For example, if the goal of an audiologist for a given child is consistent hearing-aid monitoring and use, the likelihood of attainment increases if the goal is included as part of the child's treatment plan. However, inclusion of goals into the treatment plan requires active communication with the family and case manager, and frequent interactions with the (re)habilitation specialists working with the child. These interchanges involve actively seeking and providing information as well as providing instruction when needed. An added benefit of this process, however, is that it provides the audiologist feedback relative to the appropriateness of the hearing-aid fit and its short and long-term benefits. For example, a speech-language pathologist or auditory (re)habilitation specialist working with an infant and family can inform the audiologist if the introduction or modification of amplification changes the nature and quantity of the infant's babbling. They can provide feedback about the infant's responsiveness and orientation to sound as well as information about acceptance of the hearing aids and behavioral observations of loudness tolerance. In addition, these professionals can provide the family with additional support and instruction, and thereby extend activities initiated in the audiology clinic. By communicating effectively with families and other professionals, audiologists increase the likelihood of a positive outcome to their clinical efforts.

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