

Self-Perceived Biopsychosocial Needs of Late-Deafened Adults with Cochlear Implants: Implications for Aural Rehabilitation

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Abstract

Rationale

This study was conducted to document the self-perceived biopsychosocial needs and listening expectations of late-deafened adults with cochlear implants.

Methods

Twenty-one adults completed a 40-item online survey that included structured and open-ended questions that targeted pre- and post-surgical listening expectations, listening satisfaction listening challenges, quality of life (QoL), self-efficacy, and use of post-surgical aural rehabilitative support services.

Results

Overall, the respondents were pleased with the sound quality of their cochlear implants. However, quantitative and qualitative data obtained from the survey revealed the following: 1) The respondents' ease of listening skills did not significantly improve after surgery and remained lower than expected after implantation, specifically regarding telephone and television; 2) The ability to listen to music through the CI remained a challenge; 3) Self-perception of QoL and self-efficacy (social life and independence) did not significantly improve after implantation. Only 12% of respondents reported receiving face-to-face group aural rehabilitative therapy to address ongoing listening, QoL, and self-efficacy challenges.

Introduction

The correlation between age and hearing loss in adults is extremely high, with hearing loss being one of the most common handicapping conditions in adults over the age of 65 years. The causes and onset of hearing loss vary across the population, but late-acquired deafness creates complex aural rehabilitation (AR) challenges in that it dramatically impairs independence, communication, quality of life (QoL),

self-efficacy, and emotional well-being (Kricos, Erdman, Bratt, & Williams, 2007). One form of medical intervention for late-deafened adults is cochlear implantation – a surgically implanted device that electrically stimulates the peripheral auditory nerve and auditory cortical centers of the brain, thus providing late-deafened adults with the means to physiologically regain some of their ability to hear. During the process of obtaining and being fitted for a cochlear implant (CI), it is critical for both the CI user and hearing health care providers to recognize the connection between the CI and the brain and the ongoing psychological, social, and emotional needs of the adult patients with late deafness.

Current theoretical perspectives from social cognition are evident in the biopsychosocial approach to AR (Erdman, 2009; Gagne & Jennings, 2010). Two constructs that reflect biopsychosocial factors are self-efficacy and QoL. Self-efficacy has been defined by psychologist Albert Bandura (Bandura, 1997) as the confidence one has in their ability to successfully accomplish a task. When applied to the process of cochlear implantation in adults, self-efficacy relates to how CI users perceive their ability to control their own hearing health and communication goals. Quality of Life is defined as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (World Health Organization, 1993). This definition incorporates an individual’s social well-being and social relationships. However, implantation of a biomedical device alone does not address QoL and self-efficacy issues faced by the adult population with late deafness.

Although researchers have investigated self-efficacy and QoL in CI recipients, medical practitioners and audiologists continue to focus exclusively on speech perception tests and annual mapping of the external speech processor as outcome measures for determining implant success. These traditional speech perception measures fail to document how late-deafened adults function psychologically and socially after surgery (Zaidman-Zait, 2010). Moreover, little is known about how pre-surgical implantation expectations and post-surgical performance with the CI contribute to the QoL and self-efficacy of late-deafened adults.

The public health impact of late deafness is extreme. Late-deafened adults report communication deprivation and a restricted sense of self-efficacy coupled with interference with everyday communication in-home, work, and social environments (Kerr & Cowie, 1997; Knutson, Johnson, & Murray, 2006). For late-deafened adults, the loss of hearing can be extremely traumatic, especially for those who suffer sudden hearing loss due to illness, medication, or trauma. Cheng and Niparko (1999) conducted a meta-analysis and found that profound hearing loss in adults resulted in a significant loss in adjusted costs of QoL years. Kerr and Cowie (1997) likened acquired hearing loss to the experience of chronic pain, in that the physical disorder of losing one's hearing is only a minor portion of the limiting effects caused by the physical loss of the ability to hear. Hallam, Ashton, Sherbourne, and Gailey (2006) summarized interview reflections of late-deafened adults who indicated that their loss of hearing had catastrophic, alienating and disorienting effects on their lives and personal relationships. Moreover, late-deafened adults encounter pervasive identity challenges in that their self-worth and their social-role relationships are altered by their inability to hear as they once did (Barlow, Turner, Hammond, & Gailey, 2007; Rutman & Boisseau, 1995). Late deafness also is associated with psychological distress, such as elevated feelings of anger, isolation, and anxiety (Knutson et al., 2006). Similarly, Aguayo and Coady (2001) interviewed 25 late-deafened adults in Canada and reported three emergent themes concerning the psychological and social effects of late deafness: 1) emotional trauma in becoming deaf (all respondents reported intense feelings of grief, mourning, and anxiety; 2) oppression, exclusion, and isolation within their families; and 3) general oppression, exclusion, and social isolation. The late-deafened adults in this study further mentioned that no medical health professionals were ever involved in prescribed treatment for these social and emotional challenges. They also reported dissatisfaction with their rehabilitation services, which were primarily medically oriented. In sum, late-deafened adults reported that their psychosocial needs were often overlooked and

neglected. Decreased self-confidence and loss of expectations and hope for the future constitute additional effects of late deafness on adults' perception of themselves as viable social beings (Kent & La Grow, 2007; Rutman & Boisseau, 1995). Thus, late deafness can result in restricted participation in daily social activities and interpersonal isolation that cause feelings of stress, anxiety and abandonment as well as loss of identity.

Hallberg and Ringdahl (2004) described the benefits and challenges of using a CI as "a rehabilitative device." They reported that the learning process with CIs takes time, from months to years, and that to obtain optimal benefits the CI patient requires long-term training. Given the lengthy learning process, it is vital for CI users and hearing healthcare providers to recognize the connection between the biomedical device and the whole person, rather than exclusively focusing on the connection between the biomedical device and the inner ear. In learning to use this biomedical device, patients must "retrain their brains" to process auditory information differently than they did before they experienced hearing loss. Unfortunately, much of the clinical focus of CI programming to date relates to threshold and loudness data (more peripheral functions), and does not evaluate the patient's higher-level auditory processing skills, such as listening in noise, auditory memory, auditory closure, and sequencing.

Despite the benefits associated with CIs, there are many aftercare (post-implantation) challenges for late-deafened adults. Many patients hold unrealistically high expectations—believing that the implant will immediately result in restoration of their lost hearing and repair their traumatized social identity (Aguayo & Coady, 2001). Some patients also experience frustration with adjustments they must make in their listening abilities as the implant is initially mapped and as they cope with the external components of the device (Hallberg, Ringdahl, Holmes, & Carver, 2005). Additionally most physicians and audiologists do not routinely offer group or individual AR beyond mappings to program the CI's external speech processor, due to inconsistencies in reimbursement policies for AR services by insurance companies (Laplante-Levesque, Hickson, & Worrall, 2010). Although current research reveals that implantation with follow-up with auditory perceptual training helps late-deafened adults recognize and discriminate specific segmental aspects of speech more readily (Chan et al., 2007; Dunn et al., 2010; Fu & Galvin, 2008), late-deafened adults with CIs often continue to experience psychological challenges. After implantation, many late-deafened adults struggle to adjust to their altered auditory perception and attitudes toward an unfamiliar way

of listening. For example, Knutson et al. (2006) followed a large sample of late-deafened adults with CIs over an eighteen-year period and found that these late-deafened adults experienced high levels of loneliness, anxiousness, depression, suspiciousness, and social introversion. Clinically significant levels of depression, suspiciousness, and social isolation were present in 10%-16% of the late-deafened adults, along with high expectations of success with their implants. These findings suggest that improvement in hearing acuity from a CI does not necessarily yield correspondingly better psychological status. Thus, current implementation of individual and group AR with late-deafened adults with CIs does not routinely address social and psychological factors that could adversely impact the communication abilities of late-deafened adults with CIs.

Rutman and Boisseau (1995) found several emergent themes associated with late deafness: threat to identity and perceived competence; loss issues and communication strain; and interpersonal concerns. These researchers reported that the single most devastating consequence of losing hearing later in life is the negative impact on self-identity, which includes beliefs about capacities, needs, and personal skills (self-efficacy). Rutman and Boisseau (1995) reviewed fourteen qualitative studies of late deafness and found that late-deafened adults reported suffering with feelings of anger, embarrassment, and inadequacy as a result of hearing loss. Other researchers have documented similar significant psychosocial challenges late-deafened adults encounter after cochlear implantation. Through open-ended interviews with 17 late-deafened adults with CIs, Hallberg and Ringdahl (2004) identified several emergent themes, including “coming back to life, preventing disappointment, and retraining the brain” (p. 118). The CI patients in their study had a difficult time balancing feelings of hope and despair. Although feeling hopeful about the future, they had low expectations about the benefits they might experience when using their CIs.

Traditional AR service delivery approaches emphasize top-down, clinician-determined treatment models in which the clinician designates and delivers the “best” treatment and provides the patient with short-term CI orientation. This traditional approach is limited with regard to patient psychosocial needs. Although CI manufacturers provide adult CI users with individual listening training programs via online services, the materials do not address the social and emotional aspects of life with the device. Given the psychosocial and auditory processing challenges encountered by late-deafened adults with CIs, holistic approaches to AR are warranted. Building upon Bandura’s humanization of healthcare (Bandura & Locke, 2003), many current holistic

models of AR incorporate the biopsychosocial theories of human development (Engel, 1977) and interaction cited in the works of (Boothroyd, 2007; Erdman, 2009; Gagne & Jennings, 2010). They highlight the interactive, facilitative relationship between the clinician and patient with the patient becoming empowered in the treatment process.

Although researchers have begun to document the need for holistic AR approaches for late-deafened adults with CIs, few studies specifically investigated the pre- and post-surgery expectations of CI patients for listening and communicating via their implants. Moreover, they have not looked at improvement in QoL and the effect of the CI on self-efficacy. Additional research is needed to document these aspects of the cochlear implant process with late-deafened adults. Thus, we posited that documentation of the needs of adult CI users must be obtained in order to provide empirical support for appropriate AR for this growing patient population. The purpose of this study was to report the results of an online survey to document the biopsychosocial needs and expectations of late-deafened adults with CIs.

Methods

At the University of North Carolina at Greensboro (UNCG), we have established a multi-disciplinary AR program called Cochlear Implant Connections (CIC) that provides group and individual AR with late-deafened adults with CIs. For the current study, the CIC faculty research team at UNCG designed the UNCG Needs of Adult CI Users Online Survey. This survey consisted of a total of 40 items in the following categories: patient demographics, hearing loss profile, pre-surgery expectations, post-implantation rehabilitation support services, and pre- and post-surgery QoL. The format of the questions consisted of Likert scales, multiple-choice, and open-ended questions (see Appendix). Biopsychosocial items included questions on QoL, satisfaction, and self-efficacy. Items addressing issues of self-efficacy were modeled after validated questions found in the Self-Efficacy Scale (Fleming et al., 2003), which uses a 5-point scale. The purpose of the open-ended, qualitative biopsychosocial items in the survey was to document the respondents’ perceptions of their QoL, self-efficacy, and expectations before and after CI surgery. The open-ended questions were adapted from questions developed from the Nijmegen Cochlear Implant Questionnaire (Hinderink, Krabbe, & Van Den Broek, 2000) and the Glasgow Benefit Inventory Questionnaire (Robinson, Gatehouse, & Browning, 1996).

The study design, procedures, informed consent document, and survey instrument were submitted to the

UNCG Institutional Review Board (IRB) for review. Approval was obtained prior to launching the survey online via an online survey platform supported by Qualtrics, LLC – a platform that allows researchers to build, distribute and analyze survey responses. Recruitment information regarding the UNCG Needs of Adult CI Online Survey was distributed regionally (East Coast) to participating audiologists at the University of South Florida, Duke University Medical Center, and the Center for Hearing and Communication in New York. These audiologists were recruited by the authors from contacts made at an international AR meeting. The participating audiologists shared recruitment information and online instructions for accessing the survey with their adult CI patients. Information about the survey also was distributed to adult CI patients seen at the UNCG Speech and Hearing Center.

The participants' responses to the survey were anonymous. There were no restrictions on how many questions the respondents were required to answer. Also, for open-ended questions, there were no restrictions on the number of items to which the respondents needed to address or the length of their responses. The survey was made available online for six months, from January to July 2011.

Data Analysis

The results from the survey were downloaded from the Qualtrics platform into an SPSS (version 19, IBM 2010) spreadsheet for quantitative and qualitative analyses. Wilcoxon signed ranks tests were used to test the Likert-type scaled data as to whether perceptions of pre-surgery and post-surgery status were significantly different. This nonparametric test was used, rather than traditional parametric tests, because the ordinal nature of the data.

Responses to open-ended questions about QoFL, expectations, and suggestions for hearing professional were analyzed with inductive qualitative content analysis procedures delineated by Richards (2009). Additionally, topical coding (Miles & Huberman, 1994) was used for qualitative analysis. Knudsen et al. (2012) and Laplante-Levesque et al. (2012) point out that content analysis methods could be successfully applied to document perspectives of individuals with hearing loss concerning their rehabilitation and their psychosocial factors related to their rehabilitation. Thus, content analysis was used to categorize the information gathered from the responses to the open-ended questions from the online survey. These questions targeted patient expectations prior to, and following implantation, as well as perceived QoFL after implantation and suggestions for professionals working with pre-surgery implant candidates. The statistical analyses report median scores of survey responses in order to best describe

interval data obtained from the survey. Therefore, figures were constructed group percentages.

Results

Demographics

A total of 21 late-deafened adults with CIs accessed the online needs assessment survey instrument (5 males, 16 females). However, only 17 respondents completed the entire survey (completion rate of 80%). The respondents ranged in age between 26 to 81 years ($M = 57$ years) and were from 4 eastern states in the USA, with 13 respondents (62%) from North Carolina and the remaining 8 respondents (38%) from New Jersey, New York, and Florida.

Pre-surgery Hearing Profile

The survey results indicated that the length of time the respondents had experienced severe to profound hearing loss ranged from 8 months to 60 years ($M = 29.3$ years, $SD = 20.1$ years). Eighty percent reported experiencing chronic tinnitus with their hearing loss. A majority of the respondents (70%) described the onset of their hearing loss as gradual (over 1 year or more), whereas 30% indicated that their hearing loss occurred suddenly (from 1 day to 1 week). The causes of the respondents' hearing loss included Meniere's disease (15%), head injury (5%), ototoxic medications (5%), and meningitis (10%). One-fifth of the respondents (20%) did not know the cause of their hearing loss, and 45% indicated "other" causes than those indicated above. All of the respondents who reported having hearing loss due to Meniere's Disease or ototoxic medications reported a gradual onset, but all of the respondents who reported having a head injury or meningitis as the cause of the hearing loss reported a sudden onset. Of the respondents who did not know the cause of their hearing losses or had a non-listed cause, 24% reported a sudden onset and 76% reported a gradual onset. Over a quarter (27%) of the respondents also reported having some usable hearing in the non-implanted ear.

Cochlear Implant and Hearing Aid Information

Forty percent of the adult respondents reported that they had been implanted for 1 year or less, whereas 60% had been implanted more than 1 year. The type of CI varied across the respondents. Thirty-percent ($n=6$) wore Cochlear Corporation devices, 45% wore Advanced Bionics Corporation devices ($n=9$), and 25% wore MED-EL devices ($n=5$). The split between unilateral to bilateral fittings was 75% to 25% respectively. The wear time for CI devices ranged from 7 to 18 hours per day ($M = 13.38$ hours). Sixty-seven percent of the respondents reported using a hearing aid in the

non-implanted ear, of which 27% described the hearing aid as providing usable hearing or benefit.

Satisfaction and Expectations

Question #15 on the survey asked the respondents about their pre-surgery expectations for hearing with their CI in seven listening situations: environmental sounds, television, telephone, music, conversations in public meetings, conversations with family and friends, and location of sounds. Question #26 asked a related post-surgery question about listening situations. The respondents were asked to report how well they heard currently with their implants in those same listening situations (see Figure 1). Responses to both questions were on a Likert scale that corresponded to descriptors for listening ease. Before surgery, the respondents had the highest expectations (ease of listening) for environmental sounds (58%) and television (42%). The respondents had low expectations (between 21-32%) for all of the other listening situations (telephone, localization of sounds, conversations in public meetings, conversations with family and friends, and music). The lowest pre-surgical expectation for hearing easily with the CI was for the telephone (21%). Following surgery, performance exceeded expectations in 4 of the 7 listening situation categories (telephone, conversation with family and friends, music, and environmental sounds); however, performance in only 2 of the listening situations exceeded 50% in terms of ease of listening (environmental sounds and conversations with family and friends; see Figure 1). Overall, post-surgical ease of listening performance with the CI continued to be low and did not exceed pre-surgical expectations for 3 categories: location of sounds (23%), conversation in public meetings (23%), and television (29%). The respondents reported the greatest ease of listening with environmental sounds (65%). After surgery, ease of listening to music with the CI was reported at 47%; whereas approximately one-third reported great difficulty in hearing music with their CIs. The most difficult listening situations with the CI were telephone (29%), television (29%) and conversation in public meetings (23%). Of note is that all three measures did not exceed 30% for ease of listening with the implant.

The Wilcoxon signed ranks tests showed that pre-post comparisons failed to reach statistical significance for all listening conditions: environmental sounds ($Z = -1.56$, $p = .118$), location of sounds ($Z = -0.27$, $p = .785$), music ($Z = -0.84$, $p = .401$), telephone ($Z = -0.66$, $p = .512$), television ($Z = -0.321$, $p = .748$), speech conversation with family members and friends ($Z = -1.41$, $p = .159$), and speech conversations in public meetings ($Z = -0.71$, $p = .475$).

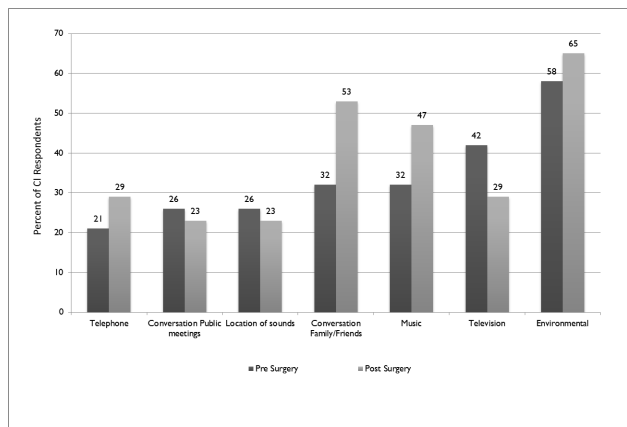


Figure 1. Comparison of respondents' self-reported pre-and post-surgery perceptions of their listening ease in seven listening situations.

The open-ended responses about pre-surgery expectations for improvement in hearing and QoL were elicited with survey question #17, which asked: "Overall, what were your expectations on how the implant would help you?" Analytical coding (Richards, 2009) was used to categorize the open-ended responses and 17 phrases were identified for coding (Table 1). Descriptive coding was applied to yield only one category, all positive expectations. Topical coding (Miles & Huberman, 1994) then revealed the following two subcategories: Hearing expectations (better speech perception, better music perception, improved use of phone), QoL expectations (lead a normal life, to not have to struggle for all communication needs), and regain employment. Hearing expectations related to listening on the phone, listening to music, and less reliance on lipreading. The responses reflected that all adult CI users expected the cochlear implant to help them. However, the level of pre-surgery expectation ranged from simply to hear better and discriminate what people were saying in conversations to high expectations of hoping the implant would allow the individual to lead a normal life, hold a job, and "to rejoin the human race and not be isolated anymore." What became most apparent about the QoL expectations expressed by the respondents was the variability among the range of expectations from their hoping for anything to hoping for everything. An example of a hearing expectation was "I thought that I would be able to have discrimination of what people were saying, better hearing in different environments, being able to listen to music again, and carry on normal conversations. I hoped I would have better hearing for safety factors." One powerful QoL comment from a respondent was that they wanted, "To rejoin the human race and not be isolated any more."

Table 1. Pre-surgery hearing and quality of life expectations. Summary of coding of respondents' pre-surgery hearing and quality of life expectations.

HEARING EXPECTATIONS
<ul style="list-style-type: none"> • I was hoping that it would help me to hear better than I was. • I had moderate expectations. (I) was hoping to hear anything! • I thought that I would be able to have discrimination of what people were saying, better hearing in different environments, being able to listen to music again, and carry on normal conversations. I hoped that I would have better hearing for safety factors. • That it would help improve the accuracy with which I heard and understood conversations and voices. • That I would hear...perhaps not as well as before but I could hear nothing so any improvement would help. • I hoped I would be able to hear with it and it would make me less dependent on lipreading. I hoped I could hear on the phone with it. • I was hoping it would restore at least some hearing in my deaf ear. • To use regular phone, not TTY. • She is doing better than she thought she would with the cochlear implant.
QUALITY OF LIFE EXPECTATIONS
<ul style="list-style-type: none"> • Expected to feel better about life. • I was hoping it would let me lead a normal life to the extent that could hold a job and have conversations with others even in crowded places. • I was looking for any help at all - anything that was better than the non-functionality I was experiencing with almost no hearing left. • To rejoin the human race and not be isolated any more. • Not to have to struggle for all communication needs. • I expected great success. • You thought things would be better immediately. • Very hopeful.

Post-Implantation Listening Challenges

Survey question #30, prompted respondents to list the top three challenges they continued to face in using their CIs. Descriptive coding yielded two categories: auditory processing and interpersonal listening. Topical coding of the Auditory Processing category revealed three sub-categories: auditory discrimination, listening in noise and public environments, and localization and hyperacusis (oversensitivity to sound) (Table 2). For example, one respondent expressed “I can hear

Table 2. Post-implant listening challenges. Summary of coding of respondents' auditory processing and interpersonal listening challenges.

AUDITORY PROCESSING	
Category	CI Patient Responses
Auditory Discrimination (Speech, Word Discrimination)	<ul style="list-style-type: none"> • I can hear speech, but sometimes it is hard to understand the individual words. • Speech discrimination. • I still have great trouble with word discrimination • Distinguishing sounds from one another.
Listening in Noise and Public Environments	<ul style="list-style-type: none"> • Hearing conversation in noisy environments. • Trying to hear people in a crowded restaurant. • Public environments/church. • Trouble hearing in a large auditorium. • Performances like plays and shows. • Listening in poor acoustical environments such as gyms and pools.
Localization and Hyperacusis	<ul style="list-style-type: none"> • Getting used to sound seeming so loud. • With only one implant, and no hearing aid, I have trouble with localization.
INTERPERSONAL LISTENING	
Category	CI Patient Responses
Interpersonal Group Communication	<ul style="list-style-type: none"> • To hear. To communicate with people. • People think I can hear better than I do, so they talk away from me or too fast. • Frustration in participation in conversation. • Trouble in distinguishing what is said when multiple people respond. • Large gatherings, example parties.
Listening to Music	<ul style="list-style-type: none"> • I miss music. • Hearing music. • I still am not able to hear the things I want to hear like music.

speech, but sometimes it is hard to understand the individual words.” Another respondent expressed difficulty in that “sound seeming so loud.” Topical coding of the Interpersonal Listening category revealed two subcategories: interpersonal group communication and listening to music. Within this

category, respondents described the challenges they had in communicating in group situations and in listening to music. For example, in describing challenges of interpersonal communication, one respondent said, “People think I can hear better than I do, so they talk away from me or too fast.” Another respondent described their ongoing concerns that “I still am not able to hear the things I want to hear like music.”

Quality of Life

Figure 2 displays a comparison of the respondents’ self-reported pre- and post-surgical perceptions (survey questions #16 and #27) of how the cochlear implant affects three aspects of their QoL: self-confidence, social life, and independence. Prior to surgery, the respondents had moderately high expectations (62-84%) that the CI would improve their QoL in all three areas. The respondents expected the implant to have the most positive effect on their social lives (84%). However, following implantation, only self-confidence exceeded the respondents’ pre-surgical expectations of how the implant would affect their QoL. Wilcoxon signed ranks tests were conducted to test whether the respondents’ self-confidence, social life, and independence self-perceptions changed significantly from pre- to post-surgery. The analyses showed that pre-post-implantation differences were not significant for self-confidence ($Z = -0.82$, $p = .414$) and independence ($Z = -1.34$, $p = .180$). Interestingly, the respondents’ perceptions of how the CI impacted their social lives were significantly reduced post-surgery compared with pre-surgical expectations ($Z = -2.12$, $p = .034$).

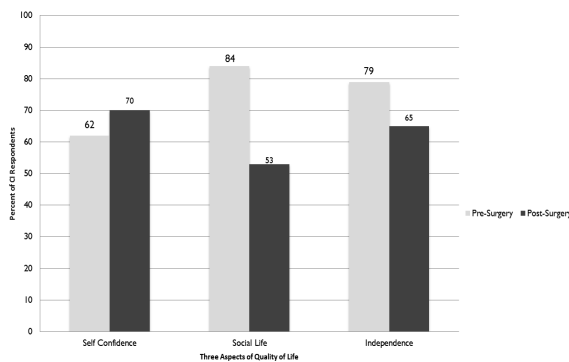


Figure 2. Comparison of the respondents’ self-reported pre- and post-surgery perceptions of how their implant affects three aspects of Quality of Life: Self-confidence, social life and independence.

Analytical coding was used to categorize the data from question #34, which addressed QoL following implantation. Descriptive coding yielded three categories adapted from the subdomains of the Nijmegen Cochlear Implant Questionnaire (Hinderink et al., 2000): Sound Perception (physical functioning), Self-Esteem (psychological functioning), and Social Functioning. Within each of these categories, the respondents’ responses were coded as either positive or negative. Participants with positive responses in sound perception reported the ability to hear music, speech, and outdoor sounds. For example, “I can hear outside noises. I can hear the birds. I can hear noises from another room and hear somewhat better in noise environments even though it is still a struggle.” Negative responses indicated continued difficulty listening to TV, phone, radio, and music. One respondent shared “Music of any kind still hopeless, for which I am very sorry.”

In the category of Self-esteem (psychological functioning), positive responses reflected that late-deafened adult CI users were more confident, independent, less anxious, and more optimistic of the future. One respondent shared, “It has totally changed my life. I am not afraid anymore.” There were no negative responses reported for Self-Esteem. The category of Social Functioning was divided into two sub-categories: Activity and social interaction. Within those two sub-categories, responses were categorized as being positive or negative. In the activity sub-category, respondents commented on an increased willingness to go places and participate in activities that improved their QoL. The only negative type of response was that post-implantation social interactions were not as good as the respondents had expected prior to the surgery. In the sub-category of Social Interaction, there were more positive than negative responses. Among the positive responses, one example was, “I feel connected with life, family, and friends.” An example of a negative social interaction response was, “Some difficulty face to face with strangers, so I still occasionally try to avoid such situations...”

Self-efficacy

Respondents were asked to rate on a five-point Likert scale their perceptions of five aspects of Self-efficacy before and after receiving their implants (Survey questions 18 & 32; see Figure 3). These aspects of Self-efficacy included self-reliance, feelings of insecurity, goal setting, ability to handle problems, and persistence in completing new tasks. Comparisons from pre-surgery to post-surgery were again tested using a Wilcoxon signed ranks tests. The respondents acknowledged positive aspects of self-efficacy had improved

Table 3. Summary of coding of themes concerning quality of life open-ended responses to survey question #34, “Briefly describe the quality of your life after getting your cochlear implant.” Three major themes adapted from the subdomains of the Nijmegen Cochlear Implant Questionnaire (Hinderink et al., 2000).

Sound Perception (Physical Functioning)
<p>Positive Responses:</p> <ul style="list-style-type: none"> • I can hear. Wow! It’s great! • I can listen to music. • [I can listen to] the sounds of music again. • As a late-deafened adult, I was able to pick up speech quickly after my implant. • Obviously better. Without it [CI] I am deaf. • I can hear one on one conversation a lot better. • The CI has improved my hearing and being able to use the phone. • The ability to use the phone and listen to the radio I hadn’t been able to do for years. • I can hear outside noises. I can hear the birds. I can hear noises from another room and hear somewhat better in noisy environments even though it is still a struggle. <p>Negative Responses:</p> <ul style="list-style-type: none"> • I have trouble understanding most people when they talk. • I wish I could use the phone more easily. • Still cannot use TV, phone, radio, hear a speaker. • Disillusioned about the results of the implant. • Music of any kind still hopeless—for which I am very sorry. • I can now understand more of what I hear, but it is still difficult. • It’s taken a very long time to get where I am with my hearing.
Self-Esteem (Psychological Functioning)
<p>Positive Responses:</p> <ul style="list-style-type: none"> • It [CI] seems to make life much easier. • More confident. • Increased my independence. • It has totally changed my life. I am not afraid anymore. • Like night and day--It gave me back my life. • Less anxiety about groups. • Personality changed to a confident person. • Feeling better about the future in general. <p>Negative Responses:</p> <ul style="list-style-type: none"> • No negative responses on self-esteem.

Table 3 cont.

Social Functioning	
Activity	Social Interaction
<p>Positive Responses:</p> <ul style="list-style-type: none"> • More willing to go places. • I can watch TV. • I can listen to the radio. • Being a successful bilateral CI user has improved my enjoyment of many activities and my quality of life. <p>Negative Responses:</p> <ul style="list-style-type: none"> • It has not been as good to communicate in order to do things I did before in everyday life. 	<p>Positive responses:</p> <ul style="list-style-type: none"> • [Hearing conversations better] allows more substantive contributions. • [Before getting the implant] I missed out on just trying to “pass” for years on my job and social life. • I’m more social, gregarious, initiate conversations, more effective on a business level. • I can hold conversations with others without having to ask them to repeat themselves all the time. • I hear conversations better. • More sociable. • I feel connected with life, family, and friends. <p>Negative responses:</p> <ul style="list-style-type: none"> • I have trouble understanding most people when they talk. • I still read lips. • Some difficulty face to face with strangers, so I still occasionally try to avoid such situations.

in all categories after getting the CI, but all five aspects of Self-efficacy failed to achieve statistical significance (self-reliance, $Z = -1.36, p = .174$; feelings of insecurity, $Z = -0.81, p = .417$; goal setting, $Z = -1.16, p = .248$; ability to handle problems, $Z = -1.51, p = .132$; persistence with new task or trying something new, $Z = -1.08, p = .281$). The respondents showed a significant reduction in reported overall anxiety level after implantation ($Z = -2.14, p = .032$).

After Surgery AR Support Services

Figure 4 depicts the percentage of late-deafened adults with CIs who reported receiving specific post-surgical AR support services (survey question #22). The most frequently received support service after surgery was external processor mappings performed by their audiologists (94%). Approximately 71% of the respondents reported receiving printed materials from the CI manufacturer concerning AR. Approximately 71% of the respondents reported receiving printed materials from the CI manufacturer concerning AR. Over half (59%) of the respondents reported using generic online individual resources provided by their CI device manufacturers. Just less than half of respondents reported receiving individual AR (47%), and only 12% of late-deafened adults with CIs reported receiving group AR. Moreover, only 12% of respondents reported attending informational CI workshops or using video materials supplied by the CI device manufacturers. Survey question #25 asked respondents to describe their experience with support services after implantation. Of the 16 responses obtained for this question, 6 respondents — specifically reported receiving either individual or group AR, and that AR was beneficial to them. One respondent specifically mentioned participating in both a face-to-face and online support group for individuals who had received CIs. Other respondents reported not being able to access individual or group AR. One respondent said, “Other than two assessments, the practice was essentially on my own.”

Looking Back

Three final questions on the survey (questions #35, 36, and 37) were open-ended items asking respondents to share information about what they wished they had known prior to receiving their CI, as well as advice for hearing professionals and individuals contemplating getting a CI. Descriptive topical coding was applied across the three questions and yielded six categories: time, expectations and effort, information and personal research, CI technology, support, and need for AR services, all positive expectations. The respondents’ comments to these four questions are shown in Table 4. With respect to time, respondents reported that the CI process takes time and that it is important to be patient as one learns to use it efficiently. In regards to expectations and effort, respondents cautioned new users “not to expect miracles” and for hearing professionals to prepare prospective CI users with appropriate expectations about the CI process. Moreover, the respondents noted that hearing professionals need to address related psychosocial challenges as the CI user learns to listen again. The respondents noted the importance of receiving ample information prior to surgery. With CI technology, the respondents reported wanting more

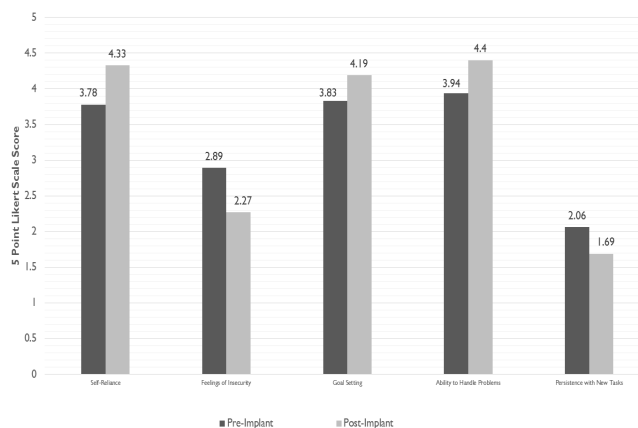


Figure 3. Comparison of respondents’ self-reported pre- and post-surgical perceptions of five aspects of self-efficacy.

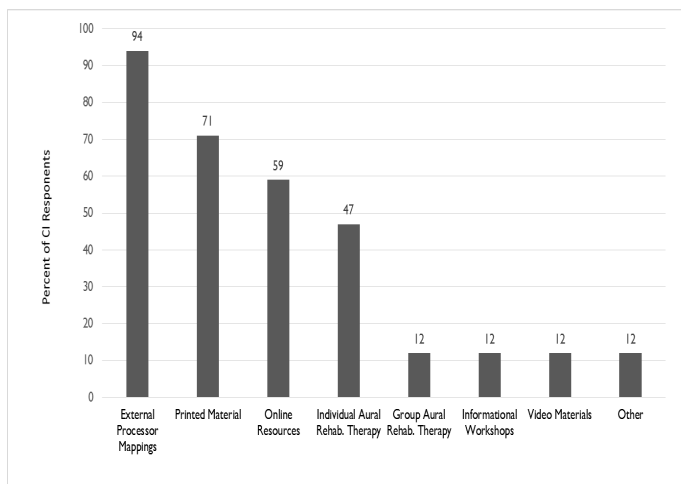


Figure 4. Percentage of respondents who reported receiving eight specific post-surgery AR support services.

information about ALDs and comparisons between the three CI manufacturers. For support, the respondents recommended talking with other CI users prior to surgery and “read all you can online!” Finally, the respondents indicated a need for AR services. One respondent’s advice for hearing professionals was that they need to realize “that it [AR] takes the rehabilitation to help the hearing process to improve.”

Table 4. Summary of reflections and recommendations from adult CI patients on the CI journey. Identified emergent themes included time, expectations and effort, information and personal research, CI technology, need for support, and need for Aural Rehabilitation

Identified Emergent Themes	Question #35: Info Before Getting Implant	Question #36: Advice to Doctors and Audiologists	#37 Advice to Prospective CI Users
Time	<ul style="list-style-type: none"> • I expected it to be better quicker. • I didn't think it would take as long for the hearing to come in where I could hear in a normal range of speech. • How long it would take to hear something. • Maybe I expected instant adaptation, and it was three months or so before I felt my CI and my brain were in sync. 	<ul style="list-style-type: none"> • Tell patients it will be awhile before it is as helpful as they want it to be. 	<ul style="list-style-type: none"> • To be patient. The hearing process will get better. • For them to know it will take a while to relearn hearing most sounds. • It will sound electronic at first but over time you will get use to it and thing will start to sound normal again. • It takes awhile before things will work. • It will sound better in time.
Expectations and Effort	<ul style="list-style-type: none"> • I had great expectations of hearing normal. • Not to expect miracles. • How well the CI could help you in your silent world. • How bad the stress would be being completely deaf. • How difficult functioning and hearing with an implant would be. 	<ul style="list-style-type: none"> • Tell the patient what to expect and how you may get very depressed at this time. • They need to have proper expectations. They need to understand that they will be expected to push themselves—that no one can do it for them. • Make sure the patients understand that learning to hear again won't be an easy process. 	<ul style="list-style-type: none"> • Be aware that it will be a hard process. • Don't think you're going to hear things perfectly right away. • Don't worry. • Keep your expectations low at time of activation. • Don't expect 20/20 hearing the way you can expect 20/20 vision with eyeglasses. Be realistic. • Don't be afraid of the surgery.
Information and Personal Research	<ul style="list-style-type: none"> • I did lots of research and felt I had the proper expectations. • I felt well-informed via my audiologist and my own research. • Would have researched other brands, even though I am satisfied with [one I have]. • I had been researching CIs since the 1970s, so I pretty much knew all about them when I got my first one back in 1997. • I didn't know the kind of questions to ask. 		

Table 4 cont.

	<ul style="list-style-type: none"> I received a lot of good information before I decided to get an implant. 		
Identified Emergent Themes	Question #35: Info Before Getting Implant	Question #36: Advice to Doctors and Audiologists	#37 Advice to Prospective CI Users
CI Technology		<ul style="list-style-type: none"> About the appearance of the implant. I thought it would be more under the skin and not where I could feel it. Disappointed my hair didn't grow back. A bit more technical advice about the CI and what it does. More comparison between the three brands. MUCH more help with ALDs. 	<ul style="list-style-type: none"> Use the resources from the manufacturer of your implant. Check out all three brands.
Support		<ul style="list-style-type: none"> Put them in touch with patient that had similar losses that got implants, with good and bad results. They need a good solid family support system. Talk to implantees, including those with different brands. Put CI candidates in touch with HLAA and its local chapters so that they can meet people who have actually gotten them. Have them read first person accounts, book about personal experiences, so that they can understand the perspective of other people with hearing loss in a way that a hearing person would never be able to convey. 	<ul style="list-style-type: none"> Get one-on-one help if needed. Talk with others who have been through the experience. Talk to implantees. Read accounts of other CI users and books from other CI users. Network with them [CI users] so you will have an idea of what to expect. Read all you can online and people's books/ memoirs of their experiences.
Need for AR	<ul style="list-style-type: none"> Why I would not get any help learning to hear with the implant? More on AR. 	<ul style="list-style-type: none"> That it takes the rehabilitation to help the hearing process to improve. Suggest Aural Rehab. 	

Discussion

The purpose of this study was to document the self-described biopsychosocial and AR expectations and needs of late-deafened adult CI users before and after cochlear implantation.

Hearing Loss and Ease of Listening

In terms of respondent demographics, this study found that most late-deafened adults with CIs had a gradual onset of hearing loss rather than sudden hearing loss, and a majority of these patients experienced some form of chronic tinnitus. The online survey results revealed that a majority of the respondents wore a hearing aid in the non-implanted ear. This finding agreed with the listening technology profiles of the patients in the UNCG CIC clinic. This tendency also is in agreement with the findings of Hua, Johansson, Jonsson, and Magnusson (2012), who reported that adult patients with CIs performed better on the Hearing in Noise Test (HINT) when wearing a hearing aid on the non-implanted ear. The benefits of binaural hearing have long been recognized, and late-deafened adult patients using both CIs and hearing aids may require specific AR instruction and support services to learn how to successfully use these two very different types of biomedical devices together in listening and communication settings.

The results of the online survey revealed that most late-deafened adults with CIs were pleased or very pleased with the sound production of their implants and expressed many positive experiences and statements about the benefits. Prior to implantation, most expected to hear environmental noise and television with their CIs, very few expected to easily hear speech through the telephone, and over half anticipated not being able to hear music. Following implantation, ease of listening performance in 4 of the 7 listening conditions (using the telephone, location of sounds, listening to conversation in public settings, and listening to television) remained below low (less than 30%). The ease of listening on the telephone only reached 29% after surgery. The results of the survey were lower than those cited by Anderson et al. (2006) who reported 71% of CI users being able to receive benefit with landline phones and 54% with cell phones after surgery. These researchers also reported that only 14% of their adult CI users indicated that they could use a landline telephone with no difficulty. Results from the online survey indicated that many late-deafened adults with CIs, although pleased with the sound production of their CIs, continued to experience difficulty in many life listening situations. These findings were congruent with observations from the UNCG CIC clinic in that late-deafened adults with CIs reported frustration in

listening with their CIs and that many continued to use additional assistive listening devices such as the CAP-Tel (captioned telephone).

Music

The survey respondents identified listening to music, both before and after surgery as a listening challenge. Leal et al. (2003) reported that only 38% of their 29 adult patients with CIs found enjoyment in listening to music. The results of the current survey were consistent with this finding in that less than half (47%) of the survey respondents reported an ease of listening to music with their implants.

Several comments from the survey indicated that respondents missed music and that they desired to listen to music again. Certainly, music contributes to many people's QoL, and the CI industry has been responding to this need with advancements in internal electrode and the external speech processor's ability to code music. However, technological advancements alone cannot meet this need for better music perception. Gfeller, (2009) and Plant, Plant, and Reynolds, (2011) reported on the benefits of structured music training in adult CI users. Plant et al. (2011) found positive outcomes when incorporating music listening exercises within individual and a group AR programs for late-deafened adults with CIs. Given the importance of music on QoL, the results of the present study affirm that listening to music and experiences (such as live performances) should be included as integral components of a biopsychosocial AR program.

Auditory Processing

The process of learning to listen again with a cochlear implant involves more than learning to efficiently process the signals presented to the auditory nerve at the level of the cochlea. In reality, all of the central auditory nervous system must adapt and learn how to use the electrical stimuli provided by the CI. This auditory learning affects the neural pathways in the brainstem, thalamus, as well as the auditory cortex, so that the brain is "retrained" in listening to sound. The respondents in the current study were asked to list their continuing listening challenges with the CI. These ongoing challenges reflected facets of higher level auditory processing, such as listening in noise (figure ground), hyperacusis (sound sensitivity issues), localization, auditory discrimination, and organization. Thus, group AR listening activities should incorporate tasks dependent on higher auditory processing skills such as listening in noise, auditory memory, and sequencing.

Quality of Life

The results of this study compared the respondents' pre-surgery expectations to their post-implantation outcomes on three QoL measures. The results revealed that for the respondents in this study, social lives and independence actually declined after cochlear implantation, with the quality of the perceived social life being significantly lower than the pre-surgery expectations. Qualitative responses were both positive and negative with the negative responses reflecting persistent listening challenges post-surgery. Only the respondents' perceptions of their self-confidence exceeded their pre-surgery expectations. These findings support the contention of Heydebrand, Mauze, Tye-Murray, Binzer, and Skinner (2005) that natural and automatic adjustments in social behavior over time cannot be assumed as a consequence of receiving a CI. Thus, we assert that group AR services provide late-deafened adults with CIs the means to discuss shared QoL challenges and to share support as they move along the cochlear implant journey.

The results of the survey were in contrast with several prior investigations that reported an increase in overall QoL after implantation. For example, Zhao, Bai, and Stephens (2008) documented positive changes in QoL (i.e., self-confidence, feelings of isolation, and the ability to communicate) in 24 profoundly deafened adults 4+ years post-implantation. Correlational analyses of their data found that the key determinants for QoL improvement in CI users were improvements in communication abilities, lessened feelings of isolation, increased feelings of self-confidence, and improvement of listening abilities in daily life, such as watching television or listening to music. However, Zhao et al. (2008) did find that after CI surgery, 10 out of the 24 subjects (41%) reported that their hearing abilities, even with the CI, continued to have a negative effect on their social lives. It is interesting to note that this study assessed participants four years after surgery and not during the first year post-implantation. Likewise, Vermeire et al. (2005) examined the hearing ability and QoL in 89 late-deafened adults with CIs across three adult age groups. They found no differences in QoL over time due to age, and that QoL improved after surgery. However, their results indicated that QoL in their CI recipients reached a plateau three months after surgery and that their QoL did not significantly improve over time. In a recent meta-analysis by Gaylor et al. (2013), the results suggested that QoL improved in adult patients using one CI, but the QoL benefits in patients with two CIs was variable. The findings of the current survey and the results of investigations by Heydebrand et al. (2005) and Vermeire et al. (2005) suggested that a plateau or decrease in QoL after

surgery may indicate a lack of meaningful support services and structured AR services provided to late-deafened adult CI patients after implantation.

Self-Efficacy

Despite reporting post-implant improvement in self-reliance, goal setting, ability to handle problems, and ability to persist in completing new tasks, the participants did not demonstrate significant improvement in self-efficacy after receiving their implants. The analyses did, however, show that they reported being less anxious after receiving the implant. It is important to note that responses to self-efficacy questions, such as those posed in the current survey are not typically employed by hearing healthcare professionals during post-implantation follow-up care. Yet these areas of biopsychosocial functioning are critical components of a holistic AR approach that adult AR groups should address as advocated by Erdman (2009).

After Surgery AR Support Services

Findings from the current study revealed that adult CI users received excellent follow-up care in the mapping of the external speech processor. Additionally, many of the respondents received printed and video materials online by audiologists and CI manufacturers. However, less than half of the respondents reported receiving any individual AR, and only 12% reported receiving group AR services. This typical standard of clinical care for adult CI users stands in stark contrast to the standard of care for children with CIs, who routinely receive both individual and group aural habilitation therapy following implantation (Ertmer, 2005; Estabrooks, 1998, 2006). This difference may be due to an assumption that late-deafened adults with CIs do not need AR to adapt to their new biomedical device because they have prior hearing experience. The current investigation demonstrated that late-deafened adults' adaptation to their CIs extends far beyond periodic mappings and their speech discrimination scores. Moreover, results of the current study highlighted that losing hearing in adulthood and then learning to hear again with a CI presents a host of QoL challenges that can best be addressed and supported in a group AR setting with other adult CI users experiencing the same process. Thus, the adaptations of late-deafened adults to cochlear implantation (a biomedical device) can be likened to a patient undergoing a hip replacement (another biomedical device). When adult patients receive hip replacements, they are automatically enrolled in physical therapy. Yet, as the findings of the current study revealed, adult CI users are rarely enrolled in group AR services following surgery. Clinical observations of patients with late deafness who attended the UNCG CIC Clinic support

participation in a group AR – that it helps to “normalize” the CI process for adult CI users and specifically assists them during their first year of adapting to the new biomedical device. In such group AR settings, members share common experiences and acquire self-advocacy strategies from each other (Gagne & Jennings, 2010; Jennings, 2009; Preminger, 2007). We therefore strongly advocate that adult CI users be afforded the same individual and group AR services as children with CIs receive (Tucker & Compton, 2012).

A theme that emerged regarding what the respondents wished they had known prior to receiving the implant was the time involved in learning to adapt to the CI. This theme about time also surfaced in their advice to hearing healthcare professionals and prospective CI users. Given the complexity of adapting to a CI by the human auditory system, more research is needed to determine expected benchmarks of progress in learning to listen with the implant. It can be posited that these benchmarks may extend well beyond the first year after surgery. For example, one of UNCG CIC referring audiologists reported to us “something magic happens at six months after the speech processor is turned on.” We have also observed that our CI patients begin to experience marked improvements in speech perception approximately six months after implantation. Thus, during this six-month time frame after surgery, late-deafened adults with CIs will continue to need instruction, listening practice, and biopsychosocial support in managing their expectations and in learning to use this new biomedical device. Group AR provides a means where more experienced CI users can assist new CI users as they go through this adaptive process. Additionally, we recommend that in assessing hearing function of late-deafened adults with CIs, an assessment of central auditory skills should be conducted. The results of the responses to the current survey emphasized that a holistic biopsychosocial AR program should incorporate listening exercises that target central auditory processing skills such as listening in noise and localization as well as opportunities for CI users to engage in reflections of shared experiences and challenges in the CI process.

One limitation of the current study was that the sample size was relatively small and the respondents were from the Eastern portion of the USA. Future investigations need to include a larger and more diverse sample from across the country. Another limitation was that only CI users with access to a computer completed the survey. Accommodations for a paper survey option would help capture the perceptions CI users with less computer access.

Summary and Conclusions

This study employed an online survey format to document the pre- and post-surgical biopsychosocial needs and expectations as well as listening and AR needs of late-deafened adults with cochlear implants. Major findings of the survey revealed that: 1) ease of listening remains low after implantation, especially in the areas of telephone and television use, listening in public settings, localization of sound, and listening in noise; 2) listening to music remains a challenge for a majority of CI users; and 3) two areas of QoL (social life and independence) are not necessarily improved after implantation. Although respondents did comment that they believed themselves to be well-informed before receiving their implant, several mentioned that they wished they had better understood the amount of time it would take to effectively use their new CIs, how difficult listening with the implant would be, and why they would not receive any assistance on learning to hear with the implant. These respondents believed the process would be quick and relatively easy. The results of the survey found that only 12% of late-deafened adults with CIs responding to the survey had received group AR. In conjunction with the previous findings of AR researchers (e.g., Erdman, 2009; Gagne & Jennings, 2010; Heydebrand et al., 2005; Jennings, 2009; Preminger, 2007), the results of the present study suggested that group AR for late-deafened adults with CIs can provide a safe place for patients to engage with other CI users, who, like themselves, encounter challenges in the process of learning to listen with a biomedical device. In such interactive and patient-centered settings, hearing professionals can provide needed instruction and biopsychosocial support to help patients understand what to expect during the first year after implantation.

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UNCG COCHLEAR IMPLANT SURVEY

CONSENT

1. Yes, I agree to take the survey. No, I do not wish to take the survey.

(If Respondent selected yes, then they would immediately be allowed access to the survey.)

DEMOGRAPHICS

2. What is your gender? Male Female

3. What is your age (in years)?

4. Where do you live?

Eastern NC (between Raleigh and the coast);

Central NC (between Winston Salem and Raleigh, including Raleigh);

Western NC (between Asheville and Winston Salem, including WS);

Other (please enter your current state of residence).

HEARING LOSS AND IMPLANTATION

5. How long have you had your hearing loss? (in years)

6. How long ago were you implanted?

Less than 6 months

6 months to 1 year

1 to 2 years

More than 2 years

7. What is the brand (manufacturer of your implant(s))?

Cochlear Corporation

Advanced Bionics (ABC)

MED-EL

8. What was the cause of your loss of hearing?

Age

Noise Exposure

Meniere's Disease

Head Injury; Meningitis

Medications (like chemotherapy)

Don't Know

None of the Above

9. How did you lose your hearing over time?

Suddenly (with one day to one week)

Gradually over several months; Gradually over a year or more

10. Did you experience tinnitus (ringing in the ears) with your hearing loss before surgery?

Yes

No

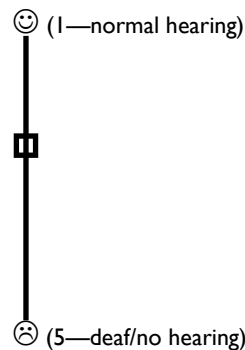
11. How many hours a day do you wear your implant(s)?

Hours

12. How many implants do you have? One Two

13. Do you wear a hearing aid in the ear that was not implanted? Yes No

14. How much hearing do you have in the ear that was not implanted? Please move the slider on the scale to indicate how much hearing you have in the non-implanted ear. Top (smile) means normal hearing and bottom (frown) means deaf/no hearing. (1 to 5 sliding scale)



PRE-SURGERY EXPECTATIONS

15. Before you got your cochlear implant, to what extent did you expect to hear:

Environmental sounds

Not at With With some Easily Very

Television

Not at With With some Easily Very

Telephone

Not at	With	With some	Easily	Very
<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Music

Not at	With	With some	Easily	Very
<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Conversations in public meetings

Not at	With	With some	Easily	Very
<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Conversations with family and friends

Not at	With	With some	Easily	Very
<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Location of sounds

Not at	With	With some	Easily	Very
<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. Before your cochlear implant surgery, how did you expect a cochlear implant would affect your:

Self-confidence

Worse	About the	Better
<hr/>	<hr/>	<hr/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Social life

Worse	About the	Better
<hr/>	<hr/>	<hr/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Independence

Worse	About the	Better
<hr/>	<hr/>	<hr/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. Overall, what were your expectations on how the cochlear implant would help you?

18. Before you got your implant:

Did you see yourself as a self-reliant person?

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Did you set important goals for yourself?

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Did you see yourself as capable of handling problems?

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Did you give up if you are not successful when trying something new?

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. Before you received your implant, rate your anxiety level.

- ___ Very bad
- ___ Bad
- ___ Poor
- ___ Neither good nor bad
- ___ Fair
- ___ Good
- ___ Very Good

POST-SURGERY EXPERIENCE AND SELF PERCEPTIONS

20. During the first year after receiving your implant, how many times did you meet with your audiologist?

- Never
- More than 5 times
- 3 to 4 times
- 1 to 2 times
- Once

21. How often do you meet with your audiologist NOW? (times per year)

22. What kind of support services did your audiologist/physician provide for you once you received your cochlear implant? Check all that apply:

- External processor mappings;
- Individual aural rehabilitation therapy;
- Group aural rehabilitation therapy;
- Informational workshops;
- Printed materials;
- Online resources;
- Online resources;
- Video materials;
- Other.

23. How often have you used the following materials/resources to help you practice listening with your cochlear implant?

Online resources

Not at all Several Monthly Weekly Daily

Video resources

Not at all Several Monthly Weekly Daily

Audiotape resources

Not at all Several Monthly Weekly Daily

Printed resources

Not at all Several Monthly Weekly Daily

Friend or family member reading out loud to you

Not at all Several Monthly Weekly Daily

Individual aural rehabilitation therapy

Not at all Several Monthly Weekly Daily

Group aural rehabilitation therapy

Not at all Several Monthly Weekly Daily

24. Rate how effective the following materials/resources have been in your practice in learning to listen with your cochlear implant.

Online resources

Very ineffective Ineffective Somewhat ineffective Neither effective or ineffective Somewhat effective Effective Very effective

Video resources

Very ineffective Ineffective Somewhat ineffective Neither effective or ineffective Somewhat effective Effective Very effective

Audiotape resources

Very ineffective Ineffective Somewhat ineffective Neither effective or ineffective Somewhat effective Effective Very effective



Printed resources

Very ineffective Ineffective Somewhat ineffective Neither effective or ineffec- Somewhat effective Effective Very effective

Friend or family member reading out loud to you

Very ineffective Ineffective Somewhat ineffective Neither effective or ineffec- Somewhat effective Effective Very effective

Individual aural rehabilitation therapy

Very ineffective Ineffective Somewhat ineffective Neither effective or ineffec- Somewhat effective Effective Very effective

Group aural rehabilitation therapy

Very ineffective Ineffective Somewhat ineffective Neither effective or ineffec- Somewhat effective Effective Very effective

25. Briefly describe your experiences with support services and resources after your cochlear implant surgery.

26. After you got your cochlear implant, to what extent can you hear:

Environmental sounds

Not at With With some Easily Very

Television

Not at With With some Easily Very

Telephone

Not at With With some Easily Very

Music

Not at With With some Easily Very

Conversations in public meetings

Not at With With some Easily Very

Conversations with family and friends

Not at With With some Easily Very

Location of sounds

Not at With With some Easily Very

27. After your cochlear implant surgery, how does your cochlear implant affect: your

Self-confidence

Worse About the Better

Social life

Worse About the Better

Independence

Worse About the Better

28. How pleased are you with sound from your implant?

- ___ Very Displeased;
- ___ Displeased;
- ___ Neutral;
- ___ Pleased;
- ___ Very Pleased.

29. Rate your overall satisfaction with your cochlear implant.

- ___ Dislike Extremely;
- ___ Dislike Very Much;
- ___ Neither Like nor Dislike;
- ___ Like Very Much;
- ___ Like Extremely.

30. List the top three challenges you face if using your cochlear implant. (Qualitative, open-ended written response.)

31. To what extent has the cochlear implant affected your

Self-confidence

Much Worse Somewhat About the Somewhat Better Much

○ ○ ○ ○ ○ ○ ○

Enjoyment in life

Much Worse Somewhat About the Somewhat Better Much

○ ○ ○ ○ ○ ○ ○

Independence

Much Worse Somewhat About the Somewhat Better Much

○ ○ ○ ○ ○ ○ ○

View of the future (hopefulness)

Much Worse Somewhat About the Somewhat Better Much

○ ○ ○ ○ ○ ○ ○

Self-worth (the way you feel about yourself)

Much Worse Somewhat About the Somewhat Better Much

○ ○ ○ ○ ○ ○ ○

32. Since getting your implant:

Do you see yourself as a self-reliant person?

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

○ ○ ○ ○ ○

Do you feel insecure in your ability to do things?

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

○ ○ ○ ○ ○

Do you set important goals for yourself?

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

○ ○ ○ ○ ○

Do you see yourself as capable of handling problems?

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

○ ○ ○ ○ ○

Do you give up if you are not successful when trying something new?

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

○ ○ ○ ○ ○



33. Since getting your implant, rate your anxiety level.

Very Bad

Bad

Poor

Neither Good nor Bad

Fair

Good

Very Good

38. Are there any other experiences or perceptions with the cochlear implant that you would like to share?

34. Briefly describe the quality of your life after getting your cochlear implant.

35. What information do you wish you had known before getting your cochlear implant?

36. What advice would you give audiologists and doctors working with adults who are considering cochlear implantation? (Qualitative, open-ended written response.)

37. What advice would you give a person who is thinking about getting a cochlear implant?