

2015

The assessment of quality of life in cochlear implant users who range from young children to young adults compared to typical hearing peers

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**THE ASSESSMENT OF QUALITY OF LIFE IN COCHLEAR IMPLANT
USERS WHO RANGE FROM YOUNG CHILDREN TO YOUNG ADULTS
COMPARED TO TYPICAL HEARING PEERS**

By

Katlin Mae Mullen

**An Independent Study
submitted in partial fulfillment of the
requirements for the degree of:**

Master of Science in Deaf Education

**Washington University School of Medicine
Program in Audiology and Communication Sciences**

May 15, 2015

**Approved by:
Christine Gustus, M.S.S.H., Independent Study Advisor**

Abstract: This project reviewed how cochlear implant users, ranging from 1 year old to 18 years and older, rated their quality of life. I wanted to see if the literature reviewed proved a positive progression in one's rating of quality of life as they age.

Acknowledgements

First and foremost, I would like to take this opportunity to thank Christine Gustus for her patience, support, time, and encouragement throughout the development of this paper. It has been such a privilege learning from you these past two years and I could not have asked for a better advisor when writing my Independent Study. You were always reassuring and allowed me to come to you with any concerns, ideas, or questions. I cannot thank you enough for the guidance and wisdom you have shared with me.

To my sisters, friends, and classmates, thank you for always being a listening ear, a shoulder to lean on and a constant source of laughter.

I would like to thank my parents for instilling a passion for education and their continuous support and encouragement throughout my education. Thank you for always believing in me and reminding me that everything happens for a reason.

Finally, I would like to thank my fiancé Kyle. Without you our house would be a mess, I would not have any clean clothes, and my sanity would be lost. You have kept me going when the going got tough. Teamwork makes the dream work!

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Introduction

The cochlear implantation team looks at many factors before deciding that a person should receive a cochlear implant (CI). What is the person's hearing loss? Are they a good candidate? Do they understand the auditory training involved after receiving a cochlear implant? These are just some of the questions asked about a candidate before implantation. Then, the candidate has questions about his or her cochlear implant. How will my hearing be different after receiving the cochlear implant? How often should I visit my audiologist after being implanted? Who do I contact if I have issues with my cochlear implant? Then, teachers have questions such as: What is in the child's phonetic inventory? What words does the child have receptively or expressively? Where is the child on the play skills checklist? These are all viable questions. But one question that may not be on the forefront all the time is this: How will one's quality of life be affected by the use of a cochlear implant?

Within the current literature, researchers are beginning to study the quality of life for the cochlear implant user. Quality of life is defined as one's perception of their position in life in the context of the culture and value systems in which they live and in relation to his goals, expectations, standards, and concerns (Patrick et al., 2011). Fifty percent of deaf children expressed concern with a lack of friendship and social acceptance compared to sixteen percent of normal hearing children (Loy, Warner-Czyz, Tong, Tobey, & Roland, 2010). Meadow and Trybus (1979) assert that emotional adjustment problems of deaf children are three to six times greater than that of the hearing population. The emotional and social component of one's life greatly impacts multiple facets of his/her life. Knowing that socially and emotionally, deaf children experience deficits compared to typically hearing peers, one must wonder how that affects the person with hearing loss's quality of life.

The objective of this literature review was to examine how individuals, ranging in age from 1.5 to 50 years old, would rate their quality of life after receiving a cochlear implant in comparison to typically hearing peers. The importance of peer interaction is underscored by the finding that children who are unable to establish positive peer relationships at young ages are more likely to demonstrate poor social adjustment in later childhood and adolescence (Beirman, 2004; Howes & Phillipsen, 1998). Knowing deaf children feel less socially accepted, the literature was reviewed to determine if quality of life was affected in a positive or negative way in correlation with age of participants. The beginning of the multi-channel cochlear implant in the pediatric population brought with it the promise of improved speech perception, speech production, and language development, in many cases to age appropriate levels. Its proven success in these areas now leads to questions beyond speech and language performance to questions of psychosocial adjustment and psychosocial behaviors and adjustment (Loy, et. al., 2010). Knowing that speech and language can be brought to age appropriate levels by a cochlear implant user can make one wonder if that will impact their social acceptance and improve their quality of life. Differences within particular stages of life can be affected inversely as one becomes older. Due to the inverse affects, the literature looks at the quality of life ranging from young children, to adolescents, and finally to young adults, all who were prelingually deaf.

Throughout this paper, quality of life is rated and examined in multiple contexts. The social rating of quality of life is reviewed in multiple studies, as well as examinations of contributions from parents of earlier mentioned cochlear implant users. The conclusion will present conditions which may have affected one's quality of life across the chronological ages.

Hearing Aid Users Quality of Life

Multiple benefits were hypothesized with the invention of the cochlear implant. DeLuzio and Girolametto (2010) discussed that cochlear implantation would bring about enhanced auditory skills, use of an oral communication mode, and acquisition of useful levels of spoken language. These benefits were not always available to a hearing aid user with a profound hearing loss before the existence of cochlear implants. To examine how one's quality of life differed after cochlear implantation, the quality of life before implantation was examined.

Loy et al. (2010), discussed the difficulty deaf children felt among their hearing peers. Capelli (1995) investigated the social development of children who are deaf or hard of hearing through measurement of peer relations (Capelli, 1995). It was hypothesized that in comparison to hearing peers, deaf or hard of hearing children using only hearing aids were at risk in their social, emotional, and behavioral development. To examine this hypothesis, Capelli (1995) gathered information across multiple domains to assess the child's overall psychosocial development. These domains will be discussed more in depth later in the paper.

Capelli (1995) recruited 23 participants who were deaf or hard of hearing, from an early intervention roster from the audiology department at a children's hospital. All of the children were attending regular classes in their school districts and were matched with 23 hearing peers. Distribution by gender was: 17 females and 6 males; distribution by grade was: Grade 1, n=1; Grade 2, n=6, Grade 3, n=5, Grade 4, n=2, Grade 5, n=5, and Grade 6, n=4 (Capelli, 1995). Hearing loss was also scattered throughout the participants. First, the hearing loss was categorized by degree: mild, moderate, severe, and profound. Distribution of bilateral losses

was: mild, n=5; moderate, n=6; severe, n=4; and profound, n=2. Six other children had asymmetric losses. All of the participants wore functioning hearing aids (Capelli, 1995).

As mentioned above, multiple domains were assessed to accumulate an overall psychosocial development rating among the students. To study children's social status and popularity among their peers, the researchers used sociometric assessments, such as peer nomination and sociometric likeability scales. The research also studied social knowledge, such as children's understanding of social interaction and their ability to use that understanding. The measure consisted of 50 items that measured three subscales: performance goals, relationship goals, and negative concern goals (alpha coefficients > 0.79). The affective knowledge of children was also measured by examining social anxiety and self-competence. To measure social anxiety, the Social Anxiety Scale was administered. It consists of 10 questions, which the children respond "always true", "sometimes true", or "never true" (alpha coefficient = .76) (Capelli, 1995). This measurement looked at the children's fear of negative evaluation and social avoidance and distress. The children's self-worth and self-competence was also measured by using The Self-Perception Profile for Children (Harter, 1985). This measurement tool consists of 36 items which had an internal consistency of .71 to .86. The Self-Perception Profile for Children evaluated the children on their feelings toward scholastic competence, social acceptance, athletic competence, physical appearance, behavioral conduct, and global self-worth. Internal consistency ranged from .71-.86. A three month test-retest reliability ranged from .70 to .80, demonstrating a reliable measure and a nine-month test-retest reliability ranged from .69 to .80 (Capelli, 1995).

When given sociometric assessments, which are quantitative methods for measuring social relationships, the likeability ratings and social preferences of deaf and hard of hearing

children were compared against typical hearing peers. Children with a hearing loss were found more likely to be more socially rejected than their peers on likeability assessments, but there were no significant differences between the two groups on the Social Anxiety Scale (Capelli, 1995). The Self-Perception Profile for Children was administered to both groups and both groups were found to rate their perception of self-competence to be comparable. However, children who were deaf or hard of hearing perceived themselves as less socially accepted than did peers with normal hearing. Social status was examined among deaf or hard of hearing children and broken into groups of high (n=14) and low (n=9) social ranking children. There was no difference found between the high and low status of children with hearing loss. Developmental differences among social skills were found among the children who were deaf or hard of hearing. To assess any developmental differences the children were divided into two groups: (1) younger children, grades 1-3 (n=12) and (2) older children, grades R1-6 (n=11). On sociometric assessments, 7 (58%) of the 12 younger children were found to have low social status compared with 2 (18%) of the 11 older children who were deaf or hard of hearing. On the Social Anxiety Scale, older children with hearing loss were found to fear negative evaluation by their peers. On the Game Playing Goals Questionnaire, the older children who were deaf or hard of hearing stressed the importance of relationships more than younger children who were deaf or hard of hearing (Capelli, 1995).

This study, by Capelli (1995), yielded results showing that younger deaf or hard of hearing children view themselves as being less accepted by others compared to their typical hearing peers, while older children who were deaf or hard of hearing expressed more concern about their peer evaluations. Capelli hypothesized that perhaps the younger children had yet to develop social skills supporting the formation of peer relations. The older children's anxiety

about peer evaluations may have originated from their own experiences when younger, consequently resulting in greater concern and awareness of peer judgment (Capelli, 1995).

Measurement Instruments

When assessing the Quality of Life throughout multiple stages of life, it is imperative to obtain the most accurate results one can. There are multiple ways to gather information to measure one's Quality of Life. There are questionnaires, parent reports, interviews with the cochlear implant user, and surveys which can represent a feeling of one's quality of life. Within this section, I will examine the different measurement tools which are commonly used when examining quality of life.

Assessing children at the preschool age can be difficult due to the lack of language they might have at the time of the assessment. DeLuzio and Girolametto (2011) examined the peer interaction of preschool children with and without hearing loss, which looked closely at the social development of the children. To assess the social development, the Interpersonal scale of the Vineland Social- Emotional Early Childhood Scales (Cicchette & Sparrow, 1998) was used. This evaluation tool was completed by the child's preschool educator with the assistance of the primary investigator.

Bat-Chava and Deignan (2001) investigated the peer relationships of young children with cochlear implants. To investigate these relationships, interviews with the parents of the participants were conducted. The participants were interviewed face-to-face and they were all asked the same set of questions. There were two types of measures: questions from Achenbach's Child Behavior Checklist (CBCL) (Achenbach, 1992) and variables coded from parents' narratives. The questions from the CBCL asked parents to list certain activities children

participated in and then asked the parents to give specific details about it, such as how does the child perform and how often do they participate. The variables coded from narratives contained open ended questions which the parents reported on and the information was translated into qualitative data analysis. Ordinal scales were developed for the dependent variable.

The Kinder Lebensqualitätsfragebogen (KINDL-R for Measuring Health-Related Quality of Life) (Ravens-Sieberer and Bullinger, 2001) in Children and Adolescents, revised version, is an established generic health-related quality of life questionnaire suitable for children between the ages of 4 and 17 years old (Loy et. all, 249). There are 3 other versions of the questionnaire, the Kiddy KINDL (4-7 year olds), the Kid KINDL-R (7 to 13 year olds) and the Kiddo KINDL-R (14-17 year olds). With these questionnaires, there is a corresponding parental questionnaire. Each different measure included 24 questions which were equally distributed between six domains: Physical well-being, Emotional well-being, Self-esteem, Family, Friends, and School. The questionnaires are based on a five point Likert scale: never, seldom, sometimes, often, all the time. When using this assessment, each individual completes to questionnaire separately from family members.

A study conducted by Kushalnagar et al. (2011), used self-administered instruments. The Youth Quality of Life-Deaf and Hard of Hearing (YQoL-DHH) is used with youth ages 11-19 years old. It contains 41 items, takes 15 minutes to complete the paper version (30 minutes for the DVD version) and is readable at the fourth grade level. It assesses QOL in three areas: participation, self-acceptance and advocacy, and perceived stigma.

(See Figure 1)

Why Examine Quality of Life

The primary factor handicapping oral communication between two people is hearing loss. The presence of a hearing loss causes delays in pragmatic development, such as social skills and emotional regulation, which relate to social life throughout the lifespan. These difficulties caused by hearing loss may affect personality development negatively, delaying the adolescent in developing appropriate social behaviors (Capelli, 1995). As Capelli reported, children who were deaf or hard of hearing and who used hearing aids, suffered from feeling more rejected by their peers as well as concern about peer acceptance and evaluation. To provide opportunity for better communication for children and adults who do not benefit from hearing aid use, cochlear implantation is a possible route for candidates who qualify. There are considerations before an individual with hearing loss can be considered a candidate for a cochlear implant. These include: medical and audiological criteria, realistic expectations of the candidate, social structure, way of communication and educational opportunities which need to be considered before one can receive a cochlear implant.

Deaf children who are raised by deaf parents may acquire social skills naturally in an environment where communication is dependent on visual information and not on oral cues. However, deaf children raised by hearing families may not acquire an understanding of the subtleties of social language because of factors such as the absence of overhearing. They may feel uncomfortable in social situations and/or may not be accepted by hearing peers because they cannot pick up on important social-verbal behaviors. Deficiencies in vocabulary and other aspects of the English language affect the child's ability to express his or her needs, thoughts, and feelings in the hearing world, all resulting in a lack of social development (Moog, Geers, Gustus, Brenner, 2011). The person with the cochlear implant has been found to overcome the

language impairment, when the language is explicitly taught to them. Cochlear implantation has been proven to contribute to the following (Deluzio and Girolametto, 2010):

- 1) Significant increase in speech clarity and comprehension of speech.
- 2) Significant growth in receptive and expressive language skills.
- 3) Better performance for children who received a cochlear implant before the age of 5 years.
- 4) Successful outcomes for children with hearing loss who experience hearing loss before or during the time of gaining speech and language skills.

After receiving a cochlear implant and learning spoken language, an implant recipient is more likely to experience a positive psychosocial adjustment due to the greater access to spoken language. One of the goals of cochlear implantation is “normalization” of daily function (Warner-Czyz, Loy, Roland, Tong, & Tobey, 2009). To understand the “normalization” of daily function, studies will be discussed that examine people’s ratings of quality of life compared to those with normal hearing.

Young Children (Ages 1-11 years old)

Young childhood is a critical age when language is being developed and social relationships are being formed. Unlike adolescents, who have had the opportunity to be around peers for a number of years, young children are usually not immersed in social relationships until they enter their local preschool. During those preschool years, children are educated in all developmental domains: cognitive, fine motor, gross motor, social-emotional, and language. Young children’s successful engagement in peer interaction is reported to provide significant contributions to children’s social, emotional, communicative and academic development (Ladd,

2005). The development of early peer relationships influences social acceptance, self-esteem, and the ability to form social relationships later in life (Antia, 1994; Ladd, 2005).

Knowing the importance of establishing positive peer relationships early in life, it is imperative to examine the peer interactions of preschool children with and without hearing loss. Ultimately, peer relationships have been reported to positively influence children's outcomes and provide a buffer against future developmental problems (DeLuzio & Girolametto, 2011). The ability to create meaningful exchanges, which includes the ability to initiate peer interactions and respond to peers, typically develops during the preschool years. Children usually begin to form these relationships through preschool, daycare, or informal play groups and these early relationships help develop positive social relationships as the children age. For typically developing children, the ability to establish peer relationships is achieved through play and the children's cognitive ability and language skills (DeLuzio & Girolametto, 2011). As language develops, the type of play a child initiates also develops. Solitary play eventually transforms into parallel play, which eventually transforms into cooperative play, involving two children interacting through the use of language to facilitate play (Burriss & Tsao, 2002). Besides one's language developing through the experience of play, other developmental areas pertaining to one's quality of life develop: social-emotional learning skills (Bierman, 2004), emotional control and regulation and the ability to infer what people are feeling from their nonverbal behavior (Hay, Payne & Chadwick, 2004). All of the above mentioned developing areas strongly influence one's quality of life. Children with hearing loss do not initiate play schema in the same way typically hearing peers do. They typically do not insert themselves into an ongoing play activity, whereas hearing peers will join in on the play or make a comment on the play (Brown,

Remine, Prescott & Rickards, 2000; Roberts, Brown & Rickards, 1996). Instead, deaf or hard of hearing children wait and hover or interrupt the ongoing play by taking a toy away.

To investigate if the peer interactions between children with hearing loss and children with typical developing hearing differed, DeLuzio and Girolametto (2011), assessed 12 children between the ages of 37 to 62 months, who had a congenital hearing loss and whose hearing loss was identified by 10 months of age. These children were videotaped in play groups playing with controlled materials, such as a toy farm. Interactions were considered finished when a child changed the topic, a child involved in the exchange moved away, or the children became involved in an activity unrelated to the previous interaction (DeLuzio & Girolametto, 2005). One research question the authors asked was whether the children with hearing loss differed from the children with typical hearing in the frequency, type, and modality of initiation strategies used. The results indicated that there was no significant difference in the frequency of initiations between the two groups of children and in the proportions of initiation strategies used by the two groups. It also was shown that the verbal initiation strategy was the most used strategy by both groups of children (DeLuzio & Girolametto, 2005). Another research question investigated was whether the hearing control group initiated interactions with the children with hearing loss as often as they initiated with the hearing matched children. By conducting t-Tests, it was proven that the mean frequency of initiations addressed to children with normal hearing (mean=20.3) was more than twice of the initiations addressed to children with hearing loss (mean=9.6) (DeLuzio & Girolametto, 2005). This difference proved to be statistically significant, with a large effect size, $t(11) = -3.20$, $p = .008$, $d = 0.92$. The findings from this research question suggests the need for further investigation, as to why the children with hearing loss did not receive as many initiations as typically hearing peers.

. The next study delves into preschooler's ratings of their quality of life, including how they rate friends and school. To compare and contrast the rating of a child's quality of life, Warner-Czyz et al. (2009), conducted a case-controlled study, which assessed both the parental and the child ratings of quality of life. Many studies pertaining to quality of life take into consideration both the parental and child's rating of quality of life, which some hypothesize may cause a problem due to the parents having difficulty judging less observable aspects, like self-esteem and socio-emotional functioning. For the purpose of this study, Warner-Czyz et al. (2009), hypothesized that a child's quality of life stems from his or her developmental level and anticipate no difference between children with cochlear implants and children with normal hearing of the same chronologic age. It was also hypothesized that quality of life was negatively associated with age of identification of hearing loss and age at implantation and is positively correlated with duration of cochlear implant use.

The participants in the study were 50 families who had preschoolers who used a cochlear implant and 45 of those families also contributed the parental assessments. The children had to have a severe-profound hearing loss and use at least one cochlear implant. The only exclusion criteria used was if the participant was unable to complete the questionnaire as presented in interview format (Warner-Czyz, et al, 2009). Unlike other studies which examine quality of life, this study did not regard age of implantation, age of identification, or duration of cochlear implant experience as exclusion criteria. In other words, children who had only had their device for 6 months could participate in the study, if they were able to answer the questions in interview format. The age of the participants ranged from 4-7 years of age during the time of the interview and 62% of participants used an oral communication mode (Warner-Czyz, et al 2009). The control group consisted of 25 hearing participants between the ages of 4 and 7 years old.

To assess the participants, the Kiddy-KINDLR, used for children between the ages of 4-7, was administered face-to-face. As mentioned in the measurement tools section, the KINDLR questionnaires rate participants over 6 domains: physical well-being, emotional well-being, family, friends, social well-being, and school. Twelve questions were asked and the children's responses were ranked on a 3 point Likert scale: never, sometimes, and very often. If the child responded "no" to any question, the administrator would clarify with closed set questions looking more in depth into the original question. The parental questionnaire contained 24 items assessing the six aforementioned dimensions plus 22 additional items to supplement the limited information provided by the child-self report questionnaire (Warner-Czyz et al, 2009). Unlike the child questionnaire, the parental assessment used a 5 point Likert scale: never, seldom, sometimes, often, and all of the time. Parents completed the questionnaire away from their child and the administrator to ensure the answers reflected the parent's assessment of the child's well-being (Warner-Czyz et al, 2009).

The results of the child's rating of quality of life was compared to the age-matched hearing peers by the use of two sample t-tests. Quality of life ratings for the children with a cochlear implant were a mean average of 82.8 and a standard deviation of 9.7, while the children with normal hearing had a mean average of 80.8 and a standard deviation of 10.3 (Warner-Czyz et al, 2009). From these results, the authors concluded that there was not a significant difference in the ratings of quality of life between preschool students with cochlear implants and those with normal hearing. By only assessing children within a particular age range, the authors were able to examine children who were developmentally at similar cognitive, emotional, and social levels. The results of the parental questionnaire yielded similar findings to the preschool children's quality of life ratings. The parental questionnaire generated a mean average of 78.1 and a

standard deviation of 9.6 (Warner-Czyz et al, 2009). Parents rated their child's quality of life positively for the following domains: physical well-being, emotional well-being, and school. The remaining 3 domains, friends, family, and self-esteem, were rated less positively by parents (Warner-Czyz et al, 2009). Overall, among the three populations surveyed, preschool students using a cochlear implant, the parents of preschoolers with a cochlear implant, and typical hearing peers, parents of the children with cochlear implants assigned their children with the lowest rating of quality of life.

Adolescents (Ages 12-17 years old)

Adolescence is often viewed as a difficult period of time during human development, where a person goes through a significant change in multiple aspects of their life. It is defined as the period during which physically, mentally, socially and emotionally the biggest changes occur (Sahli & Belgin, 2006). It is thought that socially and emotionally the hardest problems and conflicts take place during adolescence (Capelli, 1995). The individual person becomes interested in what kind of person he/she is, what he/she looks like and what he/she feels about himself/herself. He/she uses self-perceptions to seek answers to these questions. Self- image, which develops with environmental factors, as well as individual factors, plays an important role in determining the way the adolescent approaches himself/herself. This approach, in other words whether he/she finds himself important or unimportant, determines his/her self-esteem (Loy et al, 2009). Self-esteem forms the individual's thoughts, emotions, and behaviors in his/her future life. In other words, an individual's self-esteem forms the adolescent's personality's core. To bring about a high level of self-esteem, one must evaluate themselves positively.

Aforementioned, before the advent of the cochlear implant, older children who were deaf or hard of hearing were more concerned about how their peers viewed them, leading to a lower self-

esteem compared to normal hearing children. Unfortunately, adolescents take into consideration what he/she looks like, and deaf or hard of hearing adolescents may think that cochlear implantation would affect their appearance in a negative way, contributing to esthetic worries. If those worries become so critical to the adolescent, they may refuse to use the equipment, which could lead to continued communication difficulties for the adolescent. For the purpose of this paper, I am focusing on adolescents who wear their devices during waking hours.

As mentioned before, the transition into adolescence is viewed as an ever-changing period of time where an individual is faced with a multitude of outside factors influencing how one feels about himself/herself. Deaf adolescents are not only experiencing these psychosocial changes, but they are also confronted with the challenges of being deaf in a sound-dominated environment, which is not always aware of their auditory and visual needs (Leigh, Maxwell-McCaw, Bat-Chava & Christiansen, 2009). To investigate the psychosocial adjustment of cochlear implant users, Moog et al., conducted a study examining a group of adolescents who were implanted at a young age and then were educated in the mainstream setting for the majority of their academic years. When assessing the social skills and self-esteem of adolescents with a sensorineural hearing loss, a key component needs to be taken into account: the identity the individual aligns oneself with. She/he could assign themselves as members of the hearing community, the Deaf community or a mix of the two communities. Deaf children who are raised by deaf parents, may acquire appropriate social skills in an environment where communication is based upon visual cues instead of oral cues (Schirmer, 2001). Deaf children who are raised by hearing parents may not understand the subtleties of social language. They run the chance of feeling uncomfortable in social situations and not being accepted by hearing peers due to an absence of interpreting important social-verbal behaviors (Moog et al, 2011). Due to a deficit in

vocabulary and other aspects of the English language, a person with a hearing loss may have difficulty expressing his or her needs, thoughts and feelings in the hearing world and have difficulty understanding feelings expressed through spoken language.

In the Moog et al. study, participants were recruited from a previous study conducted from 1996-2000 when they were in early elementary grades. A total of 112 high school students who participated in the previous study returned for testing between 2004 and 2008. An additional 21 teenagers filled out and returned the questionnaire but did not physically return to participate in the study (Moog et al. 2011). There were 4 subgroups of participants who were assessed to provide information for this study:

1) On-site participants: 112 high school aged cochlear implant users. The participants ranged in age from 15.0-18.5 years old. 26% of this group used sign and speech to communicate and 73% said they seldom or never used sign.

2) On-site participants: 86 participants of the 112 cochlear implant users completed an additional two questionnaires that were added in 2005. The proportion of these participants also reported using speech and sign for communicating (26%).

3) Off-site participants: 72 participants from the original sample did not partake in the on-site battery testing. Twenty three of these participants moved without providing a forwarding address. Questionnaires were mailed to the remaining 49 nonparticipants for whom addresses were available, with a \$50 incentive for completing and returning the questionnaire, of which, 21 responded. Six of these participants reported using speech and sign to communicate, and 1 student responded using sign only. Sign was used more frequently in the off-site group than the on-site group of participants.

4) Normal-hearing controls: Forty six high school students recruited from the St. Louis area were offered \$50 to complete a 3 hour session which included completing a variety of tests and questionnaires. The Peabody Picture Vocabulary Test (L.M. Dunn & Dunn, 1981) was administered to the hearing group to assess intelligence and the standard score was 109.6. The high school students who used a cochlear implant were administered the Wechsler Intelligence Scale for Children-III (Wechsler, 1991), and received a standard score of 103.1, illustrating that the normal hearing control group might have been slightly more cognitively/developmentally advanced than participants with a hearing loss (Moog et al. 2011).

To assess psychosocial functioning, the participants and their parents completed questionnaires which examined the following: Academics, Social skills (cooperation, assertion, and self-control), Self-esteem, Group identification, Student experiences, and Reading comprehension. The student form also measured empathy for others. The parent form also measured responsibility and behaviors that may interfere with the acquisition of social skills (externalizing problems and internalizing problems) (Moog et al. 2011).

In terms of the social skills, standard scores estimated that adolescents using cochlear implants achieved similar results in social skills relating to gender and age matched students of the control group (mean=100; SD= 15). The cochlear implant students scored within 1 standard deviation of the control group on both the Parent Rating Scale (mean = 105.3; SD=15.3) and the Student Rating Scale (mean=98.5; SD=12.8). The Problem Behavior mean score was also within the average range for children with hearing loss, falling at 98.5 with a SD of 12.8 (Moog et al. 2011). The parental ratings also were consistent with ratings obtained from these same parents, when they completed the Meadow-Kendall Social-Emotional Adjustment Inventory (Meadow-Orlans, 1980), 8 years prior. When assessing self-esteem, the participants scored themselves on

a rating scale ranging from 1-4, 4 being the highest. Twenty-five percent of the participants with a cochlear implant assigned themselves a 4 and 62% assigned themselves somewhere between a 3-3.5 indicating the student has fairly good self-esteem. The remaining 13% had ratings reflecting 2 or 2.5, reflecting a lower self-esteem. Of the off-site participants, 100% rated themselves as less than 3 (Moog et al. 2011). The final area assessed in the Moog et al. study is the group identification of adolescents. The group of high school adolescents using a cochlear implant was evenly divided between hearing, deaf, and mixed identification. 30% assigned themselves with the Deaf community, 33% with the hearing community and 37% assigned themselves within the mixed community (Moog et al. 2011). Student experiences, extracurricular activities, sports, and jobs were also assessed. The majority of high school cochlear implant users fell within the average range for each category compared to the hearing control group.

It is important to follow up with participants as they become older and achieve longer use with their devices to examine their feelings on their quality of life. As Moog et al. (2011) concluded, community identity does not correspond to ratings of quality of life in adolescent cochlear implant users. The majority of cochlear implant users in this study rated themselves as having similar quality of life as the hearing control group, which supports the notion that the cochlear implant can serve as a vehicle for positive psychosocial adjustment due to greater access of spoken language (Fagan, Pisoni, Horn, & Dillon, 2007; Geers, 2006; Spencer & Marshark, 2003; Wheeler, Archbold, Gregory, & Skipp, 2007).

Another study which examined the psychosocial adjustment of adolescent cochlear implant users was conducted by Loy et al. In a study entitled, "The Children Speak: An Examination of the Quality of Life of Pediatric Cochlear Implant Users," a health related quality

of life questionnaire was distributed to 84 profoundly deaf individuals, as well as their caregivers and results were compared with hearing individuals and their caregivers. Caregivers were surveyed, as well as the adolescent participants, because they have valuable insight into the psychosocial dimensions of their child's life. The KINDL-R Questionnaire for Measuring Health-Related Quality of Life in Children and Adolescents was distributed to two age groups: an 8-11 year old group and a 12-16 year old group. The purpose of this study was to examine if deaf children with cochlear implants demonstrated, on the basis of their own responses, psychosocial issues similar to those of typical-hearing peers, and if their parents are reliable reporters regarding their child's health-related QOL. In the 12-16 year old age group, the authors hypothesized that cochlear implanted children would demonstrate overall QOL scores similar to typical hearing peers. The authors also hypothesized that the cochlear implant users would have qualitatively different responses in psychosocial domains in which deaf children traditionally have difficulty, such as social situations and feelings of success in school. (Loy et al. 2010). It was also hypothesized that parents qualitatively demonstrate observational skills sufficient to perceive clearly and sensitively their child's emotional and social state of well-being in domains that allow direct observation, but provide qualitatively different responses in domains for which there is little opportunity for observation, such as in the school setting (Loy et al, 2010).

The Kiddo KINDL-R for the 12-16 years old subgroup, and a corresponding parental questionnaire were used as the assessment tools. There were six multidimensional subscales assessed: physical well-being, psychological well-being, self-esteem, family, friends, and functioning in school. The participants then rated their answers based on the KINDL-R Likert

scale: never, seldom, sometimes, often, and all the time. The subscale scores were combined for a total overall score, with 0 representing the minimal QOL and 100 representing maximum QOL.

Of the participants, the mean age at the time of the study was 13.7 years old and the mean age of implantation was 5.83 years old, yielding the mean length of implantation being 7.87 years (Loy et al, 2010). This adolescent group of students with a cochlear implant rated their QOL similarly to typical-hearing peers in all subscale domains and on the total QOL score. However, implanted adolescents rate their QOL less positively than their normal hearing peers on the friends subscale. Cochlear implanted adolescents received a mean score of 68.35 out of 100 and normal hearing peers received a mean score of 78.25. Parents rated their children as having a higher QOL score in regards to success at school than the hearing impaired adolescents rated themselves.

Although hearing impaired adolescents rated their QOL lower than hearing peers in the friends subscale, overall both hearing impaired and normal hearing adolescents rated their QOL similarly, indicating that the use of a cochlear implant does not appear to negatively impact QOL beyond adjustment to life as a whole (Loy et al, 2010). Spearman rank correlations were performed to analyze the specific subscales and the hearing impaired adolescent's scores in comparison to age of cochlear implant activation and the duration of cochlear implant use. In regard to the QOL scores and the age of cochlear implant use, a negative correlation was found, suggesting that adolescents with a younger age at cochlear implant activation rated their QOL more positively than adolescents with an older age at cochlear implant activation. A strong positive correlation was found between the adolescent's QOL score and the duration of implant use, indicating that such adolescents with a longer duration of cochlear implant experience assigned more positive ratings to their overall QOL score compared with adolescents with a

shorter duration of use (Loy et al, 2010). What can be concluded from these studies is that the use of a cochlear implant increases how adolescents with a hearing impairment rate their QOL and such a rating is comparable to what hearing peers would assign themselves.

Adults (ages 18 years and older)

During the transition between adolescent to young adulthood, human beings experience significant changes. People are forced to think about their long term goals and what they wish to achieve in life. After secondary school, what are their options? Attending college brings about certain changes and entering the job force, requires changes as well. The benefits individuals may have once received from a cochlear implant may no longer be consistent in their adult life. Many studies have not been conducted to examine the long term follow up of cochlear implant users and their quality of life as they get older. Due to a lack of participant involvement and poor study design, it became difficult for researchers to publish longitudinal studies tracking the same individuals over time. In a quality of life study conducted by Calmels et al. (2004), there were not any significant results by the 5 year follow up date. The number of participants declined from 60 participants at the 1 year mark to 29 participants at the 5 year mark. That is just one of the reasons why longitudinal studies with adults have been difficult to conduct. In order to analyze how an individual's quality of life may have changed or not changed over time, one needs to be able to keep in contact with that same individual.

Beadle et al, were able to conduct a long term study focusing on the functional outcomes and academic-occupational status of cochlear implant users, 10 to 14 years post implantation. This study also focused on device use and function, speech perception and speech intelligibility outcomes. For the purpose of this paper, I will be focusing on the functional outcomes and

academic-occupational outcomes of the individuals. Aforementioned, quality of life is defined as the perception of one's position in life in the context of the culture and value systems in which he/she live and in relation to his goals, expectations, standards, and concerns (Patrick et al, 2011). While this study does not specifically assess the ratings of the individual's quality of life, it does examine the way in which cochlear implant users live in relation to their goals, expectations, standards, and concerns, all of which can be compared with the postsecondary goals of the participants.

The 30 participants of the study were all profoundly deaf individuals, implanted consecutively between January 1989 and December 1992 and all received a Nucleus 22 multichannel cochlear implant. From implantation to follow-up, each individual had between 10 to 14 years of device use. Of the 30 participants, 19 subjects were still attending secondary school at the time of the follow-up while 11 had successfully completed secondary school and had moved forward either into an elective school, such as college, or into the work force. Due the age of the participants and their current placements, I will be focusing on the 11 participants who had transitioned out of secondary school. Seven of the participants had elected to transition into a college or a university studying a range of academic and vocational areas (Beadle et al, 2005). All 7 of these individuals access the curriculum through either oral/aural communication or total communication, some with the assistance of interpreters or note takers. The four participants who were currently working had occupations in the following areas: a nursery nurse, an engineer, a pharmacist in training and an administrator for the family business. All of these participants communicated orally.

It is important to assess the functional and academic-occupational outcomes of deaf individuals because as implanted children progress into adulthood, it is hoped that they will

contribute to society on equal terms as their hearing peers (Beadle et al, 2005). With the positive contributions that the cochlear implant is expected to bring about to the users, it is thought that cochlear implant users will be able to contribute productively to society. More longitudinal studies on other implanted adults would need to be conducted to confirm this hypothesis, but in regards to this longitudinal study, the individuals were able to contribute to society on the same terms as hearing peers.

When examining long term cochlear implant users, there are outside factors contributing towards one quality of life besides the domains typically assessed, such as: social emotional, physical well-being, school, etc. There have been concerns expressed that cochlear implant function might degrade over time, that devices and electrodes might migrate and extrude in the growing child, or that there might even be a deleterious effect of long-term stimulation of the cochlear nerve (Waltzman, Cohen, Green, & Roland, 2002). This study examined the long term performance of the device, re-implantation (if any), and educational outcomes of its users.

From the years of 1987 until 1995, 133 profoundly hearing impaired children received cochlear implants at New York University Medical Center. Of those 133 children, 81 prelingually deaf children from New York University Medical Center were followed for 5 to 13 year post-implantation and formed the study population (Waltzman et al, 2002). Each participant was confirmed of having a bilateral sensorineural hearing loss at the time of the study. Of those participants, 76 children were implanted with a Nucleus 22 device and 5 children were implanted with a Clarion cochlear implant. Eight of those participants required re-implantation due to device malfunction at some point during those 5 to 13 years of follow-up. A specific year was not included. All of those 8 children who were required to be re-implanted continued to use their same device or a newer device after the re-implantation. Communication

modes of the participants were also accounted for. Seventy children (86%) who were subjects for the study used oral communication, 10 (12%) used total communication and 1 child, who was blind, used a combination of hand spelling and oral communication. The 4 remaining participants who did not use oral communication, received their implants at ages 10, 12 and 13. The one remaining child had a diagnosis of CHARGE syndrome and exhibited multiple handicaps due to the syndrome (Waltzman et al, 2002).

To assess the participants, age appropriate word and sentence recognition tests were used to measure speech perception. These tests were administered pre-implantation, post-implantation, and then at the follow-up meeting 5 to 13 years later. Results revealed significant gains in speech perception, use of oral language, and ability to function in a mainstream environment. There was no decrease in performance over time and no significant incidence of device or electrode migration or extrusion, and device failure did not cause deterioration in long-term outcomes (Waltzman et al, 2002).

Upon beginning my research in the area of quality of life in pre-lingually deafened adults, I was unable to find multiple studies which contained follow-up with cochlear implant users as they aged. By examining both the functional and academic outcomes, as well as the effects of long term use of a cochlear implant, I was able to conclude that the use of cochlear implants overtime continued to benefit the user and their functional ability in daily life. Knowing that using a cochlear implant for a sustained amount of time does not seem to affect one's perceptual, linguistic abilities and academic outcomes, it might be hypothesized that the user's quality of life would remain consistent throughout his/her life.

Parental Input

Throughout the studies examined in this paper, cochlear implant users have been asked to rate their quality of life on a number of topics. Researchers have looked at implant users physical well-being, emotional well-being, self-esteem, family, friends, and school life. The benefits to the cochlear implant user are thought to bring multiple changes in a person's life, such as enhanced auditory skills, the use of spoken language and improved speech clarity. With the ability to use spoken language, children being mainstreamed into the general education setting, has been enhanced. These children have better school achievement, social versatility, broader options for further education, better employment, and social independence and better quality of life into adulthood (Huttenen and Valimaa, 2010). After reading all of the benefits of an oral communication mode for a cochlear implant user, it is important to assess not only his/her view on their quality of life, but also the parents rating of their child's quality of life. As an outside source looking into their child's daily life, they may view interactions differently from the child's perspective.

Edwards, Hill, and Mahon (2012), felt that many deaf children, especially those with additional needs would have difficulty completing a self-report measuring their quality of life, so a decision was made to develop an instrument for parents to complete. This questionnaire would be used to observe if parents felt their child's quality of life improved, declined, or stayed the same after receiving a cochlear implant. When developing this questionnaire, the authors based their questions on domains established from other quality of life measurement tools and discussion of parental concerns about their child's development and well-being. Each item was phrased in terms of the degree of concern felt by the respondent regarding the issue (Edwards et al, 2012). Parents rated the questions based on a 5 point scale ranging from "not at all

concerned” to “extremely concerned”. By forming the measurement tool based upon the parent’s concerns, it allowed the responses to be appropriate from the parental point of view. It would not be appropriate to ask a parent “Does your child tell their teacher their needs?” because the parents are not at school with their child and would not have a frame of reference to rely on. It is also inappropriate to have parents rate items that are not visible aspects of their child’s life, such as emotional feelings.

All of the respondents of the study were recruited from schools for the deaf or mainstream schools with specialist units for deaf children. Of the children with hearing loss surveyed, 11% used sign as their primary mode of communication, 63% used a combination of speech and sign and 26% used speech alone. The mean age of the deaf children was 7.0 years old and the mean age for the hearing children was 8.1 years old. Parental responses were subjected to principal components factor analysis. This resulted in four interpretable factors that accounted for the 70% variance. There were four subscales on the final questionnaire: communication and independence, emotional well-being, peer comparison, and acceptance by peers. To assess reliability and validity, t-Tests were used to compare the deaf and hearing groups of children on each of the four subscales and a total quality of life score, which was composed of the sum of the scores on all four subscales. This revealed significantly lower quality of life scores on all four subscales as well as a lower total quality of life score for the deaf children compared with their hearing peers (Edwards et al, 2012). This provides good construct validity of the questionnaire. The questionnaire was mailed to participants and included pre-paid addressed envelope for returning the responses. To encourage more participation, anonymity was ensured. By conducting the study via a questionnaire with anonymity, it left out personal information, such as a child’s speech and language progress, out of the author’s hands. Such

information could have been related information regarding how a parent viewed their child's quality of life.

The results of the Edwards et al. study suggested that 85 of 89 parents who completed the questionnaire, reported that their child's quality of life had improved as a result of a cochlear implant. Of those 85 parents whose child had additional needs, 3 reported that their child's overall quality of life had not improved. Of those children who did not have additional needs, only one reported that quality of life had not improved. This indicates that an overwhelmingly number of parents in the study felt as if receiving a cochlear implant helped improve their child's quality of life. This information, indicated by closed responses (yes/no), proved to rate similarly to cochlear implant users ratings on their own quality of life. For parents who have children with a hearing loss as well as additional needs, there were more concerns about their child's quality of life than those parents whose children did not have additional needs. Those parents of children with additional needs rated their child's quality of life poorer in comparison to parents of children without additional disabilities. Parents of children with additional disabilities were concerned with their child's communication and independence, emotional well-being, and acceptance by peers. However, questions about comparison with peers seemed to not concern them anymore than parents of children without additional needs (Edwards et al, 2012). Further studies would need to be conducted to determine if other parents of children with additional needs also felt the same concerns regarding their children's quality of life.

Conclusion

In general, the studies are showing that children with hearing loss are rating themselves similarly in terms of their overall quality of life, compared to typical developing peers. There

were deficits found in certain domains, such as friends and family. One study which examined young children (ages 3-11 years old), it was found that typically hearing peers initiated interactions with children with hearing loss twice as less as they did with fellow typically hearing peers. In another study, it was found that parents of young children with hearing loss rated their child's quality of life less than the child themselves did. The studies which examined adolescents (ages 12-17 years old), found that the adolescents rated themselves similarly to typically hearing peers on their overall quality of life score but continued to exhibit a deficit in the friends domain. Unlike the studies which examined young children, the adolescent studies showed that parents rate their child's success at school higher than the student rated it themselves. Overall, the use of a cochlear implant increases how adolescents with a hearing impairment rate their QOL and such a rating is comparable to what hearing peers would assign themselves

This literature review indicated that there is an association between peer relationships and one's rating of quality of life. For younger children, ages 1-11 years old, there was a difference in the amount of peer interactions between hearing children and children with hearing loss and the parents of children in that age range felt that their children were at a deficit in terms of friends, family, and self-esteem. Adolescents, ages 12-17 years old, also found differences in the domain of friends compared to peers with typical hearing. In both age groups, the ratings of quality of life were similar in both people with hearing loss compared to the aged matched peers.

Knowing that the domain of peer relationships is something that children with hearing loss using cochlear implants found a deficit in, it is clear that parents, teachers and other professionals involved in the development of children with hearing loss, need to help facilitate the positive development of the child's quality of life. Through modeling and explicit

instruction, people working with children with hearing loss can enhance a student's pragmatic language, which in turn can help benefit their peer relationships. As noted in the above mentioned studies, children with hearing loss do not feel as comfortable in their peer relationships as they do in other domains assessed, such as physical well-being. It is important to help foster the development of peer relationships for children with hearing loss and the most important component to assist in that progress is their language.

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Figure 1

This figure is a description of the measurements used in reviewing one's quality of life.

Name of Evaluation	Age Appropriate	What is assessed?
Child Behavior Checklist (CBCL)	Parental Assessment (Parents of children 2-3 years old and children 4-18 years old)	-Social withdrawal -Somatic complaints -Anxiety and depression -Destructive behavior -Social problems -Thought problems -Attention problems -Aggressive behavior -Delinquent behaviors
Kiddy KINDL (Kinder Lebensqualitätsfragebogen)	4-7 year olds	-Physical well-being -Emotional well-being -Self-esteem -Family -Friends -School
KINDL-R (Kinder Lebensqualitätsfragebogen)	7-13 year olds	-Physical well-being -Emotional well-being -Self-esteem -Family -Friends -School
Kiddo KINDL-R (Kinder Lebensqualitätsfragebogen)	14-17 year olds	-Physical well-being -Emotional well-being -Self-esteem -Family -Friends -School
Vineland Social-Emotional Early Childhood Scales	Parental Assessment (Parents of children birth-5.11 years old)	-Interpersonal relationships -Play and leisure time -Coping skills
Youth Quality of Life-Deaf and Hard of Hearing (YQOL-DHH)	11-19 year olds	-Participation -Self-acceptance and

		advocacy -Perceived stigma
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