

■ Clinicians' Perceptions of Cochlear Implant Benefits in Adults with Prelingual Deafness

■ Perceptions des Cliniciens Concernant les Avantages des Implants Cochléaires chez les Adultes Atteints d'une Surdit  Prélinguistique

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Abstract

The purpose of this exploratory research was to better understand the cochlear implant experience of adults with prelingual deafness from the perspective of service providers. Through a focus group format, clinicians shared their perceptions of the factors that influence candidacy decisions and outcomes in this challenging patient population. All data were coded inductively and analyzed drawing from a grounded theory method. The findings indicate that the benefits of cochlear implantation for adults with prelingual deafness who undergo late implantation are influenced by individual and external factors and are characterized by great variability. The central phenomenon emerging in this study was that cochlear implantation facilitates communication for adults with prelingual deafness, both in the domains of traditional hearing related communication abilities and social functioning. Areas for further study were identified in order to better understand and assess the benefits of cochlear implantation for people with prelingual deafness.

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Cette  tude exploratoire a pour but d'examiner du point de vue du fournisseur de services l'exp rience que vivent les adultes qui ont une surdit  pr linguistique et qui ont re u un implant cochl aire. Par le biais d'un groupe de discussion, les cliniciens ont partag  leur perception des facteurs influen ant la s lection des candidats et les r sultats attendus pour cette population pr sentant des d fis particuliers. Toutes les donn es ont  t  cod es et analys es selon la m thode de la th orie ancr e. Les r sultats indiquent que les avantages de l'installation tardive d'un implant cochl aire chez des adultes ayant une surdit  pr linguistique sont tributaires de facteurs individuels et externes, lesquels entra nent une variation importante. Cette  tude fait principalement ressortir que l'implant cochl aire facilite la communication chez les adultes ayant une surdit  pr linguistique, tant au niveau des habilit s auditives de communication  valu es traditionnellement que du fonctionnement en soci t . Elle pr cise aussi des domaines o  il faut poursuivre la recherche pour mieux comprendre et  valuer les avantages de l'implantation cochl aire chez les personnes ayant une surdit  pr linguistique.

Key Words: prelingual deafness; cochlear implants, outcome; clinician's perspective; qualitative research

Hearing loss poses a significant barrier to spoken communication. Modern hearing technology such as implantable cochlear stimulators (cochlear implants) have had a significant positive impact on communication in young children with prelingual hearing loss (Waltzman & Cohen, 1998) and in adults with postlingual deafness (Dorman, 1995). However, studies on adults with prelingual deafness suggest more limited gains in speech recognition abilities following implantation (Schramm, Fitzpatrick, & S guin, 2002; Waltzman, Roland, & Cohen, 2002; Zwolan, Kileny, & Telian, 1996). Despite limited improvement on objective measures after surgery, clinical experience suggests that many prelingually deafened recipients continue to wear their implants and derive satisfaction from their devices (Dorman, 1998; Zwolan et al., 1996).

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The decision on candidacy for cochlear implantation is made during a comprehensive medical evaluation where a team of clinicians works closely with the patient. Due to the poor results reported for adults with prelingual hearing loss, many implant centers grapple with the decision to implant these patients and may even exclude them as candidates. One woman recounted how the “experts” put it bluntly: “I was a ‘bad’ candidate. I would not ‘do well’ with the implant” (Tucker, 1998, p. 31).

The purpose of this exploratory research was to better understand the cochlear implant experience for adults with prelingual deafness from the perspective of service providers. Since the perceptions of clinicians are integral to understanding this phenomenon, they were selected as the starting point in seeking answers to the research question: What are the major advantages (and disadvantages) of cochlear implants in adults with prelingual deafness and how can they be assessed? The study also aimed to answer the following questions, from the clinicians’ perspectives, for this patient group:

- Does a cochlear implant make a difference in their life?
- How do we define improvement or lack of improvement?
- What conditions or factors influence cochlear implant “success”?

Participants and Method

The participants were recruited, through personal contact, from a cochlear implant program in Canada where 35 adults and adolescents with early onset deafness had been implanted. Due to the low incidence of profound deafness and the specialized nature of this intervention, the potential participant pool in the study region was limited to four audiologists. The audiologists had a combined total of 21 years’ experience in cochlear implants and together they had worked with a total of 240 implanted patients including 43 with prelingual deafness. The Research Ethics Board of the University of Ottawa approved this study and all participants were fully informed of the purpose of the study.

A qualitative approach is appropriate to construct knowledge in this clinical area because previous studies suggest that the benefits perceived by users are not captured by traditional clinical assessment protocols (Zwolan et al., 1996). It seems useful, therefore, to adopt an ontological position in which reality is viewed as subjective and multiple. Marshall and Rossman (1999) state, “Qualitative research is pragmatic, interpretive and grounded in the lived experiences of people” (p. 2). This study draws on a grounded theory research enquiry to develop a framework for the key aspects of cochlear implant outcomes in this challenging population. An important aspect of grounded theory is that the context must be considered in order to generate useful results (Pettigrew, 1990). As a clinician who has struggled with the issues, I believe that service providers

are uniquely positioned in this context. This research was guided by a constructivist approach as I engaged in a dialogue with clinicians to probe contextual information in order to understand the core concepts from which to construct plausible relationships.

Data Collection

A focus group interview approach was used to guide the study with an expectation that the group synergy would generate more ideas than individual interviews. The interview consisted of an audio taped session of approximately 75 minutes with four audiologists. As the researcher, the first author adopted the role of moderator asking open-ended questions (see appendix) to encourage the participants to share their expectations of the experience. An audiology colleague with experience in qualitative research who was familiar with cochlear implantation recorded extensive field notes throughout the interview process. In particular, the note-taker was asked to highlight any topics leading to intense discussion, differing opinions or noticeable enthusiasm. Prior to the interview, a very brief individual questionnaire was administered to document the providers’ experience with cochlear implant patients as well as their impressions of the main differences in working with this special population. This information was used to briefly describe the participants in the focus group and helped the researcher understand some of the variation in the participants’ reflections on the topic.

Data Analysis

Strauss and Corbin (1990) state: “Theories can’t be built with actual incidents or activities as observed or reported; that is, from raw data” (p. 7). Therefore, a coding process, using a constant comparative method described by the authors, was adopted to analyze the focus group interview data. All data were carefully transcribed from the audiotapes by the interviewer (EF), and reread several times for coding over several weeks to allow categories to emerge. The categories that eventually led to the conceptual framework were arranged in accordance with Strauss and Corbin’s (1998) analytical approach through open, axial and selective coding. All phrases were first coded to identify categories of information (e.g. better hearing abilities, better speech skills, patient disappointment, etc.). The similarities and differences between the categories were subsequently considered in order to discover how these categories related to each other (e.g., benefits from an implant). Finally, these more comprehensive explanations about the topic and relationships between categories were integrated to develop the final themes and construct the theoretical model. In addition, field notes from the note-taker and the interviewer’s written reflections post-interview were categorized according to key themes (e.g. patient expectations, limitations of speech perception tests) and guided the development of the final concepts and categories.

Findings

The model presented in Figure 1 was developed to represent the data analyzed from the focus group interview and questionnaire. The figure is a schematic guide for the reader rather than an exhaustive presentation of the data. The following section reports the primary categories derived from the analysis supplemented by quotations to provide the reader with a contextually rich description of the findings.

Central Phenomenon: Facilitating Communication

A central phenomenon is defined by Strauss and Corbin (1990) as “the central idea, event, happening, incident about which a set of actions or interactions are directed at managing, handling, or to which the set of actions is related” (p. 96). The expert clinicians were fundamentally concerned about how a cochlear implant could facilitate communication for adults with prelingual deafness. This concern was focused not only on traditional hearing and communication abilities, but also on family and social functioning. The model in Figure 1 presents this central phenomenon of facilitating communication.

Objective and Qualitative Outcome Measures

A goal of this study was to examine how best to assess benefit in adult patients with prelingual hearing loss. The clinicians proposed that a comprehensive evaluation should comprise objective clinical measures and functional measures. The clinicians also talked about the evaluation as dynamic in nature. There is a diagnostic

component of the evaluation that allows them to focus their rehabilitation and counseling strategies to meet the unique and changing needs of the patient. Objective measures such as speech recognition tests should tap skills at different auditory levels: closed-set, open-set sentences, open-set words (multisyllabic and monosyllabic) and phonemes, as well as speech reading enhancement. Quality measures need to be developed and should be aimed at probing auditory functioning pre- and post-implant and measuring indicators of improvement in the home, social and work environments.

Outcome: Benefits and Negative Aspects of Cochlear Implantation

Benefits:

The audiologists provided numerous examples and described in some detail how even a little more “hearing” improves communication experiences for patients. Discussions of benefit included a range of several dimensions of communication: hearing sounds, speech recognition, using the telephone, connectedness to the environment, and enhanced speech reading ability. Clinicians described how even limited auditory benefit (not measurable on standard speech perception tests) facilitated communication for patients:

“...she finds it useful at work because she can hear someone calling her name from behind her. She doesn’t get any open-set [speech recognition] but she can identify if someone is talking to her now whereas before she would often be oblivious unless someone tapped her.”

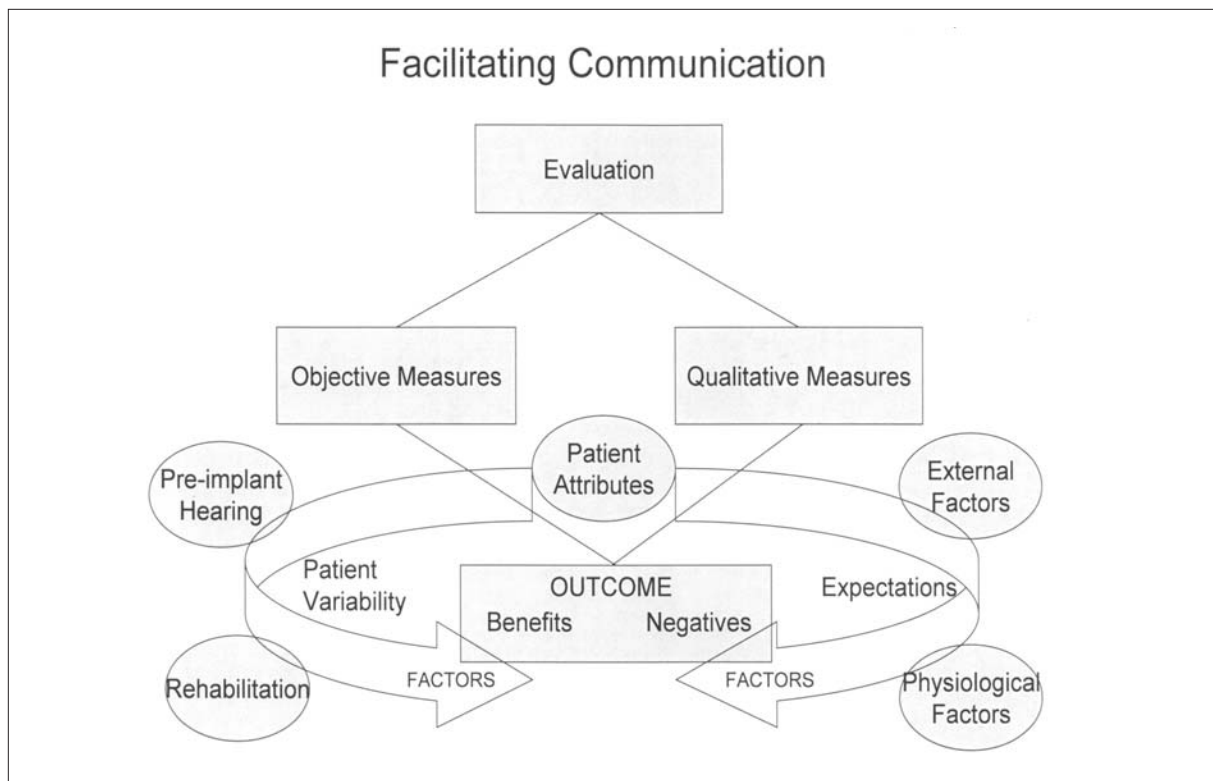


Figure 1. A model of facilitating communication in adults with prelingual deafness

"I have a patient that has...really nothing on any speech perception measures; however, she will...put her implant on the minute she wakes up and won't take it off until she goes to bed...."

The clinicians talked about how, in listening to the reports of their patients, they had learned to define benefit broadly. They described enhanced communication observed by family and colleagues at work and in social environments as well as benefits related to safety. Several examples of greater self-confidence and quality of life enhancements were offered to illustrate these "softer" and less measurable benefits: "...it helps her, she is signing, but her family is hearing, so they both speak and sign with her, and she just feels a lot more connected, a lot more a part of them."

"With the two (patients) I've seen, it's boosted their confidence...one to the point where she accepted a promotion at work...so enough confidence to go ahead and try this new position. And the other patient [was] willing to go back to school...."

"I remember one patient saying she was always afraid her little daughters would play hide and seek and she would not find them and before she got her implant she got into a panic mode because...she couldn't find where they were and she found them in the bathroom finally....now they can giggle in the basement and she knows where they are so just that security aspect for her meant a lot."

Negative aspects:

Negative aspects of the cochlear implant experience primarily related to patient or family disappointments with the outcome. For example, one audiologist described a patient's realization that "he's hearing more but not necessarily understanding more and he's realizing maybe it's limited for him in terms of what he can do." Audiologists reflected upon their patients' prior expectations and perception of performance. In pre-implant counseling, clinicians tried to decrease their patients' expectations and regularly reminded them of realistic outcomes, the hard work involved and the range of results. Another negative aspect of the process for both clinicians and patients occurred when there were minimal rehabilitation services available. Clinicians noted that unlike many implanted adults with acquired deafness, adults with prelingual deafness seem to require specific auditory-based therapy to process the new information provided by the implant. Finally, some patients who were members of the Deaf culture received negative reactions from their peers; however, the audiologists stressed that they tried to prepare this special minority group of patients for this potential situation.

One clinician shared a concern that the implant was perceived as a panacea by some patients as expressed by one patient who said she might "be able to get married if she got an implant." The expectations of other individuals in the person's social or work life were

described as also affecting the patient's feeling of implant success.

"I know this patient when she returned to work, her expectations were very clear but her co-workers expectations weren't and she had to deal with that...."

"The end result might be less with them so it might not be as obvious to other people, the improvement in prelingual deaf people."

One audiologist described speech perception measures as a negative experience: "...probably the one negative aspect I think of is the evaluation....They come out and some of them actually have tears in their eyes....it's hard, I think, for us as well...because we're supposed to be a motivating factor, an encourager but when we do that, I almost feel we've taken a step back...."

Factors affecting outcome with a cochlear implant

Clinicians shared their perspectives on the patient characteristics and other environmental factors that may lead to different implant experiences for this patient population. Several factors that impact how much a cochlear implant facilitates communication and how much counseling or rehabilitation is required post-implant were identified during the focus group interview. Based on the analysis of our focus group interview data, these were grouped into five primary areas:

1. Pre-implant hearing, age at onset of profound deafness and oral communication skills
2. Rehabilitation and other support services
3. Physiological conditions such as etiology, neural survival, and cochlear anatomy
4. External factors such as family and social supports
5. Patient attributes such as motivation, perseverance and commitment to rehabilitation

Patient variability and expectations

The audiologists frequently referred to specific observations of individual patients rather than making global statements about the performance of prelingually deafened cochlear implant recipients as a group. They stressed the importance of patient expectations in defining whether a cochlear implant was perceived as beneficial for communication. They often highlighted patient variability and qualified that any statement about outcome could not be applied to all patients. An audiologist was especially likely to engage in this type of reflection when describing a patient who was encountering difficulties: "...the impact varies; there is a range; there's a lot of different people that fall in the pre-implant category; scores vary from person to person; each one of these patients is so individual; all of our patients are very different...."

Discussion

The findings of this study highlight the complexity of defining and evaluating the outcome of cochlear

implantation in adults with prelingual deafness. We have learned that consideration of the individuality of patients is central to their evaluation. Improvement as defined by these clinician-participants needs to be specific to each patient and takes several forms: better hearing and communication, improved self-esteem/confidence and greater inclusion. Evaluation measures should go beyond traditional speech recognition tests and encompass multiple dimensions of improvement including measuring satisfaction as reported by patients and other significant people in their lives. Several investigators who have measured benefit using only speech perception tests have acknowledged the need for instruments to more accurately document outcome (Schramm et al., 2002).

These findings are consistent with the work of Zwolan et al. (1996) who found that the majority of implanted adults with prelingual deafness who participated in their survey reported satisfaction with their devices although they had no speech recognition ability. Tucker (1998), who writes as a prelingual cochlear implant recipient, describes herself as a “bad” (p. 51) implant user who likes and relies on her implant.

Further research is required with service providers and, in particular, with individuals with prelingual deafness, both those who have received cochlear implants and those who have decided not to undergo implantation. Such research would add to a better understanding of the expectations of individuals with prelingual deafness, their perceptions of the benefits of cochlear implants and their post-implantation service needs. This research can contribute to a model for assessment which extends beyond the current clinical focus on speech recognition outcomes to include better hearing and communication, improved confidence and greater participation in society.

Validity

It is essential to evaluate any research work against several quality criteria. Although qualitative research employs different methods and generally focuses on different questions than quantitative approaches, it is equally concerned with rigor and accuracy in conducting and reporting research. Quality standards to evaluate qualitative research have been developed and described by several investigators (Popay, Rogers, & Williams, 1998). In this exploratory study, construct validity was enhanced through the use of clear procedures and questions with a select group of participants and through detailed field notes and audio recordings of the interview. The data were collected, transcribed and coded by one investigator with considerable experience in cochlear implantation including previous research investigating traditional outcomes in individuals with prelingual hearing loss. The working relationship between the investigator and the clinician-participants likely contributed to the natural flow of conversation and the ease with which the clinicians participated in the group

interview. While the scope and duration of this project did not permit formal verification of the findings with the informants (member checking), the relationship between the investigator and the clinician-participants allowed data clarification when necessary. Reliability was ensured through audio taping of the entire interview and careful documentation of all procedures for data collection and analysis. Comparing the emerging theory with the extant literature also enhanced the internal validity or “truth value” and overall trustworthiness of the proposed theory.

Limitations

The primary limitations of this study relate to the use of one main data source and one focus group due to the scope of the project and the specialized nature of the population. The contextual nature of the knowledge may also have influenced the results in that this study was conducted with experienced audiologists from one implant center, resulting in views which may be tightly bound to the clinical domain in which they have evolved. The dearth of literature on this topic was also limiting in comparing the theory to existing knowledge; however, this also supports the need for research on the topic.

Clinical Significance

The utility of research results is an important consideration. This project is an important first step in developing a framework and tools for the evaluation of cochlear implant outcome in patients with prelingual deafness. Identifying what constitutes benefit in this patient population is essential to finding the right measures to evaluate outcome. It became apparent that when audiologists in the field have the opportunity to reflect on their patients and outcomes, they find the procedure useful in understanding the problem. One clinician stated: “That was great because even talking among ourselves, I think we were about to do some good brainstorming....” A second clinician added: ...“just the fact that we’re talking about it, we’re going to take away information that we learned today that we can apply to our patients.”

Future research should also include patients and others to obtain new insights into why these adults use their implants despite poor speech recognition results. Ultimately, such an understanding will assist both the clinicians who are responsible for providing guidance as well as the persons who hope for better “hearing”.

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Appendix

Questions for Focus Group Interview

Instructions: Please use case examples (unnamed) whenever possible to support your comments as the contextual information will be helpful in understanding the experiences and opinions you are sharing.

How does a cochlear implant make a difference in the life of an adult with prelingual deafness? Please share both negative and positive impacts that you have observed.

How do we define improvement or lack of improvement in these adults? For example, does this mean improved speech recognition scores?

What conditions or factors influence “success” with a cochlear implant in this patient population?

What strategies (or services) will assist these adults in making use of their implant?

What are the important elements of pre- and post-implant evaluations?