

2015

Exploratory analysis of the effectiveness of cochlear implant support groups on the quality of life of adult cochlear implant recipients

Carmen Valero-Aracama

Washington University School of Medicine in St. Louis

Follow this and additional works at: http://digitalcommons.wustl.edu/pacs_capstones

Recommended Citation

Valero-Aracama, Carmen, "Exploratory analysis of the effectiveness of cochlear implant support groups on the quality of life of adult cochlear implant recipients" (2015). *Independent Studies and Capstones*. Paper 700. Program in Audiology and Communication Sciences, Washington University School of Medicine.
http://digitalcommons.wustl.edu/pacs_capstones/700

This Thesis is brought to you for free and open access by the Program in Audiology and Communication Sciences at Digital Commons@Becker. It has been accepted for inclusion in Independent Studies and Capstones by an authorized administrator of Digital Commons@Becker. For more information, please contact engesz@wustl.edu.

**EXPLORATORY ANALYSIS OF THE EFFECTIVENESS OF COCHLEAR
IMPLANT SUPPORT GROUPS ON THE QUALITY OF LIFE OF ADULT
COCHLEAR IMPLANT RECIPIENTS**

by

Carmen Valero-Aracama, Ph.D.

**A Capstone Project
Submitted in partial fulfillment of the
Requirements for the degree of:**

Doctor of Audiology

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

May 20, 2016

Approved by:

Christina Koehler, M.S., Capstone Project Advisor

Lisa Potts, Ph.D., Secondary Reader

Abstract: The purpose of this investigation was to determine the impact of support groups on the quality of life of adult cochlear implant users. Standardized surveys and a card-sorting task were used in addition to qualitative interview questions that were developed to compare the quality of life of cochlear implant recipients who attend versus those who do not attend a support group.

Copyright by

Carmen Valero-Aracama, Ph.D.

May 2016

ACKNOWLEDGEMENTS

I would like to thank Christina Koehler, M.S., and Lisa Potts, Ph.D., for their support and encouragement developing, carrying over and completing this Capstone Project. Both of their positive and constructive feedback has contributed to making this a very positive personal experience for which I feel extremely grateful. I would also extend my gratitude to Carolina Hausmann-Stabile, Ph.D. for her guidance, encouragement and support, especially during the study design development and study analysis.

I extend my gratitude to William Clark, Ph.D. and Maureen Valente, Au.D. for having great expectations of all of us and helping us shoot for excellence and to all the PACS staff, to Beth Elliot, Rene Miller and Beth Fisher for all your support through the years.

I would like to express my most sincere appreciation to all the participants in the present study, for their generosity and kindness offering their time and their personal stories about their life journey with a hearing loss and with cochlear implants. The legacy I have received from the present study has allowed me to learn and grow in the field of audiology and I am eager to continue listening and learning from those who I shall be offering audiological services in the future.

I would also like to thank my wonderful family that loves me and that even from far away encourages me and supports me every step of the way. I also want to thank all my dear friends who always believe in me and support me and make me feel very fortunate to be in their lives. And most of all I would like to thank my sweet boy Luca, my inspiration, my reason to live and prosper and my encouragement to work harder. Luca, thank you for bringing me the light.

Research reported in this publication was approved by Washington University's Institutional Review Board (IRB ID # 201411038) on 11/13/14.

TABLE OF CONTENTS

Acknowledgments.....	iii
List of tables and figures.....	v
Abbreviations.....	vi
Introduction and Review of the Literature.....	1
Methods.....	9
Results.....	13
Discussion.....	22
Conclusion.....	27
References.....	29
Appendix A.....	40
Appendix B.....	44

LIST OF TABLES AND FIGURES

Table 1. Participants’ demographic information.....37

Figure 1. Results from Community Participation Indicators: Levels of socialization with family and friends relative to age of participants in support group and non-support group participants.....38

Figure 2. Results from Community Participation Indicators: Everyday activity levels relative to age of participants in support group and non-support group participants.....38

Figure 3. Results from Community Participation Indicators: Level of involvement in community events and entertainment relative to age of participants in support group and non-support group participants.....39

ABBREVIATIONS

AR: Aural rehabilitation

ASC: Activity Sort Card

CI: Cochlear implant

CPI: Community participation indicators

GBI: Glasgow Benefit Inventory

HA: Hearing aid

QOL: Quality of life

NS: Non-support group attendees

SG: Support group attendees

INTRODUCTION AND REVIEW OF THE LITERATURE

Hearing Impairment Effects on Quality of Life

Hearing impairment is regarded as one of the most common clinical conditions among the elderly in the United States (Niparko & Agrawal, 2009). Additionally, surveys show that 28 million Americans are deaf or hearing impaired (NIDOC, 1996) and that number has been projected to increase to 40 million by 2020 (Niparko & Agrawal, 2009). Hearing impairment limits the ability to effectively communicate in everyday situations, and therefore, it has detrimental effects on many aspects of daily living including the potential for loneliness and negative impacts on mental health (Wallhagen, Strawbridge, Shema, Kurata & Kaplan, 2001; Raina, Wong & Massfeller, 2004).

According to the World Health Organization “quality of life” (QoL) is defined as “individuals’ perceptions 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” (WHO, 1997). Rather than just evaluating health status, life satisfaction, mental state or wellbeing, QoL should be viewed as a multidimensional concept that comprises an individual’s perceptions of these and other aspects of life (Eiser & Morse, 2001; Varni, Burwinkle & Lane, 2005). Numerous studies have indicated poorer overall QoL in adults with hearing loss resulting in poorer mental health (Mo, Lindbæk & Harris, 2005; Orlans, 1985), physical and social functioning as compared to adults without hearing loss (Strawbridge, Wallhagen, Shema & Kaplan, 2000; Dalton *et al.*, 2003; Chisolm *et al.*, 2007). Orlans (1985) reported increased levels of paranoia, depression, withdrawal, irritability and nervousness in individuals suffering from severe to profound sensorineural hearing loss. Decreased QoL has been correlated to social isolation (Weinstein & Ventry, 1982) and increased emotional handicap (Mulrow *et al.*, 1990),

and in the elderly population, auditory rehabilitation becomes important when aiming to improve functional and psychological outcomes (Weinstein & Ventry, 1982). Adults' QoL has been shown to improve with the use of hearing aids (Mulrow *et al.*, 1990; Yueh *et al.*, 2001), as well as with the use of cochlear implants (Maillet, Tyler & Jordan, 1995; Faber & Grøntved, 2000; Francis, Chee, Yeagle, Cheng, & Niparko, 2002; Lassaletta, Castro, Bastarrica, Sarriá, & Gavilán, 2006; Klop *et al.*, 2008; Looi, Mackenzie & Bird, 2011; Straatman, Huinck, Langereis, Snik & Mulder, 2014).

Options for Amplification: Hearing Aids and Cochlear Implants. Who is a Candidate for a Cochlear Implant?

Audiological intervention benefits a large portion of adults with hearing impairment through the use of hearing aids (HA), hearing assistive technology, and communication strategies. These interventions result in improvement of an individual's communication, auditory perception and minimize the restrictions caused by the hearing loss (Chisolm *et al.*, 2007; Kiessling *et al.*, 2003). However, for those individuals with severe to profound sensorineural hearing loss who no longer benefit from HAs, cochlear implantation might be a viable treatment (Klop *et al.*, 2008). Cochlear implantation is an established procedure for individuals who are candidates (NIH, 1995; Summerfield & Marshall, 1995); after surgical implantation and audiological services, severe-to profound hearing-impaired individuals have regained access to hearing (Zaidman-Zait, 2011). Cochlear implants (CI) bypass the damaged portions of the ear, delivering electrical pulses directly to the auditory nerve. Although they do not "restore" hearing and they are not considered a "cure" for hearing loss, cochlear implants allow individuals to perceive the sensation of sound, giving them, in most cases, access to speech understanding. Criteria for candidacy include individuals who can obtain maximum benefit from the device,

with bilateral severe-to-profound sensorineural hearing loss and inability to benefit from hearing aids (Peasgood, Brookes & Graham, 2003). In recent years, with the introduction of the hybrid CI, there has been a criterion expansion for implantation including individuals with residual low-frequency hearing (Gantz, Turner, C. & Gfeller & Lowder, 2005). Medical clearance is required before implantation, which includes good physical and mental health.

Given that hearing through a CI is different from acoustical hearing, time is needed to relearn how to hear. Individuals undergoing cochlear implantation should also have the motivation, patience and commitment to continue using the CI and oftentimes to participate in aural rehabilitation (AR) programs (Gates *et al.*, 1995).

Effects of Cochlear Implants on Adults' Quality of Life

Cochlear implant technology generally provides useful auditory benefit to recipients and improved speech understanding in quiet and noisy environments (Shitani, Himi, Yamaguschi & Kataura, 1997; Shiroma, Tako, Kawano, Kubo & Funasaka, 1997). However, the degree of success is not known until after adaptation to hearing through the implant. Cochlear implantation outcomes have commonly focused on performance, which is typically measured with speech recognition testing (Bredberg *et al.*, 2003). However, the benefit provided by enhancing the QoL, namely the perceived mental and physical wellbeing of the user (Parment, Lynn & Glass, 2002), has been suggested as a more realistic measure of success of cochlear implantation. Multiple reports indicating improvement in the QoL after cochlear implantation have been published: improvement in speech understanding and communication has been widely documented (Faber & Grøntved, 2000; Francis *et al.*, 2002; Klop *et al.*, 2008; Lassaletta *et al.*, 2006; Mo *et al.*, 2005; Tyler & Kelsay, 1990) and oftentimes with increased levels of self-confidence and self-esteem

(Faber & Grøntved, 2000; Francis *et al.*, 2002; Klop *et al.*, 2008; Lassaletta *et al.*, 2006; Looi *et al.*, 2011). Other commonly reported benefits of cochlear implantation on the QoL of recipients are the improvements in the psychological wellbeing of individuals (Hogan *et al.*, 2001; Rembar, Lind, Arnesen & Helvik, 2009; Tyler & Kelsay, 1990) and the improvement in social relations and social functioning (Francis *et al.*, 2002; Hogan *et al.*, 2001; Klop *et al.*, 2008; Mo *et al.*, 2005; Tyler & Kelsay, 1990).

Maillet and colleagues (1995) identified limiting factors such as length of deafness before cochlear implantation in the satisfaction of CI recipients. However, these authors still reported increased QoL inversely related to the length of deafness in their study. Peasgood and colleagues (2003) reported increased QoL of “non-traditional” recipients referring to early-deafened late-implanted individuals despite obtaining low speech recognition scores. Similarly, Straatman and colleagues (2014) found improved QoL in prelingually deafened adults, which was not correlated with their speech recognition scores.

Quality of Life Assessment

There are several approaches to evaluate the QoL of CI recipients: overall-health questionnaires are frequently used with the advantages including recipients perceived costs and benefits (Palmer, Niparko, Wyatt, Rothman & de Lissovoy, 1999). Additionally, disease specific questionnaires assess the QoL in physical, functional, psychological, and social domains affected by the condition or intervention. An alternative way to assess the QoL has been to measure individual’s participation in the community or their change in involvement in different everyday and leisure activities.

Generic QoL assessments usually collect information from ill as well as healthy

individuals in a community. These tools inquire about social interactions, wellbeing, and community difficulties, and usually analyze utility costs (Klop *et al.*, 2008). Examples of generic QoL assessments include the Ontario Health Utility Index (HUI2 and HUI3; Feeny *et al.*, 2002) and the Australian Assessment of QoL (AQoL; Hawthorne, Richardson & Osborne, 1999). These questionnaires are useful to identify health problems and assessment of outcomes in the community (Klop *et al.*, 2008); however, when compared to disease specific questionnaires in studies with CI recipients, fewer domains in these generic assessments are able to capture changes in QoL. Similarly, the Nottingham Health Profile, which is another generic tool, was found to lack sensitivity assessing the QoL of CI recipients because it was unable to measure changes in QoL of CI recipients (Karinen, Sorri, Valimaa, Huttunen & Lopponen, 2001).

Disease-specific assessments have been frequently used to estimate the changes in QoL of CI recipients. Commonly assessed factors of disease-specific QoL questionnaires include those that evaluate the person's QoL as affected by the illness or disability and after receiving treatment. By using post-treatment standardized questionnaires, such as the Glasgow Benefit Inventory (GBI), participants are able to self-report changes in health status after cochlear implantation (Robinson, Gatehouse & Browning, 1996). This test was developed specifically for otorhinolaryngological interventions and has been widely used to evaluate QoL of CI recipients. The Nijmegen Cochlear Implant Questionnaire (NCIQ) is another disease-specific tool that was developed focusing on physical, social and psychological functioning (Hinderink, Krabbe, & van Den Broek, 2000). Multiple studies have found it to be sensitive for measuring changes on QoL of adult CI recipients (Straatman *et al.*, 2014; Hinderink *et al.*, 2000; Klop *et al.*, 2008; Damen, Beynon, Krabbe, Mulder & Mylanus, 2007). However, because in disease-specific questionnaires the number of responses is limited and not tailored to the researchers' study goals,

some criticize that they may not be sensitive enough for evaluating QoL (Bergeron & Ferron, 2005).

An alternative way to measure QoL is by evaluating individuals' participation in activities within their community. With that goal in mind, Heinemann and colleagues (2013) developed the Community Participation Indicators (CPI) and classified individuals' involvement in three areas: engagement, evaluation and enfranchisement. Engagement refers to frequency of involvement, whereas evaluation is reflected in the participants' satisfaction in the activities involved. Enfranchisement refers to a set of values that give meaning to participation in multiple categories, and it reflects how much the individual feels respected by his or her community. Because the CPI has been recently developed, a limited number of researchers have utilized this tool. Nevertheless, the CPI could be an alternative option for QoL assessment in the adult CI population.

Another measure of the adult activity engagement for patients after recovering from an illness or treatment is the Activity Sort Card (ASC; Baum & Edwards, 2001). The ASC is an occupational therapy assessment tool that uses 89 images depicting people engaged in various real-life activities. Patients are asked to sort them by which one they have done at some point in life and which ones have been modified in frequency after the illness or intervention (Lyons, Zhongze, Tosteson, Meehan & Ahles, 2010). The benefit of using this measure over other measures of function is that only the activities in which the individual is involved are measured, focusing on the changes after intervention rather than on activity limitations (Ware *et al.*, 2007).

Closed-set quantitative questionnaires are commonly used tools to assess the QoL of adult CI recipients (Rembar *et al.*, 2009), however because the number of responses are limited

and tend to generalize, such questionnaires result in low sensitivity for QoL, and often researchers' specific questions are not answered. On the other hand, the ASC is an occupational therapy tool and therefore, the ASC's sensitivity to specific aspects of rehabilitation after cochlear implantation might be limited. In contrast, a qualitative approach to evaluating the perceptions and experiences of CI recipients might offer a more precise picture of the effects of cochlear implantation on the QoL of these recipients (Malterud, 2003). The focus of this kind of qualitative research is finding meaning and interpretation rather than statistical measures. Several researchers have used qualitative methods to study the effect of CIs on QoL of recipients (Hogan, 1997; Hallberg & Ringdahl, 2004; Finlay & Molano-Fisher, 2008; Rembar *et al.*, 2009) and focused on patients' views and emotions after cochlear implantation. Open-ended questionnaires and qualitative interviews have also been used in the literature to evaluate the QoL of CI recipients (MO *et al.*, 2005). A combination of both quantitative and qualitative methods would address different aspects of the QoL of CI recipients.

Peer Support Groups for Cochlear Implant Recipients

Peer support groups can play a significant role in aiding individuals going through a challenging experience by connecting with others going through a similar situation (Brownson & Heisler, 2009). Individuals who suffer from many different illnesses or problems commonly find self-help or mutual-help groups to aid them as they cope with their situation (Kyrouz & Humphreys, 1997). However, the accessibility to support groups for the deaf and hard of hearing is less common, and research regarding the nature and effectiveness of support groups for the hearing impaired is scarce and usually limited to groups of parents or caregivers rather than adult groups with hearing loss.

Despite having several support groups around the U.S. offering peer support to deaf and hard of hearing individuals, the effect of participation in these groups on the QoL of individuals with hearing loss is unknown. Furthermore, there is a lack of research focusing on the influence of such groups on CI recipients and their QoL. Deaf or hard of hearing or CI peer support groups are oftentimes available in large metropolitan areas. However, potential participants are oftentimes unaware of such groups, and newly identified CI candidates or individuals who might benefit during the early stages of candidacy and rehabilitation, might miss out on the opportunity to participate for that reason. Assessing how CI recipients learn about support groups and understanding the reason for attendance or lack of attendance would help identify the profile of CI recipients who might benefit from the meetings. Additionally, the usefulness of the meetings for participants and their family members and the aspects that most interest participants, such as social interaction, peer support or informational purpose, could guide meeting organizers into the development of effective peer support groups.

Objective

The overall objective of the proposed project was to evaluate the QoL of adult CI recipients who frequently attend support groups and compare it to that of recipients who do not attend support groups. Specific goals include: 1) Identifying history and lifestyle of participants who attend and compare it to those who do not attend peer support meetings, 2) determining the perceived changes in the QoL of recipients as affected by cochlear implantation, 3) determining the perceived changes in the QoL of recipients as affected by support group attendance, and 4) identifying which aspects of support groups are deemed important and beneficial by participants.

METHODS

In order to better understand behaviors of CI recipients as affected by their interaction or lack of it with support groups, a mixed quantitative and qualitative research paradigm was used. Quantitative data was collected through quality of life (QoL) questionnaires and a sorting-card activity and qualitative data was collected through personal interviews. The Human Research Protection Office (HRPO) of Washington University School of Medicine in St Louis, Missouri, gave Institutional Review Board approval for the study (ID # 201411038). All procedures were performed within the stipulated approval of the study. The researcher asked prospective participants to sign an informed consent form prior to participating in the study.

Participants

Participant selection criteria included established adult CI recipients (> 4 months use), older than 18 years of age, who use oral language as their only communication mode, and English is their primary language. Average age of participants was 63 (range 43-93 years). There were 13 females and 8 males. The median length of CI use was 7 years (from 5 months to 20 years). Two participant groups were identified: 12 adult CI recipients who periodically attend support groups (SG), and 9 adult CI recipients who do not attend support groups or only have attended once within the past year (NS). One SG and 4 NS participants had a congenital hearing loss, whereas 11 SG and 5 NS participants were diagnosed later in life with a hearing loss (from 5 to 70 years of age). Further detailed demographic data is shown in Table 1.

Recruitment fliers were distributed among six CI clinics in St. Louis (MO) and Kansas City (MO) aimed towards the NS participant group. The SG participants were recruited with presentations at support groups in the St. Louis metropolitan area: one was a support group for

the deaf and hard of hearing and the other a support group organized by Cochlear Americas. (Sydney, Australia).

Measures

Data was collected during individual meetings with participants at their homes or at a public library. Meetings lasted about an hour in which participants were asked to fill out the community participation indicators (CPI), the Glasgow benefit inventory (GBI), participate in a card sorting activity (ACS) and engage in a semi-structured interview with the researcher.

Community Participation Indicators (CPI). Participation in life roles was measured using the CPI. For each question, engagement was assessed by determining the frequency of participation in each activity (in days, hours or weeks depending upon activity), and evaluation was established by determining whether the activity was important or not for participants and whether they were doing it enough, not enough or too much (Heinemann, 2010; Hammel *et al.*, 2008). Example activities included: get out and about, keep in touch with friends by phone or Internet, volunteer and go to support groups or self-help meetings. Satisfaction rates were calculated adding the total number of activities classified as important by the participant divided by the number of important activities that participants stated were done frequently enough. The CPI are all scored so that the higher scores reflect the higher levels of participation or satisfaction for each item following a Likert-type scale with responses ranging from 0 to 4 or from 0 to 5.

Glasgow Benefit Inventory (GBI). The GBI was used to evaluate how cochlear implantation has altered the QoL of the person (Robinson *et al.*, 1996). The GBI was developed as a tool for post-treatment self-report of changes in QoL, particularly after otorhinolaryngological procedures, including cochlear implantation (Peasgood, *et al.*, 2003), and has been adapted in the present study specifying the intervention referred to as “cochlear

implantation”. The main factors evaluated in the GBI consisted of “general benefit”, “social support” and “physical benefit” following cochlear implantation. The questionnaire consists of 18 multiple-choice health status questions. Some of the questions included “Has the result of getting a CI affected the things you do?” and “Since getting your CI, do you have more or less self-confidence?” The responses were based on a five point Likert scale ranging from great deterioration to great improvement of health status, always having a “no change” option in the middle. Examples include: “much worse, to a little or somewhat worse, no change, a little or somewhat better, or much better” or “much more self-confidence, more self-confidence, no change, less self-confidence and much less self-confidence”. From low to high, the responses had a raw score from 1 to 5. Raw scores were transformed into 0-100% benefit scores following the calculations by Robinson and colleagues (1996).

Activity Sort Card (ASC). The ASC assessed individuals’ participation in instrumental, leisure, and social activities before and after cochlear implantation, quantifying changes in participation after receiving the CI (Activity Sort Card; ASC, Baum, 1995; Baum and Edwards, 2008). Participants were shown 89 photographs depicting individuals performing activities in 4 categories (20 instrumental activities, 35 low-physical demand leisure activities, 17 high-physical demand leisure activities, and 17 social activities). Participants were asked to sort the cards to find out which ones they had never done, and which ones they had done before and/or after receiving the CI. From the activities that were done, participants were asked again to sort them according to how much change they experienced after cochlear implantation: continue to do, doing less, given up, doing more, or new activity. Percent retained was obtained by dividing current total activities by previous activities. Scoring the ASC was modified by adding the

category “doing more”, since this category reflected more accurately the participants’ responses than following the original scoring system described by Baum and Edwards (2008).

Qualitative In-Depth Interviews. The author conducted and audio recorded all the semi-structured interviews with all participants in the study. These consisted of questions focused on information regarding participants’ 1) history of hearing loss 2) history of receiving a CI and 3) perception of QoL changes since receiving the CI. Additionally participants were inquired about their interest and/or knowledge about local support groups for the deaf and hard of hearing or interest about meeting other CI recipients. Those who attended peer support group meetings were also inquired about components of the meetings and about the participants’ and their families’ perceived benefit from the meetings. The interviewer encouraged participants to talk freely and in-depth about the topics presented to collect as much information as possible. The author transcribed the interviews verbatim. See appendix A for a complete list of questions for both participant groups.

Data Analysis

The quantitative results obtained from the CPI and GBI questionnaires and from the ASC were interpreted using descriptive statistics due to the small sample size. Verbatim audio recording transcriptions were transferred to Dedoose (a qualitative research data analysis software) to store, process and analyze the interview data. Qualitative data were analyzed using a constant comparative approach, in which transcripts were retrieved, coded by the author to identify key topics and to compare and contrast participants’ responses. The codes were developed to answer the main research questions, to point out personal narratives, and to describe commonalities and disagreement among participants in specific issues. The data emerging from the codes was then quantified to assess the prevalence in which the themes

appeared in the participants' responses. General topics were identified after codes were analyzed and resulted into code trees.

RESULTS

Community Participation Indicators (CPI), Glasgow Benefit Inventory (GBI) and Activity Sort Card (ASC)

Using the CPI, participants were asked about the importance of support groups and volunteering in general. All participants in the SG responded that support groups are important, in contrast to 11% of the NS group that also considered it important. When asked if volunteering was important, 83% SG participants and 67% NG participants responded it was. When satisfaction rates were calculated, 74 % and 72% of the time SG and NG participants were satisfied with the activities they participated in, respectively.

A similar trend in the area of socialization with friends and family in both groups was indicated by CPI scores, showing a decrease in score with increasing age (Figure 1). Overall SG participants showed equal or higher scores for the same age peers in the NS group (Figure 1). Similarly, a decrease in everyday activities was observed with increasing age in both groups (Figure 2) with a greater correlation with age increase in the NS. Participants in the SG also scored higher in the community events and entertainment than NS participants (Figure 3); however, there was no clear correlation with participant's age in this area.

There was an increase in the global health score of the GBI after implantation for both SG and NG participants (41% and 46%, respectively). Ninety-two percent SG participants noticed an average of 30% improvement in social support after implantation whereas 44% NS participants noticed an average of 54% social support improvement after implantation. The

remaining participants did not notice any changes in social support. The physical health score did not change in 93% of the SG participants and showed a 33% increase in 7% SG participants. In contrast, no change was noted by 55% NS participants but showed a 50% increase for 33% NS participants and a 17% decrease for 11% NS participants.

The ASC measured changes in participants' activities. However, it is important to note that quantifiable changes do not necessarily give information about the meaningfulness of the change (Hogan, 2001). Instrumental activity changes, according to the ASC scores, were indicated by 42% SG participants (from -5.6 to 10.7%) and by 22% NS participants (from 2.6 to 26.9%). Most participants in both groups noted changes in low-demand leisure activities ranging from -5 to 13% for SG participants and from 0 to 22.7% for NS participants. Thirty-three percent of SG participants experienced from 37 to 3.2% reduction in high demand leisure activities whereas 11% NS participants had a 19% reduction and 22% NS participants had a 12.5 to 35.7 increase in the same activity. The remaining participants did not report any change. Social activities increased by 3.8 to 17.6% in 42% SG participants while they decreased in 25% of SG participants (-6.7 to -3.9%) and 33% SG participants reported no changes. Conversely, social activities increased in 67% NS participants (2.9 to 38.2%), decreased in 11% NS participants (-3%) and no change was reported in 22% NS participants.

Qualitative In-Depth Interviews

Twenty-six codes were identified after analyzing all personal interviews (see appendix B for list of codes and definitions). Codes were classified into the following general topics: 1) history of hearing loss and cochlear implantation, 2) self-image and social interaction after cochlear implantation, 3) challenges with CI, and 4) support group involvement. Detailed information about support group experience was obtained only from SG participants.

History of Hearing Loss and Cochlear Implantation

Participants were asked how long they thought they had a hearing loss in the implanted ear. In the NS and SG respectively, there were 2 and 4 that had it for 10-20 years, 2 and 3 that had it for 21-40 years, 4 and 3 that had it for 41-60 years and 1 and 1 that had it for more than 60 years. When asked about hearing aid (HA) use, 89% of NS responded they did use them prior to receiving the CI (6 from 10-30 years and 2 for over 30 years). In the SG, 91% responded they used a HA prior to the CI (2 from 6 months to 1 year, 5 from 10-30 years and 4 for over 30 years). Length of CI use for NS and SG was determined (first implant for bilateral recipients) and respectively for each group, 2 and 5 wore it for 0-5 years, 3 and 6 for 6-10 years, 4 and 0 wore it for 10-15 years, and 0 and 1 for over 15 years. Finally, participants were asked if they received aural rehabilitation (AR) after implantation. Thirty-three percent of NS participants indicated receiving 3 to 12 months of AR and 77% indicated they did not receive AR. In contrast, 67% SG participants indicated receiving AR. Within this group, 63% individuals received up to 3 months of AR and 37% individuals received 6-12 months AR.

Decision to Get a Cochlear Implant. When participants were asked to list the reasons why they decided to pursue a CI, 67% of either SG or NS participants indicated that the reason was their deteriorating hearing loss. In the NS and SG, 22 and 25% of participants, respectively, indicated that they were encouraged after meeting with other CI recipients. Other reasons included recommendation by their doctor (33% for NS and 17% for SG) and decreased word discrimination (22% for NS and 25% for SG). One individual in the NS group indicated the main reason was tinnitus masking and restoring hearing. Another individual in the SG indicated a

sense of social isolation and another one mentioned his willingness to improve communication over the phone.

Cochlear Implant Expectations. The perceived success of CIs oftentimes depends on the expectations the audiologists convey to the candidates and also on the candidates' own personal expectations. Thirty-three percent of NS participants did not have clear expectations; however they felt that CIs had fulfilled their hopes. Within this group, 33% expected to hear better, 22% expected to improve clarity, 11% expected to improve their careers, and 11% expected to lower stress and to reduce guessing in conversations. Eighty-nine percent of NS said the CI met their expectations and only one participant stated it did not, however, he did not have any regrets after getting it. One NS participant stated limited satisfaction because of constant perceived static noise, and another commented on the improvement perceived in music and understanding voices.

The SG participants had expectations of better hearing, understanding and mostly felt optimistic about the CI before receiving it. Only one individual stated she expected voices to sound robotic and stated hearing better than expected since receiving the CI. Eighty-three percent of SG felt the CI met their expectations, and 60% of those participants stated it exceeded their expectations. One SG participant did not feel it completely met her expectations, another was only dissatisfied with the telephone use, and another participant did not feel it met his expectations but was positive about the implant because his word understanding had doubled.

Self-image and Social Interaction after Cochlear Implantation

Confidence in Communication with the Cochlear Implant. When participants were asked whether they felt more confident in everyday communication since receiving the CI, 78% of NS and 92% of SG participants said they did. Twenty-two percent of NS said they had never felt bad and they did not feel their confidence had changed and 8% of the SG did not respond to the

question. In addition, among the SG participants, 33% responded that their confidence was still low in large groups.

Self Image. Participants were asked about their feelings when people approached them to ask about their CI. In the NS group, 22% said people did not notice their CI with their hair covering it up and were not approached to ask about it, 33% reported explaining to others what it was “as a matter of fact”, 22% felt very confident, 11% proud and 11% expressed not having feelings about it because the participant stated “I don’t use CIs to define who I meet or where I go”. Among the SG participants, 1 reported others did not notice because it was covered by hair, but there was not a feeling of embarrassment because it had improved the recipient’s life. Forty-two percent reported being confident and/or proud, 33% reported they talked about it as a matter of fact and they did not mind it, and 17% reported having mixed feelings, having changed from being self-conscious about the implant to confident because of the benefits they felt they received from it.

Educating Others About Cochlear Implants. When asked about how they felt about educating others about CIs, all the participants that attended support group meetings said they liked doing it, but only 78% of the NS participants said they liked it, while 22% indicated they did not mind doing it but they did not bring it up.

Relationship with Other Cochlear Implant Recipients. When participants were asked if they had met or would like to meet with other CI recipients clear differences were noted between both groups. In the NS, 88% stated they did not have relationship with CI recipients outside of family members, and among those 63% stated they did not want to meet other CI recipients, 13% stated they were indifferent about it, and 25% stated they would like to meet with other CI recipients. Only one participant stated having relationships with other CI recipients on a regular

basis. In contrast, in the SG 58% had relationships with other CI recipients on a regular basis, and within that group of people, 71% stated it was with people that attended the meeting and 29% stated it was with other individuals that did not attend the meetings.

Challenges with a Cochlear Implant

In the interviews participants were asked in which areas they felt they still were facing difficulties with the CI. No difficulties were reported by 22% of NS and 8% SG participants, difficulty using the phone was reported by 44% NS and 17% SG participants, and noisy environment and crowds were difficult for 44% NS and 83% SG participants.

When asked which skills they still wanted to improve, 56% NS and 67% SG wanted to improve listening to music, 56% NS and 50% SG wanted to improve their speech understanding in noise, 33% NS and 50% SG wanted to learn more about their equipment features, 22% NS and 50% SG wanted to improve using the phone, 11% NS stated none, and 11% NS wanted to improve understanding television.

Staying Current with Technology. One of the challenges about having to use technology for everyday communication is learning how to use it and staying current with the newest technology and knowing how to access it and adapt to it. Participants were asked how they learned about new technology and most responded that they learned about it through their audiologists (88% NS and 67% SG participants). One individual in each group admitted having little contact with the audiologist, which limited how much information they received from them. Sixty-seven percent of NS and 58% SG participants found information online through forums or the CI manufacture's website. One NS participant read the minutes of SG meetings and 100% SG participants stayed current through the support group meetings. One SG participant also read the Hearing Loss Association of America (HLAA) magazine.

Knowledge About Support Groups. When NS participants were asked if they were aware of support groups meetings in the region, 56% said they were not aware or did not know details about them, and 44% knew about the meetings. Within this group 33% showed interest in the meetings in contrast to 66% who were not interested in them. From those who showed interest but did not attend the meetings, one mentioned that the location was too far from her home, another had difficulty with transportation and the third one mentioned that with her busy personal life “it has never worked out”.

Support Group Involvement

In order to evaluate the impact of support group meetings on their attendants, the SG participants were asked a series of in-depth questions about their experience at the meetings. Most participants could not recall exactly how they learned about the meetings, but at least 58% recalled their audiologist talked to them about it, 75% also mentioned meeting another CI user who was attending the meetings and 17% learned about the groups in a CI seminar. Most participants (75%) attended the meeting monthly, while 17% attended both the local CI support group and the deaf and hard of hearing support group, therefore attending bimonthly. One participant was only able to attend twice a year because of conflict with his work schedule.

When asked about the reason why they attended for the first time 42% stated they wanted to meet other CI recipients, 25% were curious about the meetings, 25% were encouraged by their audiologists, 16% were encouraged by other SG members and 8% stated “it is a pipeline into the manufacturer, to learn about their new products”. Once they started attending, 67% continued doing so because they enjoyed talking to other members, they felt it was a nice group and enjoyed the companionship, 58% stated they enjoyed learning and hearing about others’

experiences and 25% also attended to encourage and teach others. One member stated it was “a good thing” in her life.

All the participants felt the meetings had met their expectations, one felt it had exceeded them and two felt it did only for the most part, one of them noting that most other members were doing better than her and this brought frustration to this member. Most participants (58%) wanted to meet other members, one stated that he needed help making the decision to get the implant and the meetings were an important part of his decision making.

The family members oftentimes also participate in the meetings. At least 50% of the participants mentioned their partner also attended the meetings, volunteered and made friendships within the group. One participant stated that her children liked that she attends the meetings because “I have more of a social life”. One participant enjoyed having new friendships from the group and 2 felt it brought them confidence. Two participants enjoyed seeing people like them, 1 stated “I feel a bit more normal, I feel better about myself because I am much better than most”. Two participants stated that overall it was a positive influence in their lives.

When asked about participation in the meetings 92% said they enjoyed learning, meeting with peers, telling their own story and helping others. All participants enjoyed being a mentor to others within the group at least on a casual basis. Fifty percent also liked to ask questions and talk to others, and 42% also liked being a leader in a small or large group. One member stated that she only liked to listen and added “I learn so much, I don’t share much, I enjoy the meetings and I learned about CIs at the group”.

When asked about what they felt they had learned at the meetings not addressed by their audiologist, 58% learned about the new products and how to adjust the settings in their processors/remotes while 42% learned about the loop system. One participant learned that it was

possible to get bilateral implants and other stated “there are a lot more people with hearing loss than I had imagined, you are not alone. [I learned] about assisted listening devices, about captioning in theaters, about my rights.” One participant stated her audiologist was great and she did not learn much she did not know.

When attending support groups, the experiences of other CI recipients might change others’ motivation to continue doing aural rehabilitation (AR). When participants were asked if they felt the meetings had changed their attitude towards AR, 75% felt somewhat it did increase their motivation and encourage them to try new strategies or to help others in the rehabilitation process and 25% felt it did not change what they were doing or how they felt about it.

Although most of the participants were satisfied with the meetings, they were asked if they thought any changes could improve them. Eighty-three percent did not feel any changes were needed, but 17% stated wanting to see some changes. One person stated that having small break-out sessions every month was not efficient, and other stated that having the meeting early morning would be less disruptive during the weekend. Participants were asked which aspects of the meetings they liked the most and 75% concurred that they liked when invited speakers gave a talk, followed by learning about how to use the equipment and company updates (33%), listening to other people’s stories (25%), giving hope to others (8%), small break-out sessions (8%) and CART (communication access real-time translation) system (8%) to be able to follow the speakers.

DISCUSSION

In the present study, participants recruited in either group comprised some who were hearing impaired since birth and others who had lost their hearing later in life, ages ranging 43-93 years, and cochlear implant (CI) use ranging from 5 months to 20 years. Although demographic characteristics from each group were relatively comparable in all these aspects, the small sample size for either group warranted analyzing all quantitative data with caution. However, the qualitative portion of the study benefitted from having participants' heterogeneity, as it has been shown to provide much more robust raw data material (Malterud, 2003).

Overall, all participants in this study showed a positive attitude towards receiving their CI/s. The reasons to get a CI were similar in both groups, and despite having varied degrees of success in self-reported speech understanding and communication over the phone or in noisy environments, the expectations from receiving the CI in either group were met, without any regrets from any participant. Results from all the instruments utilized in this study also indicated an improvement in the quality of life (QoL) of all individuals. Similar results have been observed in other studies using open-ended questionnaires, in which receiving a CI has been described as "coming back to life" (Hallberg & Ringdahl, 2004), and it has allowed patients to "resume life as they want to live it" (Hogan, 1997). When comparing both groups using the questionnaires or the Activity Sort Card (ASC), drastic differences were not identified between the groups. The only noticeable trends were related to social support, volunteering and support group activities, in which participants in SG scored higher than those in NS. Conversely, a lower proportion of SG participants increased their social activities than NS participants according to the ASC. These results clearly indicate that personal interests from individuals in the two groups are inherently different, even with similar levels of satisfaction in their daily activities. Individuals who might

be more inclined to offer their time volunteering and see a value in support groups more likely will attend and participate in them. Likewise, support group meetings oftentimes become part of the social life of CI recipients, and individuals whose social life activities have increased since receiving the CI, might not need to reach out to support group meetings for socialization.

Although higher number of SG participants responded feeling more confident about the CI than NS participants, those who did not increase their confidence stated that they were confident before receiving the CI. This feeling was expressed mostly by participants who have always lived with a hearing loss, have learned to navigate in a hearing world and consequently have adapted to it. In a study by Peasgood and colleagues (2003) looking at the QoL of “non-traditional” (prelingual) CI recipients, most of their participants demonstrated having great lip-reading skills. Despite showing limited speech recognition, the participants in their study used their devices full-time and their improved auditory awareness contributed to increased QoL benefit. In the present study, adults with congenital hearing loss also stated having good lip-reading skills and they were still using these skills during everyday communication.

Helgeson, Cohen, Schulz & Yasko (2000) observed that cancer patients who benefit from support group meetings are those who lack emotional support in their own social network. It could be argued that the reason why some CI recipients are more likely to attend support groups than others might be related to the amount of emotional support that they receive at home. However, looking at the results of the Glasgow Benefit Inventory (GBI) questionnaire, in most cases the opposite trend was observed, with greater social support after implantation noted by SG than NS participants. However, the reality of having a life-threatening illness is completely different from that of having a sensory disability. Possibly, the emotional needs of CI recipients are better met by sharing experiences with other CI recipients in addition to family support, since

as indicated by SG participants, 50% of their partners attended the meetings as well.

Nevertheless, it is possible that for some SG participants, the meetings do provide the emotional support they are lacking and results in the feeling of knowing “you are not alone”.

Double the number of SG participants reported changes in instrumental activities compared to that of NS participants in the ASC. Two possible reasons could explain this result: on average SG participants had been using their implants fewer years (6.6 years) than NS participants (8.3 years) and therefore the changes might be easier to recall since they happened more recently in their lives. Recall bias, remembering details about their life, communication and hearing status prior to receiving the CI is a common concern in retrospective QoL assessments after successful treatments (Lassaletta *et al.*, 2006). However as the recipients are able to remove the CIs and experience a similar pre-surgery status, it is believed that the extent of recall bias might be small. Another possibility is that because NS participants do not notice great changes in instrumental activities and they reported doing well, they do not feel the need to attend the meetings as much as those who attend. This idea might also be supported by the fact that 33% NS participants reported doing AR compared to 67% SG participants. However, it is unknown if the reason for reduced AR was a decision made by the audiologist based on each patient’s needs or if it was center-dependent or audiologist-dependent. It is possibly a combination of all three factors. Additionally 22% of the NS participants reported not having any challenges with CIs, which is also an indication that at least a small portion of this population is satisfied with the outcome and do not expect any changes in the future and therefore do not foresee a need to attend the meetings.

All the individuals in SG enjoyed educating others about CIs in contrast to 78% NS who also enjoyed it and the remaining NS participants would not bring it up as a topic. Several NS

participants pointed out that their CI did not define them and that having a CI was not enough reason to meet with others or to talk to others about it. Although not everybody who participated felt the same way, there is clearly a portion of the CI-recipient population who lack an interest or the need to meet with other CI recipients or to educate others about CIs.

One of the most common limitations reported by CI recipients has been the difficulty understanding speech in background noise (Lassaletta *et al.*, 2006; Faber & Grøntved, 2000). This was one of the main difficulties reported in the present study followed by using the phone. The main skill that both groups of individuals wanted to improve was listening to music followed by listening to speech in noise and by use of phone and learning about the equipment features. The SG participants had more interest in improving more skills than NS participants, which points out to a greater desire to improve their skills using the CI, and could be another reason why attending support groups meetings is important to them.

A larger number of NS individuals mentioned going online to search for information about new technology related to CIs than SG individuals. Online forums and manufacture's websites comprise a wealth of information that is attractive to many CI recipients. The NS recipients felt it was possible to find the information they needed online and therefore did not see the need to attend any meetings. Conversely, some SG participants were more inclined to meet other CI recipients to either learn personally about the experience of receiving an implant while considering one themselves, while others wanted to meet other CI recipients because they enjoyed their company, learning about others' experiences and also because they liked encouraging others. Similarly, Gilbert, Dodson, Gill & McKenzie (2012) described the benefits of a diabetes support group, including "encouragement", "staying motivated to reach their

goals”, “self-reflection”, “a sense of community” and “assisting others”. These were similar to the values of the meetings as described by most SG participants in the present study.

The support group meetings were satisfactory for the most part to all participants. The meetings encouraged a great portion of their participants to stay motivated and continue doing AR. However, there were two participants that felt their performance was above or below the average performance of other support group attendees. When attending support group meetings it is easy to compare yourself to others and as shown in these two cases, it could encourage the person to try new strategies or to work harder to improve communication, or it could make the person feel better and more confident for performing above the average CI recipient.

Audiologists seeing CI patients should consider the recipient’s performance in speech understanding along with their attitude towards motivation for self-improvement when counseling and offering information about support group meetings. Furthermore those patients who might feel isolated and lonely could also benefit from support group meetings, as well as those who are eager to learn more about equipment features and do not get all of their questions answered during clinical appointments.

Study Limitations

There were several shortcomings to this study. First, the recruitment of participants was self-selected. For the participants who attend support groups, two local support groups were approached and informed about the study; persons who attend support groups were interested and were easily recruited. However, one of the two groups was run by a CI company and most of its participants came from one particular clinic. Therefore, because the audiologic services received might be similar for all these patients, this group might not be representative of the whole population but exclusively a large portion of the St. Louis metropolitan area. The

participants that did not attend support groups were less accessible because in order to reach out to them they had to be informed about the study at a routine audiological visit. Most patients who have had a CI for longer than a year do not frequently visit their audiologist and therefore recruitment was limited to only 9 rather than 12 participants.

Second, there were adults with congenital hearing loss as well as hearing loss occurring later in life in both groups. These two subgroups have distinctively different lifestyles and opinions regarding their own hearing loss, and in order to make a fair comparison, each subgroup should be evaluated independently. However, due to the limited number of participants, their responses were combined in the analysis. Nevertheless, it did provide more heterogeneity, which is regarded as providing more robust raw data for the qualitative analysis of personal interviews.

Third, the length and progression of each participant's hearing loss influenced how much they were able to recall about life before receiving the CI. Recall bias is a concern in any retrospective study since self perception of past abilities or limitations during the period right before receiving the CI might have been influenced by the length of that period or the degree of change in their hearing loss. Therefore, some of the tools used in this study, like the ASC, might not be the most effective to quantify realistic changes after cochlear implantation but they can still point out trends in each study group.

CONCLUSION

All CI recipients in the present study perceived an improved QoL since receiving the CI. However, when comparing those recipients who attended support groups meetings from those who did not, clear differences in their QoL could not be pointed out. Nevertheless, the qualitative approach allowed the researcher to sort out why most SG participants value the meetings and

their motivation and perceived benefit from continued attendance. The greatest interests for most recipients were 1) the social aspect of support group meetings, 2) the need to learn from others' personal experiences, 3) the need to learn about the technology and 4) for some it was about that feeling that "you are not alone". Although there are clearly many CI recipients who have no interest in peer support group meetings, there is a proportion of the population who enjoys attending and finds it to be a contributing factor for their improved QoL. For that reason, it is important that CI clinics are proactive at offering information and encouraging all patients to attend these meetings. Furthermore, attending a support group meeting could be a recommendation during the candidacy period to help prospective recipients learn about CIs through other recipients' experiences.

REFERENCES

- Baum, C. (1995). The contribution of occupation to function in persons with Alzheimer's disease. *Journal of Occupational Science: Australia*, 2(2), 59-67.
- Baum, C. & Edwards, D. (2008). Activity Card Sort, 2nd Ed. Bethesda, MD: AOTA Press.
- Bergeron, F. & Ferron, P. (2005). Utility of ear implants: Can all benefits be valued? *Cochlear Implants International*, 6 (Supplement 1), 2–3. DOI: 10.1002/cii.268.
- Bredberg, G. & Lindström, B. & Baumgartner, W.D. & Farhadi, M. & Goldberg, T. & Gstöttner, W. & Pillsbury, H., et al. (2003). Open-set speech perception in adult cochlear implant users with ossified cochleae. *Cochlear Implants International*, 4(2), 55-72.
- Brownson, C. & Heisler, M. (2009). The role of peer support in diabetes care and self-management. *Patient*, 2, 5-17.
- Chisolm, T.H. & Johnson, C.E. & Jeffrey L. & Danhauer, J.L. & Portz, L.J.P. & Abrams, H.B., et al. (2007). A Systematic Review of Health-Related Quality of Life and Hearing Aids: Final Report of the American Academy of Audiology Task Force on the Health-Related Quality of Life Benefits of Amplification in Adults. *Journal of American Academy of Audiology*, 18(33), 151-183.
- Dalton, D.S. & Cruickshanks, K.J. & Klein B.E. & Klein, R. & Wiley, T.L. & Nonhdahl, D.M. (2003). The impact of hearing loss on quality of life in older adults. *Gerontologist*, 43, 661-668.
- Damen, G.W. & Beynon, A.J. & Krabbe, P.F. & Mulder, J.J. & Mylanus, E.A. (2007). Cochlear implantation and quality of life in postlingually deaf adults: Long-term follow-up. *Otolaryngology, Head and Neck Surgery*, 136, 597-604.

- Eiser, C. & Morse, R. (2001). A review of measures of quality of life for children with chronic illness. *Archives of disease in childhood*, 84, 205-211.
- Faber, C.E. & Grøntved, A.M. (2000). Cochlear implantation and change in quality of life. *Acta Oto-laryngologica, Supplementum*, 543, 151-153.
- Feeny, D. & Furlong, W. & Torrance, G. & Goldsmith, C.H. & Zhu, Z & DePauw, S. *et al.* (2002). Multiattribute and single attribute utility functions for the health utilities index mark 3 system. *Medical Care*, 40, 113-128.
- Finlay, L. & Molano-Fisher, P. (2008). ‘Transforming’ self and world: a phenomenological study of a changing lifeworld following a cochlear implant. *Medicine, Health Care, and Philosophy*, 11(3), 255–267.
- Francis, H.W. & Chee, N. & Yeagle, J. & Cheng, A. & Niparko, J. K. (2002). Impact of cochlear implants on the functional health status of older adults. *Laryngoscope*, 112, 1482-1488.
- Gantz, B.J. & Turner, C. & Gfeller, K.E. & Lowder, M.W. (2005). Preservation of hearing in cochlear implant surgery: Advantages of combined electrical and acoustical speech processing. *Laryngoscope*, 115, 796-802.
- Gates, G.A. & Daly, K. & Dichtel, W.J. & Dooling, R.J. & Gulya, A.J & Hall, J.W., *et al.* (1995). Cochlear implants in adults and children. *The Journal of the American Medical Association*, 274(24), 1955-1961.
- Gilbert, K. & Dodson, S. & Gill, M. & McKenzie, R. (2012). Online communities are values by people with type 1 diabetes for peer support: how well do health professionals understand this? *Diabetes Spectrum*, 25(3), 180-191.

- Hallberg, L.R. & Ringdahl, A. (2004). Living with cochlear implants: experiences of 17 adult patients in Sweden. *International Journal of Audiology*, 43(2), 115-121.
- Hammel, J. & Magasi, S. & Heinemann, A. & Whiteneck, G. & Bogner, J. & Rodriguez, E. (2008). What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation*, 30(19), 1445-1460.
- Hawthorne, G. & Richardson, J. & Osborne, R. (1999). The assessment of quality of life (AQOL) instrument: a psychometric measure of health related quality of life. *Quality of Life Research*, 8, 208-224.
- Heinemann, A.W. (2010). Measurement of participation in rehabilitation research. *Archives of Physical Medicine and Rehabilitation, Supplement*, 91(9), 1-4.
- Heinemann, A.W. & Magasi, S. & Bokde, R.K. & Hammel, J. & Whiteneck, G.G. & Bogner, J. et al. (2013). Measuring enfranchisement: importance of and control over participation by people with disabilities. *Archives of Physical Medicine and Rehabilitation*, 94, 2157-2165.
- Helgeson, V.S. & Cohen, S. & Schulz, R. & Yasko, J. (2000). Group support interventions for women with breast cancer: who benefits from what? *Health Psychology*, 19(2), 107-114.
- Hinderink, J.B. & Krabbe, P.F & van Den Broek, P. (2000). Development and application of a health-related quality-of-life instrument for adults with cochlear implants: the Nijmegen cochlear implant questionnaire. *Otolaryngology, Head and Neck surgery*, 123, 756-765.
- Hogan, A. (1997). Implant outcomes: towards a mixed methodology for evaluating the efficacy of adult cochlear implant programmes. *Disability and Rehabilitation*, 19(6), 235-243.

- Hogan, A. & Hawthorne, G. & Kethel, E.G. & Giles, E. & White, K. & Stewart, M., *et al.* (2001). Health-relates quality-of-life outcomes from adult cochlear implantation: a cross-sectional survey. *Cochlear Implants International*, 2(2), 115-128.
- Karinen, P.J. & Sorri, M.J. & Valimaa, T.T. & Huttunen, K.H & Lopponen, H.J. (2001). Cochlear implant patients and quality of life. *Scandinavian Audiology. Supplementum*, (52), 48-50.
- Kiessling J. & Pichora-Fuller, M.K. & Gatehouse, S. & Stephens, D. & Arlinger, S. & Chisolm, T., *et al.* (2003). Candidature for and delivery of audiological services: special needs of older people. *International Journal of Audiology*, 42(Supplement), 2S92-101.
- Klop, W.M. & Boermans, P.B.P.M. & Ferrier, M.B. & van den Hout, W.B. & Stiggelbout, A.M. & Frijns, J. H.M. (2008). Clinical Relevance of quality of life outcome in cochlear implantation in postlingually deafened adults. *Otology & Neurotology*, 29, 615-621.
- Kyrouz, E.M. & Humphreys, K. (1997). A review of research on the effectiveness of self-help mutual aid groups. *International Journal of Psychosocial Rehabilitation*, 2, 64-68.
- Lassaletta, L. & Castro, A. & Bastarrica, M. & Sarriá, M. & Gavilán, J. (2006). Quality of life in postlingually deaf patients following cochlear implantation. *European Archives of Otorhinolaryngology*, 263, 267-270.
- Looi, V. & Mackenzie, M. & Bird, P. (2011). Quality-of-life outcomes for adult cochlear implant recipients in New Zealand. *The New Zealand Medical Journal*, 124(1340), 21-34.
- Lyons, K.D. & Zhongze, L. & Tosteson, T.D. & Meehan, K. & Ahles, T.A. (2010). Consistency and construct validity of the activity sort (modified) in measuring activity resumption after

- stem cell transplantation. *American Journal of Occupational Therapy*, 64, 562-569. doi: 10.5014/ajot.2010.09033
- Maillet, C.J. & Tyler, R.S. & Jordan, H.N. (1995). Change in the quality of life of adult cochlear implant patients. *Annals of Otology, Rhinology and Laryngology, Supplement*, 165, 31-48.
- Malterud, K. (2003). *Kvalitative metoder i medisinsk forskning: En innføring (Qualitative methods in medical research: An introduction)*. Oslo: Universitetsforlaget.
- Mo, B. & Lindbæk & Harris, S. (2005). Cochlear implants and quality of life: A prospective study. *Ear & Hearing*, 26, 186-194.
- Mulrow, C.D. & Aguilar, C. & Endicott, J.E. & Velez, R. & Tuley, M.R. & Charlip, W.S., et al. (1990). Association between hearing impairment and the quality of life of elderly individuals. *Journal of the American Geriatric Society*, 38, 45-50.
- NIDOC: National Institute on Deafness and Other Communication Disorders. (1996). National Strategic Research Plan, National Institutes of Health. U. S. Dept. of Health & Human Services, *Public Health Services*, 5.
- NIH (1995). Consensus statement on cochlear implants in adults and children. Washington, DC: National Institutes of Health.
- Niparko, J.K. & Agrawal, Y. (2009). The epidemiology of hearing loss: how prevalent is hearing loss? *In*: Niparko, J.K., ed. *Cochlear Implants: Principles and Practices* 2nd Ed. Lippincott Williams & Wilkins, Philadelphia, 39-42.
- Orlans, H. (1985). *Adjustment to adult hearing loss*. San Diego, CA: College-Hill Press.

- Palmer, S.P. & Niparko, J.K. & Wyatt, R. & Rothman, M. & de Lissovoy, G. (1999). A prospective study of the multichannel cochlear implant. *Archives of Otolaryngology, Head and Neck Surgery*, 125(11), 1221-1228.
- Parinet, S. & Lynn, C. & Glass, R.M. (2002). Quality of Life. *The Journal of the American Medical Association*, 288 (23), 3070.
- Peasgood, N. & Brookes, N. & Graham, J. (2003). Performance and benefit as outcome measures following cochlear implantation in non-traditional adult candidates: a pilot study. *Cochlear Implants International*, 4(4), 171-190.
- Raina, P. & Wong, M. & Massfeller, H. (2004) The relationship between sensory impairment and functional independence among elderly, *BMC Geriatrics*, 4, 3-5.
- Rembar, S. & Lind, O. & Arnesen, H. & Helvik, A. (2009). Effects of cochlear implants: a qualitative study. *Cochlear Implants International*, 10(4), 179-197.
- Robinson, K. & Gatehouse, S. & Browning, G.G. (1996). Measuring patient benefit from otorhinolaryngological surgery and therapy. *Annals of Otology, Rhinology and Laryngology*, 105, 415-422.
- Shitani, T. & Himi, T. & Yamaguschi, T. & Kataura, A. (1997). Longitudinal analysis of hearing ability and electrode status in post-lingually deaf adult s with cochlear implantation. *In: Takahashi, H.I. (ed.) Cochlear implant and related sciences update. Advances in Otorhinolaryngology*, vol 53, pp 229-232. Basel, New York: Karger.
- Shiroma, M. & Tako, I. & Kawano, J. & Kubo, T. & Funasaka, S. (1997). Evaluation methods of speech perception ability through cochlear implant. *In: Takahashi, H.I. (ed.) Cochlear implant and related sciences update. Advances in Otorhinolaryngology*, vol 53, pp 220-223.

Basel, New York: Karger.

Summerfield, A.Q. & Marshall, D.H. (1995). Cochlear Implantation in the UK 1990-1994 (Main Report). London: Her Majesty's Stationery Office.

Straatman, L.V. & Huinck, W.J. & Langereis, M.C. & Snik, A.F.M. & Mulder, J.J. (2014).

Cochlear implantation in late-implanted prelingually deafened adults: changes in quality of life. *Otology & Neurotology*, 35, 253-259.

Strawbridge, W.J. & Wallhagen, M.I. & Shema, S.J. & Kaplan, G.A. (2000). Negative consequences of hearing impairment in old age: a longitudinal analysis. *Gerontologist*, 40, 320-326.

Tyler, R.S. & Kelsay, D. (1990). Advantages and disadvantages reported by some of the better cochlear-implant patients. *The American Journal of Otology*, 11, 282-289.

Varni, J. & Burwinkle, T. & Lane, M.M. (2005). Health related quality of life measurements in pediatric clinical practice: an appraisal and percept for future research and application. *Health and Quality of Life Outcomes*, 3, 1-9.

Wallhagen, M. & Strawbridge, W. & Shema, S. & Kurata, J. & Kaplan, G. (2001). Comparative impact of hearing and vision impairment on subsequent functioning. *Journal of the American Geriatrics Society*, 49, 1086-1092.

Ware, J.E. & Kosinski, M. & Bjorner, J.B & Turner-Bowker, D.M. & Gandek, B. & Maruish, M.E. (2007). User's manual for the SF-36V2 Health Survey, 2nd Ed. Lincoln, RI: QualityMetric.

Weinstein, B.E. & Ventry, I.M. (1982). Hearing impairment and social isolation in the elderly. *ASHA*, 25, 593-599.

World Health Organization. (1997). WHOQOL Measuring Quality of Life. Geneva: WHO (MNH/PSF/97.4).

Yueh, B. & Souza, P.E. & McDowell, J.A. & Collins, M.P. & Loovis, C.F & Hedrick, S.C. *et al.* (2001). Randomized trial of amplification strategies. *Archives of Otolaryngology Head and Neck Surgery*, 127, 1197-1204.

Zaidman-Zait, A. (2011). Quality of life among cochlear implant recipients. *In: International Encyclopedia of Rehabilitation*, J.H. Stone, M. Blouin, Center for International Rehabilitation Research Information and Exchange (CIRRIE). Retrieved from <http://cirrie.buffalo.edu/encyclopedia/en/article/293/>

Table 1: Participants' demographic information.
 Support Group (SG), Non-Support Group (NS), Female (F), Male (M), Hearing Loss (HL), Cochlear (C), Advanced Bionics (AB), Nucleus (N).

Participant	SG/ NS	Sex	Age	Etiology	Age at onset of HL	Age at implantation	Speech Processor then	Speech Processor now
1	SG	F	68	unknown	58	58	C Freedom	C N6
2	SG	M	62	auto immune	51	54	C Freedom / C N5	C N6
3	SG	F	62	unknown	9	52	C ESprit 3G, N24/ N5 N5	C N6 / C N6
4	SG	F	67	ototoxicity	5	61	C Freedom	C Freedom
5	SG	F	74	otosclerosis	14	54	C ESprit N22	C ESprit N22
6	SG	M	76	mumps/ labyrin- thitis	5/55	72	C N5	C N5 / C N5
7	SG	F	64	unknown	0	59	AB Harmony	AB Naida
8	SG	M	54	unknown	20	52	C N5	C N6
9	SG	F	93	unknown	70	91	C N5	C N5
10	SG	M	61	unknown/ genetic	22	61	C N6	C N6
11	SG	M	60	unknown	28	56	C N5	C N5
12	SG	F	55	unknown	20	47	C Freedom / C Freedom	C Freedom / C N6
13	NS	F	67	unknown/ genetic	0	61	AB Harmony	AB Harmony
14	NS	F	57	Waarden- burg Syndrome	0	57	C N6 + acoustic	C N6 + acoustic
15	NS	F	84	unknown	65	82	C N5	C N5
16	NS	F	49	unknown	0	37	C ESprit 3G N24	C N5
17	NS	F	56	unknown/ genetic	5	46	C ESprit 3G N24 / C Freedom	C N5 / C N5
18	NS	M	44	Waarden- burg Syndrome	10	37	C ESprit 3G N24 / C Freedom	C Freedom / C N5
19	NS	M	43	unknown/ genetic	28	35	C Freedom	C N5
20	NS	M	73	Waarden- burg Syndrome	30	60	C ESprit N22 / C Freedom	C Freedom / C ESprit N22
21	NS	F	56	unknown	0	43	C ESprit N22	C N6

Socialization with Family and Friends

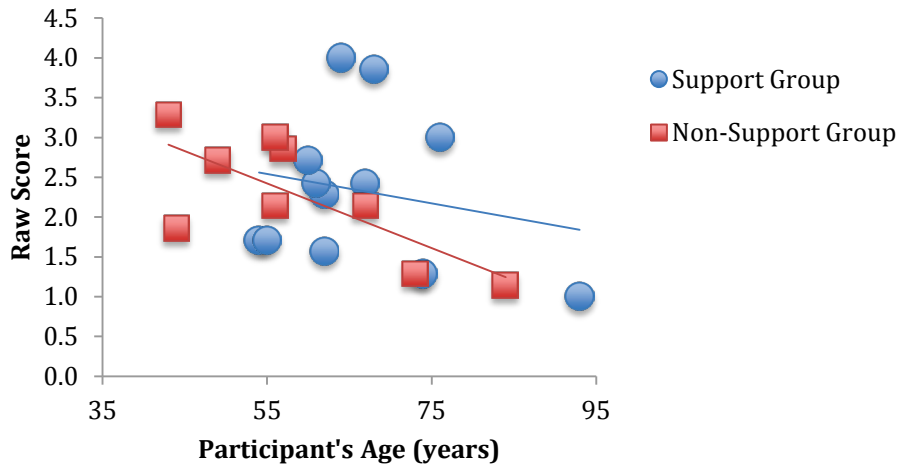


Figure 1. Results from CPI: Levels of socialization with family and friends relative to age of participants in support group and non-support group participants. Higher scores indicate greater socialization with family and friends.

Everyday Activity

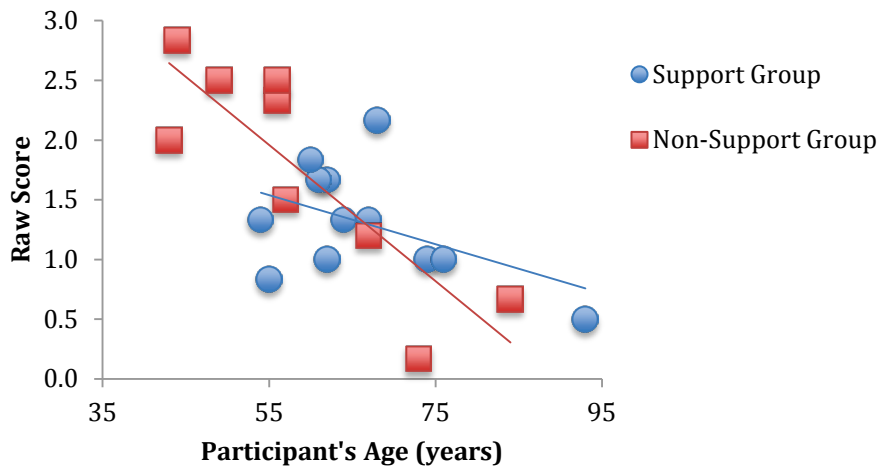


Figure 2. Results from CPI: Everyday activity levels relative to age of participants in support group and non-support group participants. Higher scores indicate greater involvement in everyday activities.

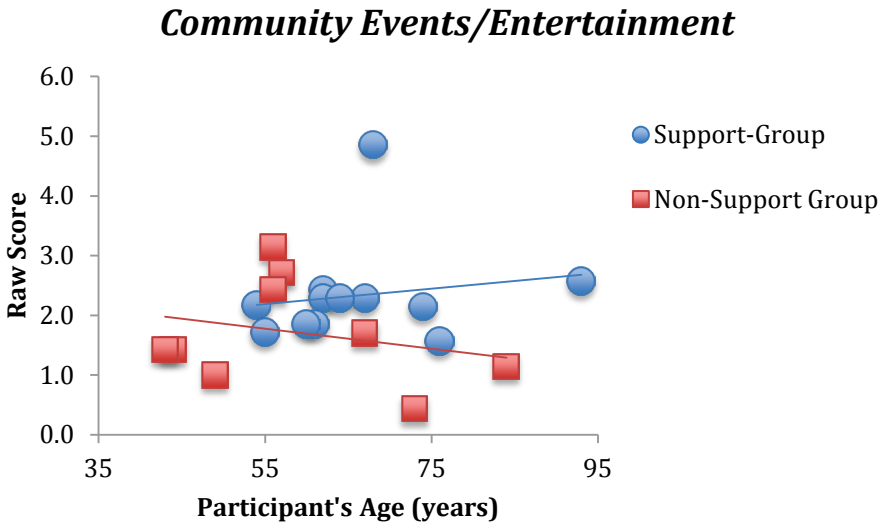


Figure 3. Results from CPI: Level of involvement in community events and entertainment relative to age of participants in support group and non-support group participants. Higher scores indicate greater involvement in community events and entertainment.

APPENDIX A

Non-attending support group participants (NS):

1. How long have you had a hearing loss?
2. How did you learn about cochlear implants?
3. Did you know anybody with a cochlear implant before you got yours?
4. What made you decide to get a cochlear implant?
5. When did you get your implant(s)? What kind?
6. Did you wear hearing aid(s) before the implant? How long?
7. Did you have any aural rehabilitation after implantation? How long?
8. What expectations did you have before receiving the cochlear implant? Did getting an implant meet the expectations you had?
9. Do you feel communication with your family/friends has changed because of the implant(s)? How?
10. Do you feel more confident in everyday communication since receiving the implant(s)? In which situations do you still have difficulties communicating?
11. Do you like talking about/educating others about the implant?
12. How do you feel when other people notice your implant and ask questions about it? Do you feel embarrassed, annoyed, proud, confident...?
13. Do you frequently meet with other CI users? Would you like to meet with other people who also have cochlear implants?
14. Do you know of any support groups for cochlear implant recipients in your area? Have you ever been to a meeting? Would you be interested in attending the meetings if available? Why?
15. What are some skills you wish to improve using your implants? For example communicating over the phone, conversations in quiet, conversations in noise, listening to music, learning more about how to use all of your the equipment features.

16. How do you stay current about new technology/processors?
 - a. Through your audiologist?
 - b. Go online or via email forums?
 - c. Go to local meetings for the deaf and hard of hearing community?

Support group participants (SG):

1. How long have you had a hearing loss?
2. How did you learn about cochlear implants?
3. Did you know anybody with a cochlear implant before you got yours?
4. What made you decide to get a cochlear implant?
5. When did you get your implant(s)? What kind?
6. Did you wear hearing aid(s) before the implant? How long?
7. Did you have any aural rehabilitation after implantation? How long?
8. What expectations did you have before receiving the cochlear implant? Did getting an implant meet the expectations you had?
9. Do you feel communication with your family/friends has changed because of the implant(s)?
How?
10. Do you feel more confident in everyday communication since receiving the implant(s)? In which situations do you still have difficulties communicating?
11. Do you like talking about/educating others about the implant?
12. How do you feel when other people notice your implant and ask questions about it? Do you feel embarrassed, annoyed, proud, confident...?
13. What are some skills you wish to improve using your implants? For example communicating over the phone, conversations in quiet, conversations in noise, listening to music, learning more about how to use all of your the equipment features.

14. How do you stay current about new technology/processors?
 - a. Through your audiologist?
 - b. Go online or via email forums?
 - c. Go to local meetings for the deaf and hard of hearing community?
 - d. Go to CI support group meetings
15. How did you learn about the support group?
16. How often do you attend the meetings? 1-2 times/year, 3-4 times/year, mostly monthly
17. How much do you interact in the group?
 - a. I only like to listen
 - b. I like to ask questions and talk to others
 - c. I like to be a leader in a small or large group within the group
18. What about with other CI users outside the group?
19. What have you learned in the group that was not addressed by your audiologist?
20. How do you feel about participating in the group?
 - a. I always learn something
 - b. I like to share my story
 - c. I like to meet peers
 - d. I like to stay current with the technology
 - e. I like to get motivated to continue improving my communication abilities with others
 - f. Other
21. How did attending the meetings impact your life? What about your family members' lives?
22. How did it impact your rehabilitation process and your motivation to continue doing rehabilitation?
23. Have you had opportunities to become a mentor to other participants?
24. What are your expectations from the support group? Do you feel the group has met your expectations?

25. What made you decide to attend for the first time? What kept you attending?
26. Is there anything you would change about the meetings?
27. What components or aspects of the meeting do you find most helpful?

APPENDIX B

CODE BOOK

Trees

History of Hearing Loss and Cochlear Implant

Social Interaction after Cochlear Implantation

Challenges with Cochlear Implant

Support Group Involvement

History of Hearing loss and Cochlear Implant

Decision to get a CI – Refers to what factors contributed into making the decision to get a cochlear implant

Implant expectations – Refers to the expectations participants had before receiving the implant about the outcome of the implantation

Length of AR – Refers to whether participants received auditory rehabilitation after implantation and the length of rehabilitation

Length of CI use, type – Refers to the Manufacturer of their cochlear implant and the model they received and the current model they are using

Length of HA use and which ear(s) – Refers to whether participants wore hearing aids before implantation in the ear that was implanted and length of use

Length of hearing loss – Refers to the amount of time in months or years since the participant first noticed or was diagnosed with a hearing loss until present

Previously known CI users – Refers to whether participants knew or talked to someone with a cochlear implant prior to receiving their own

Social Interaction after Cochlear Implantation

Confidence with CI – Refers to whether participants felt an increase in confidence during communication after receiving the cochlear implant

Educating others about CI – Refers to whether participants enjoyed and actively educated others who might be interested to learn about cochlear implants

Relationship with other CI users – Refers to whether participants had friendships with other cochlear implant users outside the support groups

Self image with CI – Refers to whether participants felt self conscious about their image after receiving the cochlear implant

Challenges with Cochlear Implant

Difficulties with CI – Refers to activities that are still a struggle for participants using their implant(s).

Skills to improve using CIs – Refers to skills that participants wish to improve using their implant(s), such as communicating in quiet, in noise, talking over the phone, listening to music or learning more about how to use all the equipment features.

Staying current with technology – Refers to how the participant receives information regarding the latest technology coming out in regards to cochlear implant technology.

Support Group Involvement

Changes and most helpful parts of SG – Refers to the portions of the support group that were most helpful or most enjoyable for the attendants and also which parts in any they

thought should be changed.

Expectations from SG – Refers to what were participants hoping to get from the support group before attending for the first time and whether it turned out to be what they had hoped for.

Impact of SG on AR – Refers to whether attending the support groups has influence the participant in the amount or intensity of aural rehabilitation done at home

Impact of SG on user's and family's lives – Refers to how family members relationship with the participant might have been influenced by the participant's attendance to support groups

Interaction with other CI users – Refers to the role of the participant at the support group with respect to other attendants

Learned at Support Group – Refers to information and experience gained from attending the support groups

Learned about Support Group – Refers to how the participant first learned about the existence and also got encouraged to attend to the first support group meeting

Participation in support groups – Refers to the participant's interest and involvement in support groups for the deaf or hard of hearing or for cochlear implant users.

Reason for attendance to SG – Refers to the reason that made them attend the meetings for the first time and why did they continue attending the meetings

Support group attendance – Refers to frequency per month of support group attendance