BARRIERS TO COCHLEAR IMPLANTATION FOR THE MD WITH DISTINCTION IN RESEARCH

by

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DISSERTATION

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Abstract

<u>Introduction</u>: Cochlear implantation (CI) is the most effective treatment for profound sensorineural hearing loss, despite the low utilization of CI in the United States. Only about 5-7% of CI-eligible adults pursue CI, for reasons which remain unclear.

<u>Objective:</u> Our research has two primary aims: 1) to identify sociodemographic disparities in CI in Texas and explore trends using an all-payer database from 2010-2017; and 2) to investigate patient-reported barriers to, and motivators for, pursuing CI.

<u>Methods</u>: Aim 1) The publicly available Texas Outpatient Surgical and Radiological Procedure Data was accessed to analyze outpatient CI cases in the entire state of Texas. Variables analyzed include patient age, sex, race/ethnicity, and insurance status. Population data from the American Community Survey were utilized to generate CI utilization rates by patient demographic characteristics. Insurance data was obtained from the Kaiser Family Foundation.

Aim 2) A single-institutional review of CI candidates between December 2010 and December 2018 was performed to identify patients who did not pursue surgery, as well as those who pursued surgery after a delayed time period or at a different institution. A 21-question survey was developed internally, aimed at identifying and ranking patients' concerns regarding surgical risks, adaptation to the CI, costs, loss of residual hearing, and lack of benefit. Current hearing aid usage and familiarity with other CI users were also analyzed. The survey was administered via email or telephone.

<u>Results</u>: Aim 1) 6,158 CI cases were identified during the study period. The number of CI per year nearly doubled from 497 in 2010 to 961 in 2017. The majority of CI recipients were white (59.5%), male (51.9%), and privately insured (47.9%). Patients over 75 demonstrated the

greatest increase in the CI rate per 100,000 population, increasing from 4.60 in 2010 to 14.30 in 2017. All racial/ethnic groups noted an increase in the CI per 100,000 population, with white patients demonstrating the highest rate in 2017, at 4.36 CI per 100,000 population. Asian patients had a 502% increase in the CI rate (from 0.42 to 2.53), compared with 87.9%, 84.4%, and 69.2% increases for White, Black, and Hispanic populations, respectively. Medicaid recipients were the only insurance group that did not experience a statistically significant growth from 2010-2017 (3.27 to 3.49, p=0.26).

Aim 2) Fifty-two survey responses were received, comprised of 27 patients who did not pursue CI and 25 patients who did. The most commonly reported barrier was a belief that CI would not significantly improve the ability to communicate, followed by concerns over the post-operative recovery process, risks of surgery, and risks of losing music appreciation. Anesthetic risk and cost were the least important reasons not to pursue CI. The most commonly reported motivator was a belief that hearing loss was affecting job performance.

<u>Conclusions:</u> CI became more widespread between 2010-2017; however, vast disparities exist in who benefitted most from this growth in CI. Black and Hispanic populations had lower CI per 100,000 population than their White peers, while patients >65 years of age accounted for the greatest increase in CI. Moreover, the decision not to pursue CI despite eligibility is multifactorial and includes concern for minimal hearing benefit. These factors should be taken into consideration when counseling patients on CI surgery. Resources should be devoted to promote CI to disadvantaged groups as identified in our research.

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INTRODUCTION

Overview of Hearing Loss and Cochlear Implants

Approximately 27.7 million American adults report hearing loss in the frequencies used to hear human speech.¹ Hearing loss is classified between three types: conductive hearing loss, sensorineural hearing loss (SNHL), and mixed hearing loss. Conductive hearing loss is defined as hearing loss that occurs as a result of problems in the outer or middle ear, with the eardrum separating the two.² SNHL is defined as hearing loss that occurs as a result of problems in the auditory nerve (hearing nerve).³ Mixed hearing loss includes both conductive and SNHL.³ Many factors can cause SNHL, including hereditary disorders, head trauma, infection, autoimmune disorders, inner ear malformations, exposure to loud noises, and advanced age. Age-related hearing loss is known as presbycusis, with age being the most significant risk factor associated with hearing loss (odds ratio [OR] 39.5; 95% confidence interval [CI] 10.5-149.4).¹

There are many treatments for SNHL, including lifestyle modifications, assistive listening devices, and surgical options. Lifestyle modifications include lip reading, monitoring body language, and having friends and family speak more loudly and slowly. The most popular assistive listening device is a hearing aid (HA). All types of hearing loss may benefit from these interventions, but for patients with profound SNHL who no longer gain significant benefit from the aforementioned options, cochlear implants (CI) are an effective surgical option. CI are a small electronic device with an external component that sits behind the ear and a surgically implanted internal component. The external component includes a microphone, transmitter, and speech processor, while the internal component includes a receiver and electrode. Compared to HA, in patients with severe to profound SNHL, CI generally improve speech perception outcomes, sound localization, hearing in noisy environments, mental health, and social functioning.⁴⁻⁶ And while costly, CI are also more cost-effective than HA in patients implanted up to at least 90 years old.^{4,7,8} Overall, CI provide patients numerous benefits relative to HA, and healthcare providers should consider referring patients with profound SNHL for CI evaluation.

The CI evaluation is an extensive process requiring a multidisciplinary team. The evaluation process begins with screening for CI candidates, generally by an audiologist, although screening can occur in a primary care clinicians' or general otolaryngologists' offices as well. The evaluation includes determining the patients' speech perception while they are wearing the best-fitted HA. Speech perception testing is commonly determined via the AzBio sentence list, which is a set of standardized, validated sentences in English and Spanish, although other tests can include single words.⁹ Currently, the Food and Drug Administration (FDA) approves CI for adult candidates who score \leq 50% on speech perception testing in the ear to be implanted, or \leq 60% when both ears are tested in the best-aided condition.¹⁰ However, audiologic candidacy for CI continue to evolve, slowly broadening to include more patients.¹⁰

After the audiologic evaluation, which includes counseling, if the patient qualifies, further assessment is completed by a CI surgeon. The CI surgeon may obtain imaging, while offering additional counseling prior to implantation. Additional preoperative input can include involvement with general practitioners, psychiatrists, and speech language pathologists to discuss auditory-verbal therapy.

CI surgery is an approximately 90-minute outpatient procedure. The electrode is inserted into the cochlea, bypassing the missing or damaged cochlear hair cells to directly

stimulate the auditory nerve.¹¹ CI surgery is relatively safe and has a few complications, which include bleeding, infection, facial nerve weakness, tinnitus, vertigo, or device malfunction. A poor hearing result could also occur, but is unlikely given the extensive CI evaluation process and counseling that patients undergo prior to implantation.¹²

The post-operative follow-up period begins 2 weeks after surgery, when the patient is seen by both the CI surgeon and the audiologist. The CI surgeon will assess for post-operative complications, while the audiologist will provide the speech processor, enabling the patient to hear sounds. Patients are subsequently seen by a CI audiologist 5-6 times in the first year to continue to program and adjust the CI, troubleshooting any issues. The patient may also see an auditory-verbal therapist to help with the rehabilitation process.

Current Trends in Cochlear Implantation

Worldwide, it is estimated that over 600,000 patients have received a CI; however, the overall CI utilization rate in the US is low.¹³ It is estimated that only 50% of pediatric CI candidates and 5-7% of adult CI candidates in the US have received a CI. CI utilization in Australia and Europe is similarly low, at rates less than 10%.¹⁴ There are a number of factors that may contribute to this low utilization rate, including a lack of screening for hearing loss in adults and a lack of referrals by primary care clinicians to hearing healthcare providers.¹⁴ Both of these factors are reflective of an overall perception that hearing loss in adults is not a significant health issue, contrary to evidence that shows that hearing loss can worsen dementia and cognitive functioning, increase social isolation, and cause depressive or anxious symptoms.¹⁴⁻¹⁷ Despite the current overall low utilization of CI, the number of CI recipients is increasing over time, though this increase is not equitably distributed.^{18,19}

Specific trends in adult CI in the US are not well understood, as prior studies are limited by insurance or geographic location. An analysis of privately insured and Medicare Advantage patients found that the overall increase in CI was driven by an increase in CI recipients older than 60.¹⁹ Moreover, the average age of CI patients in multiple adult CI studies is between 60-65 years of age, despite these studies only including CI recipients over 18 years of age.¹⁹⁻²¹ Racial and ethnic trends in CI are also not well understood. One study of CI recipients at UT Southwestern found that the majority (88%) of CI patients were White, while minority patients were half as likely to pursue surgery as compared to White patients (OR 0.47; 95% CI: 0.25-0.88). This in contrast to racial demographics of the Dallas-Fort Worth metropolitan area, with only 47% of the population classified as White, indicating that the CI population at UT Southwestern does not represent the community at large.²¹ Another study conducted at Vanderbilt University Medical Center, one of the largest CI centers in the US, similarly found that 87% of their CI recipients were Caucasian, 7% African American, and 6% other, which was not representative of their city or state where they are located.

In contrast, pediatric CI trends are better elucidated, although still limited to inpatient cases. Similar to trends in the adult population, several studies have shown that White children have been implanted at a significantly higher rate than minority children.²²⁻²⁵ White children were implanted twice as often as Black (RR: 0.52, 95% CI: 0.32-0.84, p=0.007) or Hispanic (RR: 0.53, 95% CI: 0.36-0.78, p=.0012) children.²² Amongst minority children, Asian children were implanted more than twice as often as Black or Hispanic Children (p=.0154 and p=.0098 respectively).²² In analyzing trends in insurance, the number of pediatric CI recipients with Medicaid increased from 17.4% to 35.2% (p<0.0001), which was mirrored by a significant increase in the number of pediatric CI recipients in the lowest two income quartiles (15.5% to 24.4%, p<.0001 for the second lowest income quartile; 0.3%-21.8% p<.0035 for the lowest income quartile).²² While disparities in insurance and race/ethnicity in the pediatric CI population have been published before, these studies are limited to inpatient cases or national survey samples, and therefore the exact reasons for the disparities have not been thoroughly studied.

While these studies highlight inequalities in CI, all aforementioned studies are all limited either by center, insurance, geography, or patient age. Additionally, these studies did not analyze the interaction between these sociodemographic variables, making it challenging to identify high-yield populations that could quickly improve CI utilization rates.

Multilevel, Multifactorial Barriers to Cochlear Implantation

The low CI utilization rate and disparities between implanted patients highlight significant barriers that patients face in pursuing CI. These barriers are complex, multifactorial, and exist across the entire hearing healthcare spectrum. Aside from CI, patients also have low utilization rates of hearing testing and HA use.²⁶ According to the 2014 National Health Interview Survey, 32.2% of respondents who reported difficulty hearing had never seen a clinician for hearing problems, and 28% had never had their hearing tested.²⁶ This is a fundamental barrier, as a trial HA should precede CI. But barriers still persist for patients who are plugged into the hearing healthcare system. In 2008, Huart et al. showed that 41% of members of the American Academy of Audiology reported they had not referred a patient for CI evaluation in the past 6 months.²⁷ Additionally, in listing barriers to referring patients for CI, hearing healthcare providers in the United Kingdom and Australia have reported a lack of

knowledge of CI, lack of confidence in identifying CI candidates, reimbursement issues, and access to care issues in remote areas.²⁸ Moreover, even after their CI evaluation, patients report a lack of motivation, reluctance to lose residual hearing, uncertainty about hearing outcomes, concerns about cost, fear of surgical complications, and a lack of social support as barriers to pursuing CI.^{28,29} These factors must all be appropriately addressed in order to increase CI utilization rates, mitigating disparities.

Aims of Our Studies

Disparities and barriers can only be addressed if they are identified. Prior studies regarding sociodemographic trends and patient-reported barriers to CI in the United States are limited. Our research has two primary aims:

1) to identify statewide sociodemographic trends and disparities in cochlear implantation in the state of Texas from 2010-2017

2) to identify patient-reported barriers and motivators in pursuing CI surgery from a single CI center

Overall, these studies collectively aim to identify CI barriers that can be minimized or eliminated, increasing CI utilization.

METHODS

We conducted two separate studies to address each of our aims. The methodology for each study is outlined below.

Aim 1:

Study Database

This study was exempt from UT Southwestern Institutional Review Board review. Our study utilized the Texas Outpatient Surgical and Radiological Procedure Data Public Use Data File (PUDF). The PUDF is managed by the Texas Health Care Information Council, which is responsible for collecting hospital discharge data from all state licensed hospitals, with some exemptions. A full list of state licensed hospitals is available online. The PUDF is a publicly available, deidentified dataset that covers a broad spectrum of hospital discharges, including discharges after surgery, and includes many sociodemographic variables, including age, insurance, race/ethnicity, and sex.

Study Population

Our study population comprised of all individuals undergoing CI in a state-licensed hospital in Texas from 2010-2017. We used Current Procedural Terminology (CPT) code 69930 and Healthcare Common Procedure Coding System code L6814 to identify CI Cases. Study Variables

We analyzed CI rates by age, sex, race/ethnicity, and insurance. Adults are defined as patients 18 years of age and older, and children are defined as patients less than 18 years of age. We further stratified age into the following categories: $0 - \langle 5 \rangle$ years, $5 - \langle 18 \rangle$ years, $18 - \langle 45 \rangle$ years, $45 - \langle 65 \rangle$ years, $65 - \langle 75 \rangle$ years, and $75 + \rangle$ years. Sex was categorized into either male or female. We grouped race and ethnicity as mutually exclusive groups: White, Black, Hispanic (includes Hispanics of any race), Asian, Native American (includes American Indian, Alaskan Native, Native Hawaiian, and Pacific Islanders) or others (includes those with other or an unknown race category). Insurance groups were categorized into mutually exclusive groups: Medicaid, Medicare, insured, and uninsured. These groupings are based off the Dallas Fort Worth Hospital Council Foundation primary payer groupings.

Statistical Analysis

We used descriptive statistics and rates per 100,000 (per capita) to analyze CI trends. We used population data for Texas from the American Community Survey to generate CI utilization rates by sex, race/ethnicity, and age.³⁰ Insurance data from the Kaiser Family Foundation for Texas was used to generate CI utilization rates by insurance type.

We used the χ^2 test of independence where appropriate to investigate significant associations between age, race/ethnicity, sex, and insurance type. Additionally, we assessed trends in CI rates by sub-population by using a simple linear regression model to estimate the slope and associated p-values, with year as the independent variable. All p-values were 2-sided and p<0.05 was considered to be statistically significant. We conducted statistical analyses with SAS statistical software, version 9.4 (SAS Institute, Cary, North Carolina).

Aim 2

Study Database

This study underwent UT Southwestern Institutional Board Review approval (STU 032018-085). This study utilized the UT Southwestern Adult Cochlear Implant Database. This database is a prospectively maintained database hosted on REDCap of all adult patients (18 years of age and older) who undergo a CI evaluation at UT Southwestern. There are currently over 1,200 records in the database. Each record includes patient sociodemographics, audiometric evaluations, CI evaluation results, imaging studies, surgery details, and follow-up visits.

Study Population

We queried the UT Southwestern Adult Cochlear Implant Database between December 2010-December 2018 to find English speaking patients who qualified for a CI but either elected to continue wearing HA, or who pursued a CI after a delayed period of time. A total of 199 patients were identified. Non-English-speaking patients, patients under 18 years of age, patients who did not qualify for a CI, and patients who proceeded with surgery immediately after the CI evaluation were excluded.

Patient Survey

We developed a 21-question survey to assess patient-reported barriers and motivators for pursuing CI (**Appendix 1**). The survey was distributed through REDCap and patients were contacted via email or telephone to complete the survey if not already completed. All participants provided informed consent before data collection and were notified that their data would be kept confidential. Patient demographic and audiometric information was obtained by reviewing each patient's electronic medical record (EMR).

Patients who elected to continue wearing HA were given a set of questions aimed at identifying their concerns regarding a CI. Using a visual analog scale, respondents were asked to weigh a number of factors that influenced their decision not to pursue a CI, with 100 signifying the "most important" reason, and 1 signifying that the factor was "not important at all." These factors included risk of surgery, anesthetic risk, monetary costs, time commitment, loss of residual hearing, and lack of benefit. Respondents were also provided a free text response option if a factor or reason was not listed.

Patients who pursued CI after a delayed period of time or at a different institution were given a set of questions aimed at identifying factors that motivated them to pursue CI. Respondents weighed each factor using the same scale as outlined above. These included the role of family support, effects on job performance, and deterioration of hearing. These respondents were also offered a free text response option.

Both groups also received questions limited to dichotomous responses regarding their prior hearing aid usage, familiarity with other CI users, concerns with the surgical and anesthetic complications, awareness of residual hearing, and concerns with the follow-up burden.

Statistical Analysis

A two-sided χ^2 test was used to compare differences in gender, race, ethnicity, sex, marital status, and dichotomous survey responses between groups. A Mann-Whitney U test compared differences in age and hearing healthcare utilization patterns. A Kruskal-Wallis test was performed to compare the visual-analog scale responses. P-values <0.05 were considered statistically significant. Statistical analysis was performed using SPSS 26.0 (IBM, Armonk, NY, USA).

RESULTS

Cochlear Implantation Trends in Texas

A total of 6,158 CI cases were identified from 2010-2017 in the state of Texas. The number of CI nearly doubled from 497 in 2010 to 961 in 2017. **Table 1** presents the detailed descriptive statistics of all CI cases. Overall, the majority of CI recipients were White, male, and privately insured recipients.

Children under the age of 5 accounted for 20.3% of CI recipients, the largest age group overall (**Figure 1**). However, when analyzing the CI rate as a proportion of the respective age group's population, adults over 75 made up the largest group, with a CI

per capita rate of 9.69 per 100,000 people, compared to 7.98 in children under 5 years of age. While the 18-<45 and 45-<65 age groups showed increases in their CI per capita rate, the increases were not statistically significant (p=0.12 and p=0.31, respectively).

Male made up the majority of CI recipients over the course of the study period (51.9% versus 47.8%, respectively). Though female patients experienced an 85% growth in their CI utilization rate per capita, compared to 74% growth in male recipients, males have consistently had a greater CI rate per capita since 2012 (**Figure 2**).

Additionally, most CI recipients in Texas were White (59.5%) or Hispanic (23.6%). Black, Asian, and Native American CI recipients together made up less than 10% of the total CI population (**Table 1**). All racial and ethnic groups saw a statistically significant increase in the CI per capita rate over the study period (**Figure 3**). The overall CI rate per 100,000 population is approximately equal among Asian (1.89) and Hispanic (1.80) patients; however, Asian patients had a 502% increase in the CI rate per 100,000 population compared to a 69.2% increase for Hispanic patients.

Privately insured patients made up 47.9% of CI recipients overall, which is approximately equal to the number of Medicare (27.9%) and Medicaid (20.3%) patients combined (**Table 1**). Despite the fact that both privately insured and Medicare patients experienced an approximately 76% increase in the CI utilization rate per capita over the study period, the CI per capita rate for Medicare recipients was 8.58, compared to 2.67 for privately insured patients (**Figure 4**). Neither Medicaid (3.27 to 3.49, p=0.26) nor uninsured (0.36 to 0.77, p=0.06) recipients experienced a statistically significant growth from 2010-2017.

We further explored the interaction between these sociodemographic variables. When analyzing sex by age, females constituted the majority of CI recipients between 18–<65 years

age, whereas, males accounted for the majority of CI in all other age groups. Age was significantly associated with sex when utilizing the $\chi 2$ test (p<0.0001) (**Table 2**). Assessing patients under 18 years, the majority of patients under 18 years were minorities, including 62.4% and 57.4% of all Hispanic and Asian CI patients, respectively, with age significantly associated with race (p<0.0001). Medicaid was the dominant insurance provider in the pediatric age group. In the 18-65 age group, most recipients had private insurance, and in the 65+ age group, most recipients had Medicare.

Sex was significantly associated with both race/ethnicity (p=0.0045) and insurance (p<0.0001, **Table 3**). The majority of Black CI recipients were female (56.3% versus 43.7% male recipients). However, the majority of White, Asian, and Hispanic recipients were male. Over half of Medicare and Medicaid recipients were male; whereas, an equal number of males and females had private insurance or were uninsured.

Lastly, race/ethnicity was also significantly associated with insurance (p<0.0001, **Table 4**). The majority of privately insured, Medicare, and uninsured recipients were White. Hispanic patients made up 55.7% of Medicaid recipients, and Medicaid was the predominant insurer for Hispanic patients. Though Asians only made up 3.9% of privately insured recipients, 70.7% of Asian CI patients were privately insured, compared with only 53.1%, 37.0%, and 32.5% for White, Black, and Hispanic CI patients, respectively. A comparable number of Black patients had Medicaid (40.2%) and private insurance (38.4%).

Exploring Patient-Reported Barriers to Cochlear Implantation

Of the 199 patients who were provided a survey, 52 responses were received for a response rate 26.1%. A total of 27 respondents did not undergo CI while 25 respondents eventually underwent CI, including seven that were performed at an outside institution. Sociodemographic characteristics of the study population are highlighted in **Table 5.** There were no significant differences in patient characteristics between patients who did and did not undergo surgery. The median age of patients who underwent surgery was 62 years, 48% were male, 80% were white, 88% were non-Hispanic/Latino, and 76% were married. The median age of patients who did not undergo surgery was 68.6 years, while 63% were white, 85.2% were non-Hispanic/Latino, and 55.6% were married. The Pre-Op AzBio in Quiet scores for patients who underwent surgery was 76%, compared to 55% for patients who did not undergo surgery (p=0.37).

Hearing aid usage between the two groups did not differ. Patients who did undergo surgery used their HA for an average of 7 years (IQR: 3 - 15), compared to 15 years for patients who did not undergo surgery ([IQR: 9 - 20.8], p=0.110). Patients who pursued surgery had worn a median of 3 hearing aid sets (IQR, 2 - 5) as compared to a median of 3 hearing aid sets (IQR, 1 - 4.3) for those patients who did not pursue surgery (p=0.787). Patients who pursued CI were more satisfied with their CI than patients who did not undergo surgery were with their HA. Patients who pursued CI reported a median satisfaction score of 82.0 (IQR, 62.0 - 88.5) with their CI, compared to a median satisfaction score of 36.0 (IQR, 24.0 - 54.0) from patients with HA who did not undergo CI surgery (p<0.001).

In analyzing general CI concerns, patients who underwent surgery were significantly more likely to feel that HA would not provide better hearing than a CI (p=0.040, **Table 6**) Patients who underwent surgery were significantly more likely to know someone with a CI

compared to those who did not undergo surgery (56% versus 25.9%, p=0.019); however, both groups were equally likely to know someone unhappy with their CI (4% of patients who underwent surgery versus 15% of patients who did not undergo surgery, p=0.202). While 76% of patients who underwent surgery knew what residual hearing is, only 33.3% of patients who did not undergo surgery were aware of residual hearing (p<0.001). Nonetheless, seven patients who did not proceed with CI reported that they were aware of residual hearing and were concerned they would lose it. Patients in both groups expressed the same level of concern regarding peri- and post- operative complications, cost, adjustment period, and follow-up.

Table 7 highlights free text responses of barriers from patients who did not pursue CI. Eight patients reported concerns about the sound quality, lack of improvement, or loss of residual hearing. Similar to the concerns expressed in the freetext responses, the number one objective concern patients reported was that CI would not significantly improve their ability to communicate (**Figure 5**). Additionally, this cohort was significantly more concerned with the risks of surgery and post-operative recovery process than the risk of anesthesia or cost of the surgery.

Family encouragement, job performance, personal health status, and deterioration of hearing were the top motivating factors that patients who underwent CI surgery expressed (**Figure 6**). While meeting a person with a CI was noted to be the least impactful motivator, this question received a score of 50, indicating that it is still a factor. In free text responses, patients also expressed concern over the impact their hearing loss had in social and work environments (**Table 8**).

DISCUSSION

Overview

To our knowledge, our work is the first to utilize a statewide, all-payer, outpatient database to study CI trends. Additionally, our second study is the first of its kind in the US to outline and quantify self-reported patient-driven barriers and facilitators to CI utilization. Overall, we found that the number of patients who received a CI in Texas did increase from 497 in 2010 to 961 in 2017. When analyzing the CI per capita rate, the majority of CI recipients were older (age greater than 65 years), White, male, and Medicare patients. Further, the decision to pursue CI is highly personal and influenced by numerous factors. Patients cited that a lack of improvement in communication, post-operative recovery process, and risks of surgery were the key barriers preventing them from pursuing CI. Patients who did undergo surgery had robust social support, felt that their hearing had deteriorated further, and their hearing loss was impacting their job performance.

General Trends in Cochlear Implantation Worldwide

Few studies have explored adult CI trends in the US, and while their findings generally corroborate our own, these studies utilized datasets that were limited by insurance, age, or geography. One study conducted by Fakurnejad et al., which analyzed a large, national commercial insurance database of private or Medicare Advantage recipients, supported our finding that CI has been increasing over time, and that this increase is driven predominately by older patients.¹⁹ From 2003-2016, Fakurnejad et al. identified 4145 cochlear implants, compared to our finding of 6158 implants from 2010-2017.¹⁹ Moreover, our CI per capita rate in the 75+ population was 14.30, compared to 11.6 in their 80+ age group.¹⁹ Another study by Agabigum et

al., which analyzed a national Medicare Part B dataset, found that CI in the elderly population increased 124.6%, from 1603 in 2007 to 3600 in 2016.¹⁸ Altogether, these studies emphasize the increasing utilization of CI, while also highlighting the limitations of each dataset.

Our data also enabled more thorough exploration of CI trends in the pediatric population. Prior studies have utilized the Kids' Inpatient Database (KID), which is a database that presents a nationwide sample of pediatric inpatient discharges. These studies are therefore limited in that KID does not report all cases, and additionally limited in that CI is predominately an outpatient procedure; therefore, accurate per capita rates in the pediatric population cannot be calculated.^{22,31} A study by Bradham et al. utilizing the National Health Interview Survey (NHIS), a self-reported, national dataset, from 1997-2003, estimated that there were 1065 potential CI candidates aged 12 months-6 years in Texas, and that nationwide, 55% of eligible younger children actually received a CI.³² This 55% estimation is derived from the ratio of the estimated number of young children qualifying for a CI to the CI manufacturers' report of recipients. Extrapolating this data, it would therefore be estimated that 586 children aged 12 months-6 years were implanted over their six-year study period, compared to the 1248 children aged 0-<5 years over the course of our seven year study period.³² Though this is an increase in the number of young pediatric CI recipients, our study estimates a pediatric CI utilization of 2.7% -33%, which is lower than the 55% reported by Bradham et al. Further studies elucidating these discrepancies and the unique barriers the pediatric CI populations face are warranted, as our analysis of patient-reported barriers to CI is limited to the adult population.

Europe also has a low utilization of adult CI.³³ Adult CI utilization in Europe and Australia is less than 10%, similar to the utilization rate in the US.^{14,34} Analyzing CI trends in Europe is more complex than in the US for a multitude of reasons. One study found that Germany had the highest rate of per capita CI in Europe, with approximately 45 CI per 1 million of the population. However, this data is difficult to compare to US data because Germany reports the number of cochlear *implants* and not the number of cochlear implant *recipients*, indicating that some recipients may be bilaterally implanted, and so the actual utilization rate may be lower. Additionally, smaller countries such as Luxembourg do not have CI centers, and so CI recipients often go to Germany or other neighboring countries for treatment. The differing payment structures throughout Europe also add to the complexity of analyzing CI utilization rates. It has also been noted that countries with self-funding payment models, such as Germany, have more relaxed CI candidacy criteria, and therefore more potential recipients, compared to countries with public funding payment models, such as the UK and Belgium. In contrast to the US, only the highest implanting countries (Belgium, Finland, Switzerland, and the UK) saw an increase in the number of CI recipients from 2010 to 2016; in most other countries, there was no notable increase.³⁴ These findings highlight the fact that globally, CI is a underutilized treatment despite the growing evidence that CI reduces depressive symptoms, improves cognitive function, and improves quality of life.³⁴

Specific Sociodemographic Trends in Cochlear Implantation in the US

Disparities in Cochlear Implantation by Sex

Our study included an in-depth analysis of various intersecting sociodemographic trends in CI in the state of Texas. In terms of the sex breakdown of CI recipients, males made up 52% of the CI recipients in Texas. However, when analyzing sex by age group, females account for the predominant number of cases in people between 18 – 65 years of age, similar to other studies, with males accounting for the predominant number of cases in the 65+ age group.¹⁹ We found that 57% of Medicare recipients were male, which is consistent with our sex versus age findings. The reasons for these disparities in CI between males and females are unclear. Though men are more likely than woman to have hearing loss, Tolisano et al. found that women were 1.56 times more likely to qualify for surgery (95% CI: 1.12-2.17), but were equally likely as men to pursue surgery (OR 0.98; 95% CI: 0.71-1.35).^{21,35-39}. If a clear reasoning for why female patients make up the majority of the younger CI recipients is elucidated, it may be beneficial in prompting male patients to pursue CI at a younger age. Further studies targeted towards analyzing this disparity are warranted.

Disparities in Cochlear Implantation by Insurance

We are unaware of any detailed analyses of insurance trends in the adult CI population. As we have mentioned previously, our dataset is unique in that it includes all insurance types in Texas; whereas, previous studies have focused either on the privately insured or Medicare population. In analyzing age and insurance, we found that the majority of adult CI recipients had private insurance or Medicare. Interestingly, the proportion of uninsured CI recipients was greatest in the 18-65 age group, indicating that hearing loss may be significantly affecting their work or social functioning, and paying the out of pocket cost is worth the benefit to them. In order to analyze whether there are disparities in adult CI by insurance type, or whether Texas differs from other states, more all-payer studies would need to be conducted.

Limited insurance data exists for the pediatric CI population. Early findings by Stern et al. found that only 21% of pediatric CI recipients from the KID in 1997 were Medicaid patients. In contrast, Tampio et al. analyzed KID data from 1997-2012 and found the percentage of children with Medicaid doubled from 17.4% to 35.2%.²² While we did not specifically analyze the insurance trends in the overall pediatric population over time, our finding that Medicaid recipients made up 50% of the total pediatric CI population in Texas supports the finding that an increase in Medicaid recipients is contributing to the growth in pediatric CI. However, it is estimated that 40% of children under 18 in Texas are enrolled in Medicaid/CHIP, and 11% of children in Texas is privately insured, but that is not reflective of the pediatric CI population. While several studies have noted a higher prevalence of hearing loss in low income families; children from higher median incomes families are more likely to receive a CI.^{31,43} Altogether, this indicates that the utilization of CI in privately insured pediatric candidates is still low, and this finding should be further investigated.

Disparities in Cochlear Implantation by Race/Ethnicity

Data on the racial and ethnic trends in the adult CI population are particularly limited, as few studies actually compare the racial/ethnic demographics of their CI population compared to the state population.^{20,21} While all racial/ethnic groups in Texas experienced a significant increase in their CI per capita rate, White CI recipients had a CI per capita rate nearly double that of any other race. The total CI population of Texas is 60% White and 24% Hispanic, compared to the total population of Texas which is 41% White and 40% Hispanic.⁴⁰ In contrast, we found that the pediatric CI population is more diverse and better resembles the overall population of Texas, with 38% of pediatric recipients being White and 41% are Hispanic. Texas overall has a larger Hispanic population than much of the US, which could account for the fact that other studies have shown that White and Asian children have higher CI rates compared to Hispanic or Black children.

These racial-ethnic differences in the CI population versus the population of the state represents stark disparities, and this disparity between White and minority patients is not unique to CI.⁴⁴ One reason for the lower rate of CI in minority populations could be related to insurance. Hispanic CI recipients predominately had Medicaid insurance, and we found that Medicaid recipients made up just 20% of the total CI population. Moreover, Medicaid was the only insurance type that did not see a significant increase in their CI rate over the study period. Insurance as a confounding variable still does not explain the low utilization in Blacks and Asians, as an equivalent number of Black recipients had private and Medicaid insurance, and the majority of Asians had private insurance. Analysis of National Health and Nutritional Examination Survey (NHANES) data has found that Black participants have better hearing compared to Hispanic and White participants.⁴⁵ A separate NHANES analysis of adults 70 and older found that Black participants were more likely to have recent hearing testing, but White patients were more likely to have recent HA use.⁴⁶ This discrepancy could be attributable to the fact that Medicare covers audiometric testing, but not HAs. However, poor HA use does not necessarily translate to poor CI use, as CI are covered by insurance, depending on the insurance type and degree of hearing loss. Insurance alone does not account for the disparities minorities face in accessing CI.

Few studies have been conducted in identifying specific barriers to accessing hearing healthcare in minority populations.^{47,48} Sims et al explored the low CI utilization of African

American patients in the Cincinnati area. They identified that physician mistrust, access to care issues, and a lack of hearing healthcare options contributed to low uptake.⁴⁷ Choi et al found that older Korean Americans were significantly impacted by hearing loss, but did not pursue CI due to a multitude of reasons, including cultural perceptions of health and hearing loss, cost, negative perceptions about hearing aids, language barriers, and lack of collaborative communication with physicians.⁴⁸ In particular, Korean Americans in this focus group noted that they feel most comfortable speaking Korean and prefer to only see Korean physicians.⁴⁸ Not only does a lack of representation in the CI population impact minority patients' willingness to pursue CI, but so too does a lack of representation in their hearing healthcare providers.

Patient Reported Barriers to CI

Beyond identifying larger, statewide CI trends, we sought to identify patient-reported barriers from those who decided not to pursue CI, in the hopes of potentially addressing these barriers and making CI more accessible and equitable for all patients.

Our study found that concerns over a lack of significant improvement in communication and uncertainty regarding CI sound quality was the top patient-reported barriers, both through the objective and subjective reporting. Studies from the UK and Australia also support these findings.²⁸ These concerns are not unique to CI, however, as many people report similar barriers to pursuing HA. Over half of HA users from a nationwide survey subjectively report poor benefit from HA.⁴⁹ Nearly 40% of HA users report issues with whistling and feedback, a specific concern shared by the Korean American participants in the Choi et al focus group studies.^{48,49} Through the free-text responses, our patients noted that they felt providers did not sufficiently discuss sound quality expectations following CI. While it is assumed that individuals who score lower on speech perception testing will gain the most from a CI, it is hard for hearing healthcare professionals to predict precisely how well each individual patient will do. Patients who underwent CI were significantly more likely to know someone with a CI, which could indicate that these patients had a better understanding of the post-operative sound quality expectations, or improvements in quality of life and social functioning. Minority patients made up a small proportion of the CI recipient pool, and so minorities are also less likely to benefit from this increased awareness that results from knowing CI recipients. Given the uncertainty of each patients' situation and the care that needs to be taken in setting realistic expectations, improved quality of life instruments may provide greater insight for patients into the benefits of CI, as opposed to post-operative speech perception scores.

It is interesting to note that an equal number of patients who did and did not undergo surgery responded "yes" when asked if they were concerned with the adjustment period (**Table 6**); however, patients who did not pursue CI still ranked it as their second highest barrier. This concern is understandable, given that CI is essentially an irreversible procedure and patients cannot simply remove the internal CI component as easily as not wearing their HA use if they are unhappy. Additionally, the adjustment period barrier is unique to CI, as HA often do not require as much adaptation, or have as many follow-up visits as CI do, so even experienced HA users may have expressed this concern. Though patients may be overwhelmed or frustrated by the time it takes to adapt to a CI, the long term benefits of CI over HA are substantial, including improved sound localization, delayed cognitive decline, and increased overall quality of life.^{4,5,7} No patients further explained their concerns about the adjustment period in the free-text responses, but given that we have identified this as a barrier, hearing healthcare providers should be aware and try to identify the patients' specific concerns about the recovery process and counsel them appropriately.

Patients who did not undergo surgery cited concerns about the surgical risks as their third most important barrier. However, when both groups were surveyed about general CI concerns, we found that there were no differences in the responses between both groups when asked about peri-and post-operative surgical and anesthetic risks. Moreover, concerns about the risks of anesthesia were the least important barrier. This discrepancy in why certain patients were more concerned with surgical risks than others is uncertain. Though we did not directly assess each groups' baseline health status, an equal number of participants in both groups reported they had not undergone surgery requiring general anesthesia in the past year. Possibly for some patients, this might have been their first operation, contributing to their fears. Regardless of the reasoning for this barrier, CI is overall a very safe surgery, with a complication rate of approximately 5%, and the most common side effects being tinnitus and vertigo.⁵⁰ Moreover, the rate of complications from CI surgery is much less than the risks from anesthesia, so it is unclear why patients are more concerned about the surgical complications than the anesthetic complications.^{50,51} While all CI surgeons explain surgical and anesthetic risks as part of the informed consent process, our findings indicate the need for clearer, more direct counseling of how the risks directly relate to the patient and their comorbidities to ensure that patient concerns are accurately and appropriately addressed.

A fear of losing residual hearing was the fourth highest barrier that patients reported and was discussed at length in the free-text responses. This was also reported to be a moderate barrier in the UK and Australia cohort.^{29,52} However, patients who did not undergo surgery were

significantly more likely to not know what residual hearing is compared to patients who underwent surgery. The fact that patients do not have a good understanding of residual hearing yet are concerned about losing it underscores a lack of understanding, possibly a reflection of poor healthy literacy, particularly as it pertains to hearing healthcare. Data on hearing health literacy is limited, but hearing loss has been identified as a risk factor for poor health literacy.⁵³ This presents an even greater barrier: if hearing loss cannot be addressed until the patient has improved health literacy, but hearing loss is also contributing to the poor health literacy, then this barrier is continuously compounded. Similar to setting appropriate expectations about sound quality, it is difficult to directly address patients' concerns regarding music appreciation and residual hearing. This is another domain in which exploring detailed quality of life outcomes and musical experience can help to reduce this barrier.

Overall, these barriers have been expressed by CI recipients in other countries, highlighting a global need for improvement.^{28,29} While further studies on specific quality of life measures is warranted to better inform patient expectations, most of these barriers can be addressed with thorough counseling, which was a deficiency that patients who did not undergo surgery reported consistently in free-text responses.

Prior studies of audiologists' interactions with patients found that the average counseling session lasted approximately 30 minutes, but when more time was allotted to counseling, patients had greater input and asked more clarifying questions.⁵⁴ Additionally, the counseling sessions lacked patient-centered communication and psychosocial concerns were rarely addressed.⁵⁴ This is a key area of improvement, especially given that our analysis has found that minority, Medicaid, and underinsured

recipients are underrepresented in the CI population and likely have unique psychosocial needs. A counseling training session developed by Utah State University was found to significantly decrease the audiologists' speaking time, though their quality scores by objective observers were not significantly improved.⁵⁵ Thorough counseling alone will not reduce barriers and eliminate healthcare disparities, as increased health literacy is necessary as well to accurately comprehend the counseling sessions.⁵⁶ While we acknowledge that improved counseling and health literacy are idealistic goals that are difficult to attain--due to the time constraints, communication barriers, and complex social dynamics of the CI evaluation, it is still worth pursuing, given the significant potential impact it may have in increasing CI utilization.

Patient Reported Facilitators to CI

The main motivators towards pursuing CI were patient concerns regarding the social impact of their hearing loss, particularly on job performance, as well as family support. All free text responses from patients who underwent surgery expressed that their hearing loss significantly impacted their ability to communicate with others, whether at their job or with their family. Other studies have also found that the impact on work and family life were key motivators to both CI and HA use.^{52,57} The average age of patients who underwent surgery was 62 years, compared to 69 years among patients who did not pursue surgery. While this difference is not statistically significant, it is worth noting that patients who did not undergo surgery may have already retired and therefore not realized the full impact of their hearing loss. Additionally, it is interesting that the majority of uninsured patients were in the 18-65 year old age group, or prime workforce. These patients too may have identified the impact of their hearing loss on their job performance early on. In terms of social support, while there was no significant difference in

marital status between the two groups, we did not directly analyze whether patients were accompanied, and by who, during their CI evaluation. This is again an important motivator to keep in mind for all patients, who may feel uncomfortable with the communication barrier secondary to hearing loss.⁴⁸ Even non-minority patients may feel uncomfortable speaking up, especially with a provider they just met, or overwhelmed with information, and family and friends can serve as important advocates in this regard.

Another key motivator was further deterioration of hearing, which ties directly into the negative impact of hearing loss on job performance. Patients who underwent surgery were significantly more likely to report that HA would not provide better hearing than a CI, and more likely to know someone with a CI. Knowing someone with a CI not only leads to increased awareness of CI, but also increased openness and acceptance of CI. Additionally, HA studies have found that patients' expectations and self-perceived benefit are correlated with HA use. Patients who perceived themselves more strongly as having a hearing problem were more likely to adopt HA, and patients who reported that their hearing loss was more severe used their HA for more hours daily.⁵⁸ This supports our findings that patients who no longer found benefit from their HA would turn to a more effective option.

As we highlighted above, merely tackling the barriers to CI is challenging and requires significant resources. Therefore, emphasizing these facilitators is another way to increase CI utilization. Encouraging patients to bring friends or family members to their CI evaluation, as well as informing HA users that there are still options available for them should their hearing continue to decline, are relatively lower resource initiatives.

Despite the barriers and disparities in CI, our study did find that all sociodemographic groups experienced an increase in CI over the course of our study

period. In general, an increased number of CI recipients could contribute to overall increased awareness of CI, which in turn leads to more CI recipients. This is highlighted by our finding that knowing someone with CI was a moderately influential motivator. Additionally, the US has a growing population as well as an aging population, and given that the incidence of hearing loss increases with age, so too does the pool for potential CI candidates.⁵⁹ Expanding CI candidacy criteria may also contribute to increased utilization, as more people are now eligible for CI than previously. However, the data still suggests that many additional patients could benefit from a CI.

Limitations

Our study has several limitations relevant to each specific aim.

Aim 1) Per the guidelines of the PUDF, some hospitals may be exempt from data collection, generally due to their low volume. Therefore, we feel they bear minimal effect on our results. On the contrary, using the PUDF is a strength of the study, as it includes facilities across the entire state, and not solely academic medical centers. Moreover, the data is reliant upon accurate discharge documentation from each CI center, which is another potential limitation of the study.

Aim 2) The overall sample size of this survey study is small and represents a single university CI program, limiting its external validity. Recall bias also weakens our findings, especially for patients who were implanted early in the study period. We only included adult patients, and pediatric patients likely have unique barriers and facilitators to CI. Additionally, we included only English-speaking patients. Non-English speaking or minority patients may experience unique barriers, especially in terms of their counseling, cultural perceptions of hearing healthcare, and lack of awareness of CI. However, we do not believe these limitations dramatically restrict our results, especially in the context of the findings from Aim 1 and given that such a study has never been conducted in the US. Understanding the barriers and motivators to pursuing CI improves healthcare counseling, as well as the patientprovider relationship.

Conclusion:

While the number of CI nearly doubled in Texas between 2010-2017, this increase benefitted certain groups more than others, the overall utilization of CI is still low relative to the potential number of CI candidates, and patients report a wide array of barriers to pursuing CI. Minority patients continue to have much lower CI per capita rates than White patients. Older and Medicare patients make up the majority of CI recipients, despite the fact that pediatric CI recipients are more likely to have Medicaid. Patients report concerns about the risk of CI surgery and sound quality.

Healthcare barriers and disparities cannot be addressed unless they have been fully and appropriately identified. While the root causes of these sociodemographic disparities in CI are not well understood, we believe the differences we found are not the result of differences in hearing loss, but the result of greater systemic issues. These sociodemographic disparities exist in all of healthcare and not unique to CI. While many of the causes for these barriers and disparities, such as physician mistrust, negative cultural perceptions of hearing loss, poor hearing health literacy, and inadequate counseling are challenging to overcome, the inertia required to correct these disparities should not discourage change. Care should be taken to ensure that further increases in CI utilization are equitable and accessible to all potential recipients.

Tables

Table 1: Descriptive Statistics of CI Cases in Texas, 2010-2017

Table 2: Cross tabulation of Age Group and Sex vs Sex Race/Ethnicity, and Insurance, 2010-2017.

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Variable	2010	2011	2012	2013	2014	2015	2016	2017	Total
Sex									
-Male	270	277	385	407	389	462	497	510	3197
	(54.3%)	(48.5%)	(48.4%)	(53.0%)	(50.8%)	(51.0%)	(55.5%)	(53.1%)	(51.9%)
-Female	223	293	409	360	374	442	393	449	2943
	(44.9%)	(51.3%)	(51.4%)	(46.9%)	(48.8%)	(48.8%)	(43.9%)	(46.7%)	(47.8%)
-Unknown	4	1	1	1	3	1	5	2	18
	(0.8%)	(0.2%)	(0.1%)	(0.1%)	(0.4%)	(0.1%)	(0.6%)	(0.2%)	(0.3%)
Age Group									
- 0 -< 5	138	103	139	181	140	173	177	197	1248
	(27.8%)	(18.0%)	(17.5%)	(23.6%)	(18.3%)	(19.1%)	(19.8%)	(20.5%)	(20.3%)
- 5 -< 18	96	86	132	105	116	134	158	136	963
	(19.3%)	(15.1%)	(16.6%)	(13.7%)	(15.1%)	(14.8%)	(17.7%)	(14.2%)	(15.6%)
- 18 -< 45	68	93	133	94	110	123	117	127	865
	(13.7%)	(16.3%)	(16.7%)	(12.2%)	(14.4%)	(13.6%)	(13.1%)	(13.2%)	(14.0%)
- 45 -< 65	85	134	169	167	159	194	132	159	1199
	(17.1%)	(23.5%)	(21.3%)	(21.7%)	(20.8%)	(21.4%)	(14.7%)	(16.5%)	(19.5%)
- 65 -< 75	58	79	114	106	130	151	147	156	941
	(11.7%)	(13.8%)	(14.3%)	(13.8%)	(17.0%)	(16.7%)	(16.4%)	(16.2%)	(15.3%)
- 75 & +	52	76	108	115	111	130	164	186	942
	(10.5%)	(13.3%)	(13.6%)	(15.0%)	(14.5%)	(14.4%)	(18.3%)	(19.4%)	(15.3%)
Race/ethnicity									
-White	264	342	473	523	480	562	509	513	3666
	(53.1%)	(59.9%)	(59.5%)	(68.1%)	(62.7%)	(62.1%)	(56.9%)	(53.4%)	(59.5%)
-Black	26	37	46	41	52	49	47	53	351
	(5.2%)	(6.5%)	(5.8%)	(5.3%)	(6.8%)	(5.4%)	(5.3%)	(5.5%)	(5.7%)
-Asian	4	9	23	21	15	25	36	31	164
	(0.8%)	(1.6%)	(2.9%)	(2.7%)	(2.0%)	(2.8%)	(4.0%)	(3.2%)	(2.7%)
-Native	0	0	1	0	1	1	3	4	10
	(0.0%)	(0.0%)	(0.1%)	(0.0%)	(0.1%)	(0.1%)	(0.3%)	(0.4%)	(0.2%)
-Hispanic	148	136	157	120	157	203	249	282	1452
	(29.8%)	(23.8%)	(19.7%)	(15.6%)	(20.5%)	(22.4%)	(27.8%)	(29.3%)	(23.6%)
	1							1	1

Table 1: Descriptive Statistics of CI cases in Texas, 2010-2017

-	55	47	95	63	61	65	51	78	515
Others/Unknown	(11.1%)	(8.2%)	(11.9%)	(8.2%)	(8.0%)	(7.2%)	(5.7%)	(8.1%)	(8.4%)
Insurance Status									
-Insured	223	242	359	402	375	467	399	483	2950
	(44.9%)	(42.4%)	(45.2%)	(52.3%)	(49.0%)	(51.6%)	(44.6%)	(50.3%)	(47.9%)
-Medicare	119	176	223	202	209	241	271	277	1718
	(23.9%)	(30.8%)	(28.1%)	(26.3%)	(27.3%)	(26.6%)	(30.3%)	(28.8%)	(27.9%)
-Medicaid	134	121	178	145	146	162	198	164	1248
	(27.0%)	(21.2%)	(22.4%)	(18.9%)	(19.1%)	(17.9%)	(22.1%)	(17.1%)	(20.3%)
-Uninsured	21	32	35	19	36	35	27	37	242
	(4.2%)	(5.6%)	(4.4%)	(2.5%)	(4.7%)	(3.9%)	(3.0%)	(3.9%)	(3.9%)
Total	497	571	795	768	766	905	895	961	6158

	Sex	* (P < 001)		Race / Ethnicity (P < .0001)						Total			
Age	Male	Female	White	Asian	Black	Hispanic	Native	Other	Private	Medicare	Medicaid	Uninsured	
Group													
- 0-<5	682	566	496	57	103	484	6	102	589	0	631	28	1248
	(21.3)	(19.2)	(13.5)	(34.8)	(29.3)	(33.3)	(60)	(19.8)	(20)	(0)	(50.6)	(11.6)	(20.3)
- 5-	501	462	344	37	73	417	3	89	434	1	479	49	963
<18	(15.7)	(15.7)	(9.4)	(22.6)	(20.8)	(28.7)	(30)	(17.3)	(14.7)	(0.1)	(38.4)	(20.3)	(15.6)
- 18-	373	485	537	23	67	152	0	86	580	119	92	74	865
<45	(11.7)	(16.5)	(14.7)	(14)	(19.1)	(10.5)	(0)	(16.7)	(19.7)	(6.9)	(7.4)	(30.6)	(14.1)
- 45-	522	670	848	20	64	159	1	107	900	184	45	70	1199
<65	(16.3)	(22.8)	(23.1)	(12.2)	(18.2)	(11)	(10)	(20.8)	(30.5)	(10.7)	(3.6)	(28.9)	(19.5)
- 65-	521	418	716	12	29	112	0	72	250	676	1	14	941
<75	(16.3)	(14.2)	(19.5)	(7.3)	(8.3)	(7.7)	(0)	(14)	(8.5)	(39.4)	(0.1)	(5.8)	(15.3)
- 75+	598	342	725	15	15	128	0	59	197	738	0	7	942
	(18.7)	(11.6)	(19.8)	(9.2)	(4.3)	(8.8)	(0)	(11.5)	(6.7)	(43)	(0)	(2.9)	(15.3)

Table 2: Cross tabulation of Age Group vs Sex, Race/Ethnicity, and Insurance, 2010-2017.

Percentages are in brackets, age in years. χ^2 test was used to investigate significant differences within each sub-population versus age. *18 records missing sex information.

	Race / Ethnicity (P = .0045)							Totals			
Sex *	White	Asian	Black	Hispanic	Native	Other	Private	Medicare	Medicaid	Uninsured	
Male	1933 (52.9)	90 (54.9)	152 (43.7)	766 (52.9)	2 (20)	254 (49.6)	1457 (49.6)	972 (56.7)	649 (52.1)	119 (50.8)	3197 (52.1)
Female	1724 (47.1)	74 (45.1)	196 (56.3)	683 (47.1)	8 (80)	258 (50.4)	1483 (50.4)	741 (43.3)	596 (47.9)	123 (49.2)	2943 (47.9)

Table 3: Cross tabulation of Sex vs Race/Ethnicity and Insurance, 2010-2017.

 χ^2 test was used to investigate significant differences within each sub-population versus gender. * 18 records missing sex information.

		Total			
Race/Ethnicity	Private	Medicare	Medicaid	Uninsured	
White	1948 (66)	1289 (75)	307 (24.6)	122 (50.4)	3666 (59.5)
Asian	116 (3.9)	21 (1.2)	18 (1.4)	9 (3.7)	164 (2.7)
Black	130 (4.4)	55 (3.2)	141 (11.3)	25 (10.3)	351 (5.7)
Hispanic	472 (16)	221 (12.9)	695 (55.7)	64 (26.5)	1452 (23.6)
Native	4 (0.1)	0 (0)	4 (0.3)	2 (0.8)	10 (0.2)
Others	280 (9.5)	132 (7.7)	83 (6.7)	20 (8.3)	515 (8.4)

Table 4: Cross tabulation of Race/Ethnicity vs Insurance, 2010-2017.

 $\chi 2$ test was used to investigate significant differences within each sub-population versus race/ethnicity.

	Patients who	Patients who did not	
	underwent surgery (n=25)	(n=27)	p-value
Age (Median years)	62.0	68.6	0.23
Gender			0.28
Male	48.0%	63.0%	
Female	52.0%	37.0%	
Race			0.58
White	80.0%	74.1%	
Black	4.0%	7.4%	
Asian	8.0%	0.0%	
Other/Unknown	8.0%	18.5%	
Ethnicity	-		0.96
Non-Hispanic/Latino	88.0%	85.2%	
Hispanic/Latino	0.0%	3.7%	
Other/Unknown	12.0%	3.7%	
Marital Status			0.19
Married	76.0%	55.6%	
Single	8.0%	18.5%	
Widowed	8.0%	7.4%	
Divorced	0.0%	3.7%	
Unknown	8.0%	14.8%	
Pre-Op AzBio in Quiet	76.0%	55.0%	0.37

Table 5: Demographic Characteristics of the Study Population

Table 6: General CI Concerns

	Patient underwen	ts who at surgery	Patients w undergo		
	(n =2	25)	(n=		
	Yes (%)	No (%)	Yes (%)	No (%)	p-Value
Do you think your hearing aids will provide you better hearing than a cochlear implant?	1 (4)	22 (88)	6 (24)	17 (63)	0.040
Do you know someone with a cochlear implant?	14 (56)	10 (40)	7 (25.9)	20 (74.1)	0.019
Do you know someone that is not happy with their cochlear implant?	1 (4)	23 (92)	4 (14.8)	23 (85.2)	0.202
Were you concerned about the surgical complications?	11 (44)	13 (52)	15 (55.6)	11 (40.7)	0.402
Were you concerned about anesthetic complications?	7 (28)	17 (68)	5 (18.5)	21 (77.8)	0.411
Have you had surgery requiring a general anesthetic in the past year?	10 (40)	14 (46)	12 (44.4)	15 (55.6)	0.842
Were you concerned with the period of adjustment with the cochlear implant?	14 (56)	10 (40)	16 (59.3)	11 (40.7)	0.947
Were you worried about dizziness?	12 (48)	11 (44)	10 (37.0)	14 (51.9)	0.471
Do you know what residual hearing is?	19 (76)	4 (16)	9 (33.3)	18 (66.7)	0.0005
If you have residual hearing and are aware of it, were you concerned you would lose your residual hearing?	6 (24)	17 (68)	9 (33.3)	14 (51.9)	0.345
Were you concerned about the cost of undergoing cochlear implant surgery?	11 (44)	13 (52)	13 (48.1)	13 (48.1)	0.768
Did insurance coverage play a role in your decision not to pursue a cochlear implant?	8 (32)	13 (52)	12 (44.4)	14 (51.9)	0.579
Have you ever not followed up an appointment with a physician due to an inability to afford the appointment?	2 (8)	22 (88)	1 (3.7)	26 (96.3)	0.483
Were you concerned about the number of visits that are required after implantation?	4 (16)	20 (80)	8 (29.6)	19 (70.4)	0.276
Have you ever been unable to get time off from work in order to attend a doctor's appointment?	1 (4)	22 (88)	3 (11.1)	19 (70.4)	0.274

Table 7: Barriers to CI in Patient Who Did Not Pursue CI

Free Text Responses

Comments Regarding Sound Quality/ Lack of Improvement

I was told that the CI would not really improve his hearing, and that's why I did not want to pursue implantation.

I want to know more about the sound reproduction of the cochlear implant. What will the voices sound like, etc. Did not know anything about loss of quality music.

I was concerned that I would be in the minority of patients who the surgery does not help, and that I did not want to risk losing any residual hearing that he had. I was also concerned that the Dr. Hunter would not be the one opening and closing the surgery, and that it would be residents/fellows.

I play piano by ear and thoroughly enjoy deciphering chord progressions of songs without music which I do not read. I enjoy searching for the nuances in harmonies and even compose my own arrangements. It's my understanding that the cochlear implant doesn't always cover the total spectrum in pitch frequencies therefore leaving me unable to discover such harmony nuances by ear as I do. My other concern is that should I be disappointed in this regard, then I would not be able to return to the hearing I had before the cochlear implant.

Concerned with HOW I would hear things. Would I hear voices and recognize them, or would it be mechanical sounding?

Comments Regarding Loss of Residual Hearing

I was told that I could lose hearing in my bad ear.

I virtually no have hearing in one ear. The doctor proposed putting the implant in my only good ear, and thus I was concerned that surgery could cause complete loss of hearing.

I was worried that the CI surgery would lead to losing any residual hearing I had left in her right ear. I am deaf in my left ear due to an acoustic neuroma removal. Dr. Roland, the physician who evaluated me, told me that if I were his sister, he would recommend not to get the surgery, and that was what solidified my choice to not pursue.

Comments Regarding Advances in Technology

I felt that my hearing aids could get me by enough. I also want the technology to advance in the cochlear implant field.

I found other hearing aids that helped with the volume loss and slightly improved clarity but not much. I decided to give them a try but wish I had gone ahead with cochlear implants. Thought if I could get by a few more years I might get newer technology in the cochlear implants.

Comments Regarding Cost

I was not entirely certain of the decision yet, wondering on the ability of insurance to cover the surgery.

I was told by the physician that my hearing loss was not to the level that I was approved for the procedure. My hearing has declined since but I'd have to consider the cost as well.

Comments Regarding Surgical Risks/Side Effects

I was concerned that implantation may worsen my ongoing issues with vertigo.

I have severe tinnitus. There is no guarantee this implant would fix the tinnitus.

Misc. Comments

My hearing began to regenerate as an answer to prayer.

It's scary, and I think I haven't come to terms with the fact that I might need one in the near future. I haven't met anyone with a cochlear implant so I don't know success stories in situations like mine.

I'm concerned with transportation and care after surgery.

Table 8: Motivators in CI in Patients Who Eventually Underwent CI

Free Text Responses

I've always believed that my inability to hear has had a negative impact in my participation in social and work conversations. I've coped so far, but the opportunity to correct my hearing was intriguing to me.

I was completely deaf without it.

I could no longer communicate with my wife or at work. I could no longer perceive speech, as I was only hearing noises.

I had lost hearing in my left ear many years ago, and relied on my right ear. I began to lose hearing in my right ear. Hearing aids helped, but my hearing got worse affecting both my personal and professional life. There was no other option but a Cochlear implant.

I could no longer carry on a conversation. I had no idea what a CI was - I just wanted to hear!

I had trauma to that ear, but had already lost a significant amount of hearing prior to the trauma. I only agreed to the cochlear to get the ablation of my vestibular (left ear) because I knew it would help my vertigo which had the biggest impact to doing my job. They did every test available to ensure it was my left ear that was causing the vertigo. However, and I do understand, my doctor was not willing to do the surgery unless he could implant. I previously had implants and have had them rejected and I was afraid this surgery would be no different. However, even though I had to have the implant explanted the vertigo is almost non-existent and for that I'm grateful

My hearing was so bad that I could not function normally.

Figures

Figure 1: CI rate per 100,000 population by age group, 2010-2017

Figure 2: CI rate per 100,000 population by sex, 2010-2017

Figure 3: CI rate per 100,000 population by race and ethnicity, 2010-2017

Figure 4: CI rate per 100,000 population by insurance status, 2010-2017

Figure 5: Patient Concerns Regarding Cochlear Implantation

Figure 6: Patient Motivators in Pursuing Cochlear Implantation



Figure 1: CI rate per 100,000 population by age group, 2010-2017

The total CI rate per capita rate was:

- 0-<5: 7.98
- 5-<18: 2.37
- 18-<45: 1.08
- 45-<65: 2.39
- 65-<75: 6.94
- 75+: 9.69



Figure 2: CI rate per 100,000 population by sex, 2010-2017

The total CI rate per capita rate was:

- Male: 3.06
- Female: 2.78



Figure 3: CI rate per 100,000 population by race and ethnicity, 2010-2017

The total CI per capita rate was

- White: 3.96
- Black: 1.44
- Asian: 1.89
- Native: 1.35
- Hispanic: 1.8



Figure 4: CI rate per 100,000 population by insurance status, 2010-2017

The total CI per capita rate was

- Private: 2.67
- Medicare: 8.58
- Medicaid: 3.47
- Uninsured: 0.58



Figure 5: Patient Concerns Regarding Cochlear Implantation

Respondents were instructed to use a visual analog scale by placing a marker on a continuous line to weigh each factor in which 100 signified "most important" and 1 signified "not important at all." Pairwise significant comparisons highlighted with an asterisk.

Question 1: I was concerned about the *cost* of surgery and related services, such as out-of-pocket expenses and deductibles.

Question 2: I was concerned about the risks of anesthesia.

Question 3: I was concerned about the risks of *surgery*.

Question 4: I was concerned that a cochlear implant would not significantly improve my ability to *communicate*.

Question 5: I was concerned about the post-operative *recovery* process, including the adaptive period to adjust to the cochlear implant.

Question 6: My current *hearing aids* are satisfactory for my needs.

Question 7: I did not want to risk losing my appreciation for *music*.



Figure 6: Patient Motivators in Pursuing Cochlear Implantation

Respondents were instructed to use a visual analog scale by placing a marker on a continuous line to weigh each factor in which 100 signified "most important" and 1 signified "not important at all." Pairwise significant comparisons highlighted with an asterisk.

Question 1: My *family* encouraged me to pursue surgery.

Question 2: I believed my job performance was impacted by my hearing status.

Question 3: My personal *health* changed.

Question 4: I met at least one person who had a cochlear implant and they had a good outcome.

Question 5: My hearing *deteriorated* further

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VITAE

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