

Delivering Bad News

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INTRODUCTION:

The definition of “bad news” is subjective. It depends largely on the specifics of the people involved and their situations. Nonetheless, there are common threads among the definitions of bad news. Bad news usually represents information one does not want to hear because this new information is likely to limit options and adversely affect the future.

Health professionals are usually the ones who deliver medical and health-related bad news. For audiologists, the bad news we’re charged with delivering is often related to the fact that a child has been born with hearing loss, or is indeed, deaf. As such, it is incumbent upon the audiologist to manage this difficult counseling responsibility with compassion, empathy, knowledge and skill. This article will address some of these considerations.

OVERVIEW:

Newborn hearing screening has changed many of the dynamics associated with identifying and treating children born with hearing loss. White (2008) reported that of the 50 states in the USA, 41 have newborn hearing screening legislation. Fewer than 5% of all children born in the USA were screened in 1993. In contrast, more than 95% of USA-born newborns were screened in 2006. This rapid and dramatic change has brought about many secondary changes.

In 1993, the typical diagnostic process involved the parents (usually the mother) noticing that their baby wasn’t responding appropriately to sounds. The suspicion of hearing loss would generally lead the parents to the pediatrician. The pediatrician would likely examine the child’s ears via otoscopy, offer reassurance and perhaps refer the child to an otolaryngologist for consultation, or to an audiologist for diagnostic testing. This scenario placed the parents in the position of observing and suspecting hearing loss gradually over time.

Some parents might have suspected hearing loss after a few months, but more often, it would take a year or more. As the year (or more) went on, and as their suspicions regarding hearing loss increased, the newborn and the parents got to know each other and developed strong familial bonds. By the time the diagnosis had been made, the newborn

and the parents had time and experience together. They had developed bonds, rituals and expectations. Basically, by the time the diagnosis was made, they knew each other.

In 2008, hearing screenings were performed on 95% of all newborns at or near birth and the results were available immediately. Of course, there are significant advantages related to early diagnosis and treatment of hearing loss. Smaldino and Flexer (2008) reported that, as a result of this early screening and diagnosis, some 90% of all children identified with hearing loss are likely to be mainstreamed by first grade. Clearly, the benefits of early diagnosis and treatment of hearing loss are significant.

However, approximately 90 to 95% of all newborns with hearing loss are born to parents with normal hearing. The news is typically unexpected and may indeed, represent a time of crisis for the family of the newborn. Specifically, the period immediately following the birth of a newborn is a powerful and emotional time. Parents have certain hopes, dreams and expectations for their newborn child. Professionals need to be mindful of these factors when delivering the “bad news”. Our goal is to support the family in positive ways as they learn about and address hearing loss in their newborn. It is important we do not impede emotional and psychological bonding between the newborn and the new parents.

GUIDELINES:

English, Kooper and Bratt (2004) reported pragmatic guidelines relating to informing parents of their child’s hearing loss. Their guidelines were based on those developed for physicians who, while skilled in the diagnosis and treatment of disease, often have difficulty delivering a dire diagnosis (Girgis and Sanson-Fisher (1995). In a survey by the author, those guidelines were modified and presented to 18 mothers of children diagnosed with hearing loss. The mothers reviewed the guidelines and provided ratings. Rating choices included “essential,” “desirable,” “not necessary” or “should not be done.” Based on their responses, guidelines were offered to audiologists for consideration when informing parents of their child’s hearing loss. Those guidelines are re-visited and adapted here:

1. The diagnosis of hearing loss should be delivered by the audiologist who will be managing the child, or preferably, by the audiologist who administered the tests. As the diagnosis of hearing loss in an infant is concluded after many tests typically occurring after a period of weeks, a relationship often develops between the audiologist and the parents. In general, parents are most comfortable with professionals with whom they have developed a relationship. This relationship can serve as a beneficial foundation for the parent when hearing difficult news. Indeed, it would be more “anxiety provoking” for a parent to learn the diagnosis from someone they had not met previously or with whom the parent had no prior relationship. Therefore, the news should be delivered by the audiologist who has an established relationship with the parent.

2. The audiologist should deliver the news in a non-rushed atmosphere, without interruption. It is important to make sure the audiologist has adequate and uninterrupted time to deliver this news. Administrative and secretarial staff should be instructed to hold all phone calls and other communications during this time. It is difficult and distressing for parents to comprehend the magnitude of the information being delivered. This time is to be protected and 100 percent dedicated to the parents. Additional suggestions include; a simple “Privacy Please” sign placed on the office door, the newborn’s medical chart or file should be available for review and to add notes, tissues should be available on the desk, the audiologist should turn off ringers on cell and office phones, the audiologist should turn off the computer monitor so as to not be distracted by incoming email, etc.
3. After delivering the diagnosis, the audiologist should assess the parents’ understanding of the situation. In general, this is the time for the audiologist to be silent, while allowing the parent to absorb the information at their pace and to formulate a question or another response. After the statement, “Your child has been diagnosed with a significant hearing loss,” it is typically best for the audiologist to pause and let the parent grasp this new knowledge. Usually, after a period of silence, the parent will ask a question. Their question will reflect their level of understanding. To proceed with information regarding the audiogram, hearing aids or the possibility of cochlear implants, before the parent can comprehend the news, will generally leave the parent overwhelmed.
4. The audiologist should encourage the parents to express their feelings. This is not the time for the audiologist to act as a cheerleader (Luterman, 2006). Comments such as “don’t worry, in this remarkable age of digital hearing aids and cochlear implants, your child will do fine” are not helpful at this time. Frankly, at this moment, after receiving their newborn’s diagnosis, nothing is fine. The parents are likely to be very uneasy and perhaps overwhelmed or in a state of denial or emotionally shocked. The parents most likely need support to express their feelings of sadness, grief and/or confusion before they can move on to other matters, or delve more deeply into the issue at hand.
5. The audiologist should respond with warmth and empathy. The audiologist should “read” the behavior of the parents as much as possible and respond accordingly. Empathic comments such as “I know this is difficult to hear” or perhaps “It must be overwhelming for you to hear this news” help communicate sincere, empathetic feelings and emotions to the parent. Further, these responses help validate the situation and the emotions most likely to accompany this situation. These (and similar) responses indicate to the parent you acknowledge their feelings and you are there to support them in that moment.
6. Although it certainly is helpful for parents to know what to expect in the short and long term, the audiologist should give the parents a broad time frame to follow-up on this initial meeting. Discussing earmolds, FM, amplification and

cochlear implants at this moment is likely ill-advised. These topics can be well addressed in the days and weeks to come, and almost certainly this particular day is not a good day for the parents to make important decisions. In general, a follow-up appointment is recommended within a few days. However, sometimes, before they can make any commitments (including a follow-up appointment) parents need to go home and digest the information. Whenever possible, it is best to allow the parent to provide the pace and timing of the next steps. Naturally, as audiologists, we feel a sense of urgency to start intervention as soon as possible. However, our need as professionals must take a back seat to the needs of the parents. It is appropriate for parents to schedule a follow-up appointment in a few days, or perhaps in a week, after they have had time to digest the diagnosis and think through their questions and concerns. A broad time frame for follow-up may also mean that on occasion, if the parent is unable to commit to a follow-up appointment, the audiologist may need to phone (or send a written note to) the parent in two or three days to see how they're doing and to see if they would like to schedule the follow-up appointment at a more convenient time.

7. At the follow-up appointment, review and then expand on treatment options. It is well documented that patients hear only 50% of the information reported to them by a health care provider and of the 50% they remember, only 25% is accurately recalled (Margolis, 2004). Therefore, it will be important to review all the information covered in previous meetings at subsequent times. Each time, the information is reviewed, the parents will "get" a little more.
8. People learn in different ways. For many parents, the vocabulary and the concepts the audiologist will be discussing (relative to delivering the bad news) are foreign and difficult. Many parents will struggle with the words and their meaning and many will have difficulty integrating these concepts into the image they have of their newborn child. Therefore, it is very useful and important to have a multitude of supportive "take home" materials available. For example; support materials should include basic and easy-to-read written discussions about hearing loss, amplification options, FM, assistive listening devices and cochlear implants. Sometimes it is useful to have DVDs and videos, too, which help explain basic hearing and hearing loss concepts, as well as amplification and aural rehabilitation issues and protocols. Giving parents names and phone numbers of other parents whose child has been diagnosed with a hearing loss is also helpful.
9. Document everything. It is very important to record the essence of the discussion, as well as the parents' reaction in the medical chart or record. Beyond the simple reminder the chart provides, the written record of these events helps the audiologist to know if and when a recommendation to a local mental health provider (social worker, psychologist etc) is recommended. Sometimes, if weeks (or months) go by and the parents are still unable to address the situation in a meaningful and realistic way, it may be beneficial to refer the parents to a mental health provider for additional counseling and direction. In those situations, an accurate and detailed medical record will provide useful clues into the situation

and may be enormously helpful in guiding the parents as to the best decisions for their child.

DISCUSSION

As professionals, we must be prepared and competent to not only deliver bad news, but to address patient and parental needs on their terms. We must be flexible as we observe, internalize and understand their reactions to the diagnosis and we must respond with empathy, maturity, knowledge and sincerity. Through thoughtful reflection and counseling, and by listening to the words and intentions, spoken and implied, the above guidelines may offer assistance in these difficult situations. As skilled counselors, audiologists will be better prepared to accompany parents on their journey as they learn about their child and matters related to hearing loss.

For More Information, References and Recommendations:

Beck, DL and McGuire, R. (2006): Multimedia: Better Tools Facilitate a Better Process. http://www.oticonusa.com/eprise/main/SiteGen/Uploads/Public/Downloads_Oticon/TheHearing_Review/May_2006_HR.pdf

English, K, Kooper, R., Bratt, G. (2004): Informing Parents of Their Child's Hearing Loss – Breaking bad news Guidelines for Audiologists. *Audiology Today*. March/April 2004. Pages 10-12.

Girgis, A. & Sanson-Fisher, R. (1995) Breaking bad news: Consensus guidelines for medical practitioners. *Journal of Clinical Oncology*, 13(9), 2449-2456

Luterman, D Conference Advanced Auditory Therapy Workshop: An Intensive 3 Day Professional Conference for Therapists, July, 2006

Margolis, R (2004): What do your patients remember. *The Hearing Journal*. 57(6) June 2004 pages 10-17

Smaldino, J. and Flexer, C. (2008): Classroom Acoustics: Personal and Soundfield FM and IR Systems. In *Pediatric Audiology: Diagnosis, Technology and Management*. Editors Madell and Flexer. Thieme Publications. www.thieme.com ISBN 978-1-60406-001-0 pages 192-202.

White, K. (2008): Newborn Hearing Screening. In *Pediatric Audiology: Diagnosis, Technology and Management*. Editors Madell and Flexer. Thieme Publications. www.thieme.com ISBN 978-1-60406-001-0 pages 31-41.