To Sedate or Not: Parent’s Right to Informed Consent

Editorial by Janet DesGeorges and Sara Kennedy

It is time to end the unnecessary sedation of infants for diagnostic ABR (Auditory Brainstem Response testing) in the process of the 1-3-6\(^1\) model in Early Hearing Detection and Intervention (EHDI) systems. The risk of sedation in infants is well known and should be avoided when possible. Infants who are younger than six months are at higher risk for serious adverse events.\(^2\) For many of us parents, concerns about sedation are dismissed with a "it's perfectly safe" statement. However, even a brief review of the medical literature indicates that sedation is far from a routine, predictable, standardized procedure. At a summit held on just this topic, this statement was made: "There was consensus on the panel (of differing medical practitioners involved in sedation of babies and children) that the state-of-the-art pediatric sedation system would include expert airway providers using short-acting medications like propofol with advanced monitors and ideal environmental conditions. Most of the anesthesiologists that regularly use these drugs did not consider the average sedation case to be technically challenging. These observations beg the question, “Why is pediatric sedation commonly provided with relatively unpredictable, low potency, long acting drugs like oral chloral hydrate by non-airway experts in a suboptimal monitoring environment?” The panelists answered this question by citing the various barriers (economic, political, regulatory) that currently prevent us from providing the “best possible outcomes” to children having procedures.\(^3\) Across the nation, there is no standard of care established regarding if, or when, young infants in need of a diagnostic ABR or similar test should be sedated or not. Depending on where a family goes for diagnostic testing, the practice of sedation follows irregular and undefined protocols.

One family walking through the door of an audiology practice in a hospital in Virginia will automatically be scheduled for a sedated ABR regardless of their baby's age. Another family walking through the door of an audiology practice in a hospital in Colorado will automatically be scheduled for a natural sleep state ABR until the age of six months. Why the discrepancy?

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\(^1\) The Joint Committee on Infant Hearing (JCIH, 2007) recommends that all children should be screened by one month of age, identified by 3 months, entrance to early intervention by six months of age.


\(^3\) Pride, Prejudice, and Pediatric Sedation: A Multispecialty Evaluation of the State of the Art Report from a Dartmouth Summit on Pediatric Sedation, held at the Dartmouth Hitchcock Medical Center, September 2000, page 42.
The answers are complex and can be traced to both practical and institutional responses. When parents ask the professionals in their lives about why one infant is subject to sedation, and another isn’t, different answers to that question emerge.

Some audiologists feel they can get better information when the infant is sedated, though this is disputed by others. Other reasons for sedation include the administrative convenience of scheduling in audiology practices; the relative ‘ease’ of managing the testing while under sedation versus sleeping due to normal behavior of babies/toddlers in natural sleep states; and the sedated ABR may take less time. One financial reason we have heard but not verified is that insurance companies will only reimburse for one ABR diagnostic visit, so practices don’t want to take the risk of needing to schedule more than one visit.

Based on our own stories, sleep deprived diagnostic testing is possible. Our daughters were 14 months and 22 months old when their testing was completed. In one case, one of us chose nonsedated testing because of the ENT's statement that "we used to do the testing here, but we don't have the resuscitation equipment now required." Maddie's unsedated testing did require two visits, but was felt to be valid.

Mavis Irwin, identified in 1982 when she was 15 months old, was also not sedated at the request of her parents. The closest equipment was more than five hours away. As a physician himself, Mavis' father felt strongly that sedation was risky and that it was mostly given for the convenience of the clinician. Mavis' parents spent the day dragging a very crabby toddler around town and she fell asleep nicely at the clinic, even for multiple kinds of testing. Dr. Jim Irwin notes that general anesthesia for ABRs may soon be a thing of the past anyway, because there is a new device that gets the data so quickly that there is no need for the child to be sleeping. (i.e. Vivasonic ABR)

In the medical field, the principle of "informed consent" guides, or should guide, medical practices. A patient (or parent) must be fully informed in order to participate meaningfully in making choices about health care. The principle originates from the legal and ethical right the patient (or parent) has to direct what happens to his or her body, or body of a child, and from the ethical duty of the physician to involve the patient in his or her own health care. Are parents fully informed about the nature of sedation, and its reasonable alternatives, such as sleep deprived testing, and the relevant risks, benefits and uncertainties related to each choice.

For all of the parents in our story who chose to forego sedation, the risks of sedating a child who just needed to be quiet --not unconscious-- for the procedure (however lengthy) outweighed the benefits. We believe that every parent has the right to make an informed choice about whether they want their infant sedated or not for the diagnostic ABR, ASSR, or other testing. Each family must weigh the risk of sedation with the benefits that sedated ABR may bring with the individual personality of their baby in mind. Indeed, not all parents may be able to wake the baby hours early and avoid feeding for some hours prior to an unsedated test to help their baby or toddler fall asleep more deeply when finally fed and comforted to sleep in the parent's arms or familiar child seat.
at the clinic or hospital. In the world of hearing loss and deafness, there seems to be no one ‘right’ answer for many things: communication options, educational placement decisions; technology options; genetics testing. It is time for professionals to speak up and create quality standards and practices regarding the use of sedation in diagnostic ABRs. The professional organizations have been strangely silent on this practice to date.

Should parents have the right to choose sedation or not? We think so!