

EMERGING ADULTS WITH COCHLEAR IMPLANTS: THEIR EXPERIENCES AND LIFEWORLDS

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Abstract

There is a fundamental gap in understanding the experiences and lifeworld development of emerging adults with cochlear implants (CI). Many studies using quantitative data describe the functionality of CIs with children. Moreover, there is a limited body of studies using qualitative methods such as ethnographic case studies where the narratives of emerging adults with cochlear implants are gathered to represent their experiences with being CI users. The goal of this research was to uncover the experiences of these emerging adults. In this study, five deaf emerging adults with CIs were interviewed over an extended period of time about their experiences and their social and emotional responses to the CI itself. Using a phenomenological lens, each member participated in a series of in-depth interviews and observations in order to reveal their identity, self-perception, and overall lifeworld in response to their CI. The results from this research suggest the CI is a social construction, the CIs were “not perfect” devices, participants handled adversity similarly, participants experienced increased autonomy, and the role of social support was an important factor. As a result of these data three archetypes for CI users were established based on the participants’ narratives.

COCHLEAR IMPLANTS: SOCIAL AND EMOTIONAL IMPLICATIONS

Each year, the use of cochlear implants (CI) usage is increasing dramatically. As of December 2012, nearly 324,200 individuals around the world have received this progressive technology (National Institute on Deafness and Other Communication Disorders, 2009). To date, this technology has primarily focused on the functionality and auditory and aural outcomes of these tools rather than the social and emotional responses of those who receive them. A growing number of researchers agree that more studies need to analyze the social and emotional effects that cochlear implantation has on children and adolescents (Christiansen & Leigh, 2002; Percy-Smith, Caye-Thomasen, Gudman, Hensen, & Thomsen, 2008; Schorr, Roth, & Fox, 2009; Thoutenhoofd et al., 2005.; Wheeler, Archbold, Gregory, & Skipp, 2007). As a result, little is known about the social and emotional responses of deaf adolescents and young adults with CIs from their own viewpoints.

However, a few recent studies have sought to contribute to our understanding of the social aspect of CIs on individuals. Spencer, Tomblin, and Gantz (2012), used mixed methods to investigate 41 CI users 16 years and older. A majority of these participants reflected a comfort with their dual identity and an overall satisfaction with life. Similarly, Stinson and Buckley (2013) discuss their own experiences with these devices along with 16 other CI users and/or families. Participant narratives reflect positive outcomes of CI usage and an overall fulfilling and life altering experience. Hilton, Jones, Harmon, and Cropper (2013), added to the research by using a phenomenological lens with 11 young individuals with bilateral cochlear implants. One theme that emerged from the study was contentment with bilateral devices, and also an improved self-confidence. These studies are useful in understanding the impact CIs have on groups of individuals; still, more qualitative research is needed to encompass CI users involved in different life stages and varying demographics.

PURPOSE OF THIS STUDY

The purpose of this qualitative study is to describe the experiences of specifically, “emerging adults” with CIs and the impact the device has on their social lives and self-perceptions (Arnett, 2000, p. 469).

In addition, most research thus far has used quantitative methods involving the perspectives of CI users’ families. This study is unique because it used qualitative methods to reveal the narratives of deaf emerging adults rather than responses from families.

Adolescents and Emerging Adults

Adolescence and emerging adulthood are both developmental stages that require several aspects of realization and exploration. Adolescence occurs between 11-19 years of age (Lukomski, 2007). Erikson (1980) described this time as when one creates and solidifies his or her identity. Although Erikson laid the foundation for this concept, a shift in our generation and society has led to other considerations related to when identity is formed. Arnett (2000) asserts that identity formation ensues during emerging adulthood rather than adolescence. Arnett (2000) characterizes emerging adulthood as occurring between the ages 18-25. He suggests this developmental period is distinct from adolescence and young adulthood because individuals are no longer considered an adolescent and yet are not fully immersed into the responsibilities adulthood requires. Emerging adults should be filled with ideas, perceptions, and plans for their futures. For this reason, the participants in this study were chosen based on their entrance into emerging adulthood.

RESEARCH QUESTIONS

The primary questions that guided this study were: What are the experiences of emerging adults with CIs and what is the impact the device has had on their social lives and self-perceptions? Additional questions I gained insight into were: (a) What are emerging adults’ overall perceptions of their own CI and CIs in general? (b) How do emerging adults with CIs describe their identity, quality of life, and social relationships?, and (c) In what ways do the participants say the CI has impacted their life? Using phenomenology as a methodological framework, I used in-depth interviews, observations, artifacts, and reflective memos. Overall, this study was an examination of the lives of cochlear implant users emerging into adulthood.

METHODS

Using phenomenology as a theoretical frame, five deaf emerging adults with cochlear implants were recruited from Southern California to share their lived experiences with using CIs over a 5-month period.

Participants

The participants consisted of three female and two male profoundly deaf emerging adults. All had received CIs at some point in their lifetime. Two of the participants received the CI at the age of four. Three of the participants chose a CI when they were teenagers between the ages of 15-18. The participants were in the range of emerging adulthood, aged 21-27.

Data-Collection

Multiple in-depth open-ended interviews were conducted and video taped and/or audio recorded with each participant. Throughout the process, a reflective journal, collected artifacts, and documented field notes were used during each meeting and after observations.

Transcription/Interpretation

Transcriptions took place after each meeting and each participant was able to view and comment on previously recorded and transcribed material at some point in the process. Contextualization was used in conjunction with categorization strategies to determine themes and synthesis of the content.

Phenomenology and Lifeworld

The lifeworld is a concept closely tied to phenomenology. Contributors such as Edmund Husserl and Alfred Schutz suggested “lifeworld” as relating to life experiences actions, expressions, and thought processes of daily living (Schwandt, 2007). Therefore, the lifeworld lens yields greater insight into the lived experiences of the participants and is compatible with the interpretive analysis used in this qualitative study.

RESULTS

The emerging adults in this study are analogous to travelers navigating their way through a variety of experiences with their CIs and stages of development. These five “travelers” candidly narrated their respective experiences in using a CI in both the Deaf and hearing worlds. As a result, five main themes were constructed based on participant’s responses. These themes are: (a) Phenomenological experiences of emerging adult CI users; (b) Social construction of the CI; (c) Adversity; advocate, assimilate or isolate; (d) Autonomy and social integration; and (e) The role of social support.

Phenomenological experiences

A plethora of data were collected revealing experiences ranging from hearing auditory input, school encounters, social endeavors, and identity. The overall arching theme among four out of the five participants was that they were content with their implant. Participants also reflected a fair amount of ambivalence regarding its consistency. One participant explained: “I wish I could say I hear perfectly like everyone else, but it doesn’t work that way. But, I love it. I really do love it.” Another reported several sounds as being annoying, but he also mentioned that it was a good decision to get a CI. Finally, another stated that although there were some limitations she loved her CI and was now able to feel more confident during group conversations, and special events.

Social construction of the CI

Researchers are beginning to see the social underpinnings that make the CI not only a medical intervention, but also a device that influences social constructions that make each individual’s experience unique (Hallberg & Ringdahl, 2004; Leigh & Maxwell-McCaw, 2011; Rashid, Kushalnager, & Kushalnagar, 2011) All five emerging adults in this study asserted their deafness, reported being able to hear with a CI, but also realized the CI’s limitations. In addition, miscommunication led to some frustrations for all participants but more detailed responses were acknowledged from the women. One participant noted, “When our batteries run out, we went from small d to big D.” Her observation suggests that receiving the CI does not restore the auditory sense indefinitely. In fact, the CI users in this study did not deny their deafness. They described themselves as deaf or hard of hearing. For these CI users, their family interactions, group conversations, and environmental interactions have been influenced positively and/or negatively through various life experiences shared. This suggests the social construction of the CI is an important consideration.

Adversity: Advocate, Assimilate or Isolate

Each emerging adult was confronted with opportunities to learn more about Deaf culture, the deaf community, and American Sign Language (ASL) at some point in their life. Through various exposures, all of the participants experienced some form of marginalization growing up being deaf and/or having their CI. As a result, they each

made the decision to advocate, assimilate or isolate from what could be perceived as oppressive forces.

Autonomy and Social Integration

Every participant suggested that the CI enhanced his/her confidence in some way. Their confidence promoted autonomy and social integration. One participant explained, "Without the CI, I probably wouldn't be able to have this much confidence, this much appreciation of myself." Another noted, she began taking notes in class, ordering her own food at McDonalds without communication breakdown. She also felt more confident to "live on her own" with her increased auditory capabilities. Finally, another described the implant as "opening a lot of doors for her." In short, all participants reported that their CI influenced their ability to gain independence and/or confidence in the hearing world.

The Role of Social Support

Support from friends and family were important contributors to social growth of the participants. However, along with support came reports of frustrations ranging from minor annoyances to constant arguments that were faced by some of the participants. Four of the five participants described their families as being "the most important people" in their lives. They shared praise and adoration for the academic support that their families provided. In contrast, one participant noted feeling "forced" into wearing his CI. He explained, "I wanted to be able to take my time and be comfortable but my parents wanted me to wear my CI all the time. I felt like they forced me too much. What they wanted for me I didn't want. I wanted to be who I am..." Three out of the five participants felt friends were helpful in their development. Two specifically mentioned friends providing support especially during their college experience.

DISCUSSION

Emerging adults progress through a rite of passage toward adulthood. Arnett (2000) asserted that during emerging adulthood social roles are discovered and identity development is at its peak. How does the transition into emerging adulthood affect deaf individuals with CIs? The five travelers in this study seemed to meet life's challenges and were establishing their identities that were described in Chickering and Reisser (1993). Each one showed signs of moving through the emerging adult stages toward autonomy.

Archetypes of Travelers with Cochlear Implants

The proliferation of CIs worldwide is bringing about a whole generation of deaf persons utilizing progressive technology. Yet, a CI user's journey may be different compared to a deaf person brought up in an auditory oral fashion, or even a culturally Deaf individual. This research looked at the five travelers' journeys to reveal three archetypes of emerging adult CI users, as shown in Table 1. Each archetype is described in detail with verbatim examples from the participants. These archetypes are not intended to be hierarchical. Instead, the most important aspect of these categories is whether or not the individual is comfortable with their travel "style" rather than the characteristics of a particular archetype.

Table 1

Archetypes of Emerging Adults With Cochlear Implants

Global Traveler	Native trekkers can transition into a variety of locations without hesitation or trepidation	<ul style="list-style-type: none"> • Comfortable in more than one society • Respects human difference • Able to move from one language and/or culture to another with ease.
Excursionist	Travelers never fully assimilate into their excursion location and interactions with natives are limited	<ul style="list-style-type: none"> • Comfortable in one chosen society • Visits other societies but does not develop significant social bonds • Does not learn and/or use languages outside their chosen environment.
Wanderer	Wanderers travel from place to place without assimilating into any one setting and are in a constant state of uncertainty about their surroundings and relationships.	<ul style="list-style-type: none"> • Does not feel comfortable in any particular group • May feel self-conscious about their identity • May feel uncomfortable using other languages

The Global Traveler

The first archetype for emerging adult CI users is the Global Traveler. A Global Traveler is more than a tourist. Instead, Global Travelers are native trekkers who can transition into a variety of locations without hesitation or trepidation. The CI user that is considered a Global Traveler is comfortable in more than one society, respects human differences, and can move from one language and/or culture to another with ease. Two participants that manifested this archetype noted when asked about being in Deaf and hearing worlds they "...have the best of both worlds."

The Excursionist

The second type of emerging adult with a CI can be characterized as an Excursionist. An Excursionist typically stays in one setting but out of curiosity takes short excursions to other worlds. The CI user that is considered an Excursionist is comfortable in one chosen society, visits other societies but does not develop significant social bonds, and does not learn and/or use languages outside their chosen environment. Two other participants reflected this archetype. They tended to spend more time to communicate or socialize with friends and family with whom they felt safe and accepted.

The Wanderer

The third archetype is a Wanderer. A Wanderer travels from place to place without assimilating into any one setting. Wanderers are in a constant state of uncertainty about their surroundings and relationships. CI users that maybe considered Wanderers do not feel comfortable in any particular group, may feel self-conscious about their identities, and may feel uncomfortable using languages other than their own. One

participant matching this archetype reported feeling uncomfortable and in the “grey” area with her deafness and ethnicity. This participant’s tenacity kept her moving onward, but her self-conscious feelings about her deafness prevented her from feeling embraced by other communities and/or cultures.

IMPLICATIONS

This research points to several implications for CI consumers, families, educators, practitioners and the Deaf community to consider. These implications are: (a) Maintain realistic expectations from the CI; (b) CIs are a social construction (c) CIs are likely to increase autonomy; (d) Arrange family supports and action plans for miscommunication and/or technological malfunctions; and (e) The intersection of Deaf and hearing worlds is an important consideration.

Future research should pursue the nuances involved with the social emotional and identity development of CI users of all ages, ethnicities, and genders. Qualitative and/or quantitative methods with larger populations will help validate the findings of this study and contribute to the literature.

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