

Opinion on cochlear implants in prelingual deaf children. Report.

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Opinion

The National Consultative Ethics Committee (CCNE) received an application for an opinion from some twenty persons, including parents of deaf children, representatives of associations for the deaf, and deafness and language specialists, who were concerned about the recent extension of the practice of cochlear implantation in prelingual (1) totally deaf children, i.e. children whose residual audition is not usable by means of conventional hearing aids. This implantation, which began in deaf adults some twenty years ago, is designed to avoid total destruction of the sensory cells of the inner ear. It consists of introducing into the cochlea several stimulatory electrodes along a flexible isolating tube. These electrodes activate the fibres of the acoustic nerve by electric impulses whose characteristics are determined by those of the acoustic signals. In this way, the central nerve structures receive information of acoustic origin.

The ethical problems involved in cochlear implantation are far more complex in extremely deaf young children, whose deafness is either congenital or sets in before the acquisition of language, than in subjects who become deaf after having learned to speak, i.e. who are postlingually deaf, nearly all of whom are adults.

Postlingual extremely deaf adults can themselves make the decision to be implanted, and in their case, the general experience of cochlear implantation is sufficient to allow appreciation of its effectiveness. On the whole, the results tend to be good, because satisfactory oral communication is re-established fairly often. The traces left in the central nerve structures involved in the learning and prolonged practice of oral communication conceivably play a positive part in this re-establishment.

In the case of prelingual deaf children, things are very different, in the first place because the decision to implant is made by the parents, who are often deeply perturbed by their child's deafness, and also because the period of follow up from which to appreciate the effectiveness of the implants is at present insufficient (it is generally four years at most). It is not yet known how central nerve structures which have as yet received little or no acoustic information will treat the information supplied by a prosthesis, which is all the same not identical to physiological information.

Will these nerve structures enable all children whom a thorough examination shows could benefit from an implant to acquire satisfactory oral communication, after years of learning that will require very great effort ?

Will such structures even permit much simpler sensorimotor activities, such as the perception of sounds and the ability to react to them, the facilitation of lip reading and the understanding and speaking of a certain number of words ?

The CCNE considers that for as long as the present very uncertain conditions prevail (doubtless for several years) everything possible should be done to avoid jeopardizing the cognitive development of these children. For this reason, and also on the basis of the observations reported by certain specialists, to the effect that the learning of oral French is

more efficient when it is preceded by successful linguistic experience of sign language, the Committee recommends that the mental and social development of these children be ensured by combining the learning of sign language, known to be efficacious in this field, with cochlear implantation.

This way of proceeding would have the dual advantage of already allowing the children to start communicating with their environment at the age of one year (the age at which sign learning can start), well before they are able to benefit from an implantation, and if the latter should fail, of possessing a mode of communication capable of ensuring their cognitive development and mental and emotional balance. On the other hand, it does not seem to the CCNE desirable to confine learning to sign language only, as this would deprive the children of the possibility of oral language learning. This possibility should not by any means be excluded today, especially if the optimal conditions for oral language learning are present after implantation.

The CCNE fully subscribes to the recommendation made by the ANDEM (National Agency for the Development of Medical Evaluation), which the Ministry of Health has entrusted with the task of recording the results and possible complications of the implantations performed in prelingual deaf children, that parents should be informed about cochlear implants in writing. This information should cover the principle governing the functioning of the implant, the complications that it might cause and the benefits it can be expected to confer. Parents should be made aware of the fact that no objective data are yet available on the development of oral language among implanted children or on their mental and emotional balance and social integration into an environment in which hearing is normal. Moreover, the Ministry has already asked the CTNERH (National Technical Centre for Study and Research concerning the Handicapped) to work out, within a few months, a method of evaluating these different factors, once the ANDEM has published the results of the implantations, and also to complete, within five years, a report on the condition of the children implanted. It is also necessary to explain to parents the differences between the acquisition of hearing capacities and the acquisition of language.

The CCNE has taken due note of the detailed document which the CEDIT (Committee for the Evaluation and Diffusion of Technical Innovations) has just drawn up for the information of the deaf and/or their families. The Committee feels it is indispensable to complete this information by informing parents of deaf children about the existence of sign language and about the assistance which they can obtain from associations for the deaf.

Under present conditions, the CCNE does not consider it opportune to submit the issue of cochlear implantation in prelingual deaf children to the CCPPRB (Consultative Committees for the Protection of Persons in Biomedical Research) for its approval, in view of the fact that the Ministry of Health, ANDEM and CEDIT have already been asked to carry out studies on the effectiveness of this implantation. Nevertheless, some kind of supervision of the way this method is practised should be envisaged, if only because it requires a combination of numerous different skills seldom encountered outside hospitals.

The CCNE considers that the overall problem of communicating with prelingual deaf children in itself deserves a multidisciplinary study involving the participation of all the categories of persons concerned by deafness (language teachers and researchers, ENT surgeons, child psychologists, parents of deaf children and representatives of associations for the deaf). In particular, this study would define the place and efficacy of implants in relation to other techniques of communication. It could be commissioned by the Ministries of Health and Research.

Lastly, the CCNE warns against erroneous portrayals of the implantation technique which make parents believe that cochlear implants will quickly enable their children to hear and speak. Objective information designed for the general public regarding these implants, as well as sign language, would be very useful.

Report

The implantation in the cochlea of electrodes designed for direct stimulation of the acoustic nerve fibres in deaf subjects whose sensory cells of the inner ear have all been destroyed has been practised for about twenty years in deaf adults. Thanks to increasingly well perfected electronic devices, various types of information can be extracted from the human voice and in most cases transferred to some ten or twenty sites in the cochlea. From there, this information will reach the cortical auditive areas, after the electrical activation of several distinct bundles of nerve fibres. These implants have given fairly satisfactory results as regards oral communication in subjects who had learned to speak before becoming deaf. These results prompted certain ENT surgeons to perform implantation in extremely deaf children who had no residual audition that could be used by means of conventional hearing aids. The children concerned were either congenitally deaf, or had become deaf in the first years of life, before they had learned to speak.

I

It was the extension of the indications for implants in prelingual deaf children (2) that led to the sharply hostile reactions to the implantation technique in certain circles of deaf people. They prompted the document sent by Dr. J. Dagrón, audiophonologist physician at the Melun Hospital (in France) and researcher in Social Sciences, to the Chairman of the CCNE, entitled " Notification of the CCNE of the conditions under which cochlear implantation can be applied to young deaf children - particularly the advantage of the possible application of the Huriet Law."

This document was drafted by Dr. J. Dagrón after joint reflection by a group of some twenty people comprising parents of deaf children, representatives of various federations and associations for the deaf, including the group entitled " The Angry Deaf" , language specialists (linguists, orthophonists, psychiatrists, psychologists, sociologists, and sign language teachers), a lawyer and a well known French deaf actress. In the first part of the document, the question of whether the results of implantation in adults who had become deaf can be transposed to prelingual deaf children, and in the second, several complaints and suggestions, are submitted to the CCNE for study. This remarkable effort of presentation, and the considerable emotion manifested by certain deaf subjects on occasions which included the last " National Ethics Days" organized by the CCNE (3) , led to a request to Dr. J. Dagrón to appear before the technical section of the CCNE and personally explain the different problems involved in the implantation of prelingual deaf children.

After the meeting, the rapporteurs of the CCNE responsible for studying this question (Messrs. Y. Laporte, J. Michaud and J. Seylaz) acquired complementary information in three ways :

by consulting several specialists, including ear nose and throat surgeons, orthophonists, representatives of associations for the deaf and neurophysiologists,

by attending a meeting of a group very similar to the one responsible for the notification addressed to the CCNE. The aim of this group was to focus the Committee's attention on the report entitled " Cochlear Implants in prelingual deaf Children" published by the ANDEM in September 1994 (4) . At this meeting, communication between certain participants was made possible by a sign language-oral language interpreter,

by duly noting the content of two recently published documents : the ANDEM report referred to above, in which the results and possible complications of the implantations performed by French and foreign teams in prelingual deaf children were recorded, and a document entitled Rehabilitation of the Very Deaf by Multielectrode Cochlear Implants, drafted by a group of surgeons performing these implants within the framework of the CEDIT for the express purpose of informing very deaf patients and/or their families.

II

This part of the CCNE's opinion will deal with the different points raised in the notification, in the order of their formulation, and with the comments and reactions to which they have given rise.

1. Absence of a " public investigation" of the place of the implant in medical child care

The CCNE considers such an investigation to be indispensable, if the term " public investigation" signifies a study in which all the categories of persons concerned by extreme deafness would participate (language teachers and experts, deaf children's parents, representatives of associations for the deaf, and ENT surgeons seconded by their teams of audition specialists).

The ANDEM did not tackle this question in its report, because its task was to record the results and drawbacks of implanting prelingual deaf children, and did not include the preceding stage involving the choice of the method of communication to be developed in these children. Nevertheless, the ANDEM also considers that this question deserves to be dealt objectively.

This could be done in a study conducted at the request of the Ministries of Health and Research.

2. Objective of the implant

Parents of deaf children should know -which has not always been the case- that although an implant can quickly enable the child to perceive certain sounds permitting useful reactions, it is not yet known whether it leads to satisfactory oral communication, even after years of learning, or only to the facilitation of lip reading and the understanding and speaking of a certain number of words. A clear distinction should be made between an increase in hearing ability and the acquisition of language.

3. Questioning established educational principles

According to many specialists, the learning of oral French is more efficient if it is preceded by successful linguistic experience, i.e. the acquisition of sign language. The authors of the notification consider that this acquisition should not be forgotten, which prompts them to wonder whether it is not necessary for children to learn sign language before being implanted.

This proposal seems to the Committee worth serious consideration. Firstly because we know that the acquisition of sign language, which a child can already start learning at the age of one year, will end the prelingual deaf child's isolation and allow his mental and social development, and secondly, because the post-implantation follow up period is still too short (4 years at most and usually less) to allow assessments of implant effectiveness reliable enough to guarantee that the benefits include the acquisition of an oral language sufficiently close to normal language to contribute efficaciously to the child's cognitive development.

It would be extremely hazardous to make any predictions in this field, because despite the constant improvement of the information supplied to the acoustic nerve fibres -information which, however, is often limited- the way in which these fibres are activated after an implant will always be very different from their activation under physiological conditions.

It is in fact hoped that the nervous system is so flexible, especially in the young child, that the information transmitted about the words of others to the central auditive structures by means of the implant will enable the child to learn to speak, even if this information differs from physiological information.

Several ENT surgeons and several biologists who were questioned about the feasibility and advisability of combining sign language and cochlear implants reacted favourably to this suggestion.

4. Absence of independent and multidisciplinary evaluations

5. Difficulties concerning indications and diagnosis

A document published in 1994 by the CEDIT, entitled Rehabilitation of the Very Deaf by Multielectrode Cochlear Implant, includes the following passage :

" After completion of the preoperative examination, the audiometric, audioprosthetic, orthophonetic and psychological criteria were evaluated, as well as the X-rays and stimulation test. A truly multidisciplinary meeting, at which opinions were expressed by many specialists involved in child deafness -the ENT surgeon, audiophonologist, orthophonist, audioprosthetic, psychologist and radiologist- enabled the decision to implant to be reached. The opinion of the team of educators who usually deal with the child is very important in this decision, and even during the post-implant follow up" . The above passage seems to us to show that these elements are taken into consideration, which was confirmed to us by several ENT surgeons.

6. Application of the Huriet Law

The application of this law was required both in the notification and the tract transmitted to the CCNE by the Angry Deaf association, which stressed that to extend to prelingual deaf children a technique which has given fairly satisfactory results in postlingual subjects cannot be considered as a therapy but as experimentation, because it is not known whether this technique will enable the child to acquire a real language. The association's members consider that the obligation to submit proposed implantation cases to the CCPPRB would have the advantage of their being considered by a committee whose multidisciplinary composition would make it more sensitive to the social and psychological aspects of deafness. The children's parents, who would be better equipped to reach a decision if this procedure were adopted, would be more aware that the implant is not " a miraculous cure" .

The ENT surgeons consider that as regards the long-term effects of implants in prelingual children, the present phase is one of evaluation. They agree on the need to inform parents as thoroughly as possible and point out that the indication for implantation is decided jointly by several specialists in complementary fields before it is proposed to the parents.

It should also be noted that the practice of implanting prelingual deaf children is permitted by the Ministry of Health, as it has asked the ANDEM for a report on the results of this operation, and has just entrusted the CTNERH with the dual task referred to in Section I above. It is therefore hard to see how the proposal to submit the operation to the prior approval of the CCPPRB could be accepted. This kind of measure would certainly have been useful twenty years ago, when the first implantations were performed in very deaf adults. Moreover, if a prosthesis based on a different principle were one day proposed, it would indeed be appropriate to submit it to the CCPPRB for prior approval. Nevertheless, it is true that some kind of supervision of the practice of the present implantation method should be envisaged.

III

A study of the questions raised by the notification submitted to the CCNE, and of the various items of relatively recent information available on the cochlear implant in prelingual children, thanks, in particular, to the ANDEM report, led to several conclusions :

The present short follow up period means that we do not yet know, and will probably not know for several years (see the report requested from the CTNERH) whether the implants

will endow children with a sufficient capacity for oral communication to ensure their cognitive development. Exclusive reliance on the implant and oral language learning involves the risk of seriously jeopardizing the cognitive development of many children.

On the other hand, it is known that the visual transmission of information via the learning of sign language, which can already start at the age of one year, makes it possible to end the isolation of very deaf children and ensures their psychological and social development.

In addition, the experts consider that the learning of oral French is more efficient when it is preceded by successful linguistic experience, i.e. the acquisition of sign language.

These conclusions lead the CCNE to propose that for as long as great uncertainty persists regarding the effectiveness of cochlear implants, the learning of sign language should be combined with cochlear implantation. This method of procedure would have the dual advantage of already allowing the child to communicate with his environment at the age of one year (when he can start learning sign language) i.e. long before any benefit can be derived from implantation, and also, in case the latter should fail, of providing a means of communication capable of ensuring the child's cognitive development and mental and emotional balance. On the other hand, it does not seem desirable to confine learning to sign language only, because this would deprive the children of the possibility of learning to speak, which today is by no means impossible, especially if the optimal conditions for oral language learning exist after implantation.

The CCNE adopts the recommendation of the ANDEM, which the Ministry of Health has entrusted with the task of recording the results and possible complications of implantation among prelingual deaf children, that these children's parents be informed about the implant in writing. The information should concern the principle on which the implant functions, its possible complications and the benefits expected. Parents must be made aware of the fact that no objective data are as yet available about the development of oral language, the mental and emotional balance or the social integration of implanted children in a non-deaf environment. Moreover, following the above recommendation, the Ministry has already asked the CTNERH to work out, within a few months, a method of evaluating these different elements, and to draft a report on the condition of implanted children within five years. It is also necessary to explain to parents the differences between the acquisition of hearing capacities and the acquisition of language.

The CCNE has taken due note of the detailed document recently drawn up by the CEDIT with the object of informing the deaf and/or their families. It seems necessary to the Committee to complete the information supplied to the parents of deaf children by bringing to their notice the existence of sign language and of associations for the deaf capable of assisting them efficiently.

Under present conditions, the CCNE does not consider it appropriate to submit the prospective implantation of prelingual deaf children to the CCPPRB for prior approval, given the fact that the Ministry of Health has already asked the ANDEM and CTNERH to conduct studies of the effectiveness of this operation. Nevertheless it is true that some kind of supervision of the practice of this method should be envisaged, if only because of the need to combine many different skills which are seldom found together outside the hospitals.

The CCNE considers that the general problem of communicating with prelingual deaf children in itself deserves a multidisciplinary study requiring the participation of *all the categories of persons concerned by deafness* (language experts and teachers, child psychologists, parents of deaf children, representatives of associations for the deaf, ENT surgeons and the specialists in audition with whom they cooperate). In particular, these experts could define the place and value of the implant in relation to the other techniques of communication. This study could be decided on by the Ministries of Health and of Research.

Lastly, the CCNE warns against misleading descriptions of the cochlear implantation

technique which make parents think that it will enable their children to hear and speak within a short time. The transmission of objective information to the general public on cochlear implants as well as on sign language would be very useful.

ACRONYMS

FRANCAIS ANGLAIS

CCNE : Comité consultatif national National consultative ethics
d'éthique pour les sciences committee
de la Vie et de la Santé

ANDEM : Agence nationale pour le National agency for the
développement de development of medical
l'évaluation médicale evaluation

CTNERH : Centre technique national National technical centre
d'études et de recherches for study and research
sur les handicapés concerning the handicapped

CEDIT : Comité d'évaluation de la Committee for the evaluation
diffusion des innovations and diffusion of technical
techniques innovations

CCPPRB : Comité consultatifs de Consultative committees for
protection des personnes the protection of persons
dans la recherche in biomedical research
biomédicale

Notes

1. Prelingual, i.e. before the acquisition of speech
2. It is estimated that in France about 150 children could be implanted annually.
3. The Deaf, with a capital D, are those who use sign language to communicate with each other or with the non deaf who have learned sign language. Their number in France is estimated at 50-60 000, and that of the non deaf who have learned sign language for familial or occupational reasons, at 100-150 000.

The Deaf are very much attached to their community, which was formed as a reaction to

the social rejection, especially in schools, from which it has suffered until recently. The Deaf consider the implantation of deaf children to be a new threat to their " deaf identity" (see J. Dagron and B. Ascal : *Implant cochléaire et problèmes éthiques*, Presse d'Aujourd'hui, 1994), against which they reacted by founding The Angry Deaf association in 1993. This association sent the CCNE a tract entitled " What do you think of cochlear implantation in deaf children ?"

4. The report was drawn up at the request of the Ministry of Health, and has already prompted this Ministry to entrust another body, the CTNERHI, with the dual task of working out, within six months, a method of studying the familial, educational and social integration of implanted children, as well as their mental and emotional balance, and of drafting a report on this integration within five years.