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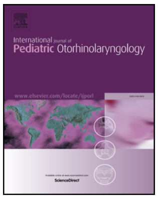

The child doesn't hear? On breaking bad news as perceived by parents and audiologists

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ABSTRACT

Objective: The object of this study was to explore how parents experienced receiving the news of their child's hearing loss, and how audiologists experienced the situation of conveying the diagnosis, in order to examine improvements to the current process.

Method: A questionnaire regarding different aspects of breaking the news was developed. 48 Arabic and Hebrew speaking parents of hearing impaired children answered the questionnaire. A similar questionnaire was filled out by 31 audiologists.

Results: Findings demonstrate parents' general satisfaction with the manner in which the diagnosis was delivered.

According to the parents' reports, receiving the diagnosis evoked negative feelings of fear, depression and difficulty believing the diagnosis. Parents' feelings were influenced by their cultural background, such as their ethnic identity, religious practice and difficulties due to language barriers.

The audiologists described concern and anxiety when breaking bad news, but they felt they were able to present the diagnosis. The audiologists felt that they were not trained in this aspect, and the ability was acquired through experience.

Both parents and audiologists agreed that the audiologist should be the professional to deliver the diagnosis. All emphasized sensitivity and professionalism as necessary qualities. Whereas audiologists were of the opinion that the most important information to transmit was the type of hearing loss, the parents were most interested in discussing their feelings, the rehabilitation process, and talking to other parents.

Conclusions: Overall, results reveal that breaking bad news of a child's hearing loss has been done fairly well. Due to the parents' reports of the need for emotional support, it is suggested that audiologists receive further training and adjust to personal and cultural differences. Recommendations include establishing an appropriate setting and ensuring that an interpreter is available when necessary. Further emotional support may be provided through establishment of a family support network.

1. Introduction

Perhaps one of the most challenging aspects of work as an audiologist is informing a family that their child has a hearing loss. Buckman [1] defined bad news as any news that adversely and seriously affects an individual's view of his or her future. More specifically Fitzpatrick et al. [2] state that parents describe the hearing loss as a phenomenon that not only affects the child, but changes the lives of the family and affects decisions such as career, finances, and place of residence.

In the past, hearing loss was tested for in the high risk population or when developmental milestones were delayed, or after failure in screening tests in well baby clinics at the age of 7–9 months, and therefore parents were somewhat prepared to receive news of hearing impairment in their child.

Nowadays, with the implementation of newborn hearing screening programs, Kurtzer-White & Luterman [3] raised the point that newborn hearing screening promoted early identification and rehabilitation, but may have left parents without enough support in the event of diagnosis of hearing loss.

Parents reported emotional reactions of shock and grief upon diagnosis of hearing loss. The period immediately after detection of hearing loss is perceived by parents as the most stressful. Furthermore, the manner in which the news was conveyed influenced their approach, for the long term, towards the hearing loss, the staff and the

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rehabilitation process. This highlights the important role of the audiologist in the manner of conveying the bad news for the future of the child, and the essential role in establishing resources and support systems that will promote positive adaptation of families after early identification of hearing loss [e.g. 4–6].

To our knowledge no paper has been published on audiologists' approach to breaking bad news. Research on medical staff members in the oncology department has revealed they did not have enough training in sharing bad news. There was a discrepancy between expectations of the sick and responses of the medical staff. While the staff attributed less importance to sentences expressing sharing, patients reported that such sentences could have helped them in the process of acceptance and coping [7].

In a survey among ophthalmologists it was understood that communication skills in breaking bad news are essential in healthcare, and should be incorporated into the training program [8].

Pediatricians agreed that learning to communicate effectively with patients was a priority. While all agreed it is important to demonstrate empathy and caring, only half reported they were confident in giving bad news, and few reported the availability of relevant programs for learning these skills [9].

In their survey Gold &Gold [10] found that speech language therapists regarded training in the subject of delivering bad news as important, but at the same time, reported receiving relatively little training in this skill.

The object of this study was to explore the situation of breaking the news of a child's hearing impairment to parents, from both sides: the manner in which parents of hearing impaired children experience receiving the news of their child's hearing loss, and the manner in which audiologists experience the situation of conveying that diagnosis.

The integration of the parents' perceived needs and the approach the audiologists describe, can lead to conclusions that will facilitate taking steps to improve the current process of breaking the news to the family.

2. Method

2.1. Subjects

2.1.1. Group 1: Parents

48 hearing parents of children with a hearing loss participated in the study. The average age of the parents was 34 (range 25–49) years old. 31 (64%) were Hebrew speakers and 17 (36%) were Arabic speakers. 34 (71%) mothers and 14 (29%) fathers filled out the questionnaire. 35 parents defined themselves as religious, 17 as traditional and 5 as non-religious.

The average age of the children at the time of filling out the questionnaire was 4:06 (range 1:3–15) years old, and the age of hearing loss detection was on average 11 months (range newborn to 2:6 years). In 34% of the children the etiology was familial hearing loss, in 14% due to CMV, 4% post meningitis, 4% prematurity and 44% unknown. The hearing loss ranged from moderate in 8 (16%) cases, to severe in 12 (25%) cases, and profound in 28 (59%) cases. In 3 (6%) cases there were additional disabilities.

2.1.2. Group 2: Audiologists

31 audiologists, 30 (97%) of them women, participated in the study. Average experience in the field was 15.5 years and ranged from a few months to 40 years. 12 reported they had little or no experience with conveying bad news to parents, while 19 reported they had experienced delivering bad news to parents many times.

2.2. Questionnaire

2 questionnaires were developed. The questionnaires contained multiple choice questions, statements that had to be graded on a scale (from 0-4; 0 = low), and some open questions.

The questionnaire for the parents consisted of 49 questions. 44 were closed-set questions (multiple choice or grading) and there were an additional 5 open-set questions. In the Arabic version an additional 4 questions referred to the language barrier and the presence of an interpreter (as the audiologists were Hebrew speakers). A "back-translation" method was used to assure identical or highly similar meanings between the original Hebrew and the translated Arabic versions according to the guidelines recommended by Guillemin et al. [11].

The questionnaire for the audiologists was based on the parental questionnaire and on other questionnaires for medical staff on sharing bad news [7,9]. The questionnaire contained 60 questions. 56 were closed-set questions (multiple choice or grading) and there were an additional 4 open questions.

Both questionnaires included demographic questions pertinent to those filling out the questionnaire.

The questionnaires consisted of questions addressing different aspects of breaking the news, such as: the recipients of the diagnosis, emotions evoked when sharing the news and the need for emotional support, type and amount of information conveyed and received, physical conditions during the discussion.

Apart from the questions contained in both questionnaires, there were specific questions in each questionnaire concerning the particular group. The parents were asked questions on the reason for referral, clarity of the information conveyed, and prior knowledge. Audiologists were asked questions addressing training and experience with sharing bad news.

In this paper we mainly address and compare the questions that were matched for both groups, and refer mostly to the closed-set questions.

The questionnaires were distributed to parents who accompanied their children for hearing aid fitting, or cochlear implant mapping follow up sessions at the Hadassah University Medical Center, or to parents through the rehabilitation centers in Jerusalem (Micha, AV or Shma Kolenu). 53 questionnaires were collected; however 5 were not fully completed and therefore not included in the analysis.

The audiologists' questionnaire was distributed via an email group of audiologists working mainly in hospitals but also in private clinics.

The study was approved by the Hadassah University Medical Center Ethics Committee.

Statistical analysis included correlation as well as Chi squared, ANOVA and T-Tests to compare between groups.

3. Results

Both parents (80%) and audiologists (92%) agreed that the audiologist is the appropriate professional person to convey the news.

Both groups believe both parents should be present at the time of diagnosis. Some recommended that there should be a social worker, doctor or another supporting family member present as well. As can be seen in Fig. 1, most of the audiologists marked the presence of a social worker as desirable, while most of the parents did not. This difference was significant ($\chi2(1) = 7.82$, $p < .05$). 53% of the parents and only 32% of the audiologists wished to have an additional family member present. The difference was marginally significant ($\chi2(1) = 3.29$, $p = .07$). The presence of a doctor wasn't rated as very necessary by either parents or audiologists; however, it tended to be more desired by parents ($\chi2(1) = 3.47$, $p = .06$).

3.1. Group 1: Parents

Findings demonstrate parents' general satisfaction with the manner in which the diagnosis was delivered and with the professional staff's conduct. For the most part (70%) the diagnosis was perceived as clear and well explained, and 57% of the parents indicated that they had received exact guidance as to the next steps they had to take after diagnosis. 31% of the Arabic speaking parents reported a language