

ADOLESCENTS' EXPERIENCES OF COCHLEAR IMPLANTATION

by

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This journey has not come to an end. It is only the start of a new beginning of hopeful dreams to come.

PLAGIARISM DECLARATION

I, Roxanne Fick, hereby declare that this mini-dissertation is my own work and that I to my knowledge have not committed any form of plagiarism.

Roxanne Fick

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ABSTRACT

The goal of this study was to explore the experiences of five adolescents who had undergone a cochlear implantation. The “Pretoria Cochlear Implant Centre” and the “Johannesburg Cochlear Implant Centre” were approached to obtain participants for the study. Four of the participants were adolescents between the ages of 15 to 18 years, while one participant was in the late adolescence/early adulthood phase, being 20 years of age. The research was conducted within the narrative metaphor. Unstructured interviews were conducted with the participants, the material transcribed by the researcher and the narratives analyzed by means of the “Three-dimensional Space Approach”. The research was conducted within the guidelines of the Postgraduate and Ethics Committees of the Faculty of Humanities at the University of Pretoria, South Africa. The narratives revealed that all the participants experience the cochlear implant as having a positive influence on various aspects of their lives, and also enabled them to move between a “society with silence” and a “society with sound”.



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CHAPTER 1

BACKGROUND

Introduction

In this chapter the research context will firstly be addressed by referring to a “society with silence”, a “society with sound”, as well as the process of moving from a society with silence to a society with sound, through technology. Secondly, a brief overview will be given of the cochlear implantation phenomenon, by focussing on the definition, history, statistics, criteria and procedure related to undergoing a cochlear implantation. Thirdly, the research question will be stated, followed by the research goals. Fourthly, the motivation for conducting this study will be portrayed. The chapter is finally concluded by an outline of the research report.

1.2 CONTEXT

The majority of people in society have the full use of all five of their senses, which include vision, hearing, smell, taste and touch (Colman, 2006). However, on the one hand some people in society are born without the use of one or more of their senses, while on the other hand people can lose the use of one or more of their senses during their life time due to, for example, accidents and/or illness. This research project particularly focuses on the auditory sense in society and depicts society at large as comprising, on the one hand of a minority society with silence, while on the other hand also being constituted by a majority society with sound.

1.1.3 A “Society with Silence”

When one enters the society with silence, one becomes aware of terminology that is not commonly known in the broader society. It is also important, for the purposes of this research project, to clarify this terminology. These terms are “Deaf” and “deaf”.

Firstly, Deaf with an uppercase “D”, is used to refer to visual people who cannot hear well enough to distinguish speech but disregard their deafness as a disability and

identify with, and partake in, the Deaf culture who have their own history. They share values, social norms, customs and technology, and in particular use sign language as their primary means of communication (eDeaf, n.d.a; Gonsoulin, 2001; Lane, 2005; National Institute for the Deaf [NID], 2010; Obasi, 2008; Reagon, 1995). To illustrate the strong identification with a Deaf culture, Cherney (1999, p. 28), provides a glimpse into John Limnidis' experience of deafness, at a time when he was active in the "Deaf President Now Movement" in 1988: "Deafness is not a handicap. It's a culture, a language, and I'm proud to be Deaf. If there was a medication that could be given to deaf people to make them hear, I wouldn't take it."

Deaf people within the Deaf culture use their hands, face, head and upper torso to create a natural, living language that is dynamic, constantly changing and developing, with its own grammar, syntax and structure. This natural living language, referred to as "South African Sign Language" (SASL), makes possible the opportunity to enjoy watching dramas and soap operas on Deaf TV on "South Africa's Broadcasting Corporation's" (SABC) Channel 3, and to have travel agencies and special tours for Deaf people who travel to South Africa (SA). This visual form of communication differs from country to country, making it unique as it is transferred from generation to generation within the Deaf culture. To sustain this Deaf culture, a Deaf person hopes to marry another Deaf person, so that they may have Deaf children who become part of their Deaf culture (Berke, 2010; Deaf Federation of South Africa [DeafSA], 2009; eDeaf, n.d.b; Gonsoulin, 2001; Lane & Bahan, 1998).

Famous Deaf people, such as Terence Parker, a former Olympian swimmer, Darren Rajbal, the most talented person in SA on "South Africa's Got Talent Show" and Wilma Newhoudt-Duchen, the first Deaf female in the world to be elected an official with experience serving on the South African Parliament, are all talented and successful members of the society of silence (Berke, 2010). Despite the talent and success of Deaf people in a society with silence, the unemployment rate of Deaf people in the society, with sound, is high. This seems to be the result of limited access to information from the society with sound and an historically low standard of education in Deaf schools, with Deaf people having very low levels of literacy compared to literacy levels of the hearing people in the society with sound. However, two Deaf service organisations assist Deaf people in becoming successful and

productive, participating members in a predominantly hearing society. One of these Deaf service organisations, called “e-Deaf”, provides holistic services to employers and Deaf employees. Another Deaf service organisation, the “National Institute for the Deaf” (NID), provides Deaf people and people with hearing loss, with support in terms of education, training, empowerment, rehabilitation, spiritual and social development, knowledge resources, care services and programmes as well as guidance and support to parents of deaf children (Berke, 2010; eDeaf, n.d.a; NID, 2010).

The relevance of an awareness of the Deaf culture enables us to make sense of the cultural debate between the Deaf culture and the Hearing culture surrounding the cochlear implant and cochlear implantation. Understanding the Deaf culture enables us to make sense of why Deaf people perceive the cochlear implant as an attack on them, and their culture, as well as the Hearing culture’s way of “curing” them. The negative perception that the Hearing culture has about deafness as preventing normal development is perceived by the Deaf culture as demeaning, belittling of the Deaf culture and their unique language and does not acknowledge the achievements of Deaf people and the diversity of lives that Deaf people lead. The Deaf people argue that the use of a cochlear implant could result in a child feeling as if he/she does not belong to either the Hearing or Deaf culture, as he/she may not participate as fully as hearing people do in a Hearing culture yet will also not have grown up in a Deaf community who communicate through sign language. As such, the Deaf people argue against parents making decisions for their deaf child/ren to be implanted and feel that deaf child/ren should be old enough to decide for themselves if they would like to undergo the optional innovative surgery of cochlear implantation and to which community he or she would like to belong. Deaf people also perceive the cost of the cochlear implant programme as diverting resources away from services of greater benefit to all deaf and hard of hearing people (Cherney, 1999; Crouch, 1997; Gonsoulin, 2001; Hyde & Power, 2000; Lane & Bahan, 1998; Power & Hyde, 1992; Skelton & Valentine, 2003).

The Hearing culture argues that the cochlear implant, used only for sensorineural hearing loss, has benefits in enabling the deaf individual to hear in a predominantly hearing society. It eliminates some of the burdens of being deaf, provides an

opportunity for some hearing and oral language and enables deaf individuals to become productive members in society. This is argued especially for individuals who go deaf after establishing their identity as hearing speaking and consequently may become personally, socially and vocationally limited as a result of their deafness. It is further argued that children who are deaf from a very young age should be implanted as early as possible to ensure development of spoken language during the child's neurologically critical period for development of spoken language. Consequently this opens up possibilities for conversations with the majority of the community who don't speak sign language (Crouch, 1997; Gonsoulin, 2001; Hyde & Power, 2000; Power & Hyde, 1992; Rice, 1993).

Considering that there are Deaf people who identify with the Deaf culture and oppose the cochlear implant, there are also deaf people who may not identify with the Deaf culture and may view the cochlear implant differently. This consequently brings me to a description of the second terminology of deaf. The second terminology, deaf with a lowercase "d" is used to refer to visual people who may have lost their hearing later in life, may have some ability to hear environmental sounds, or may have hearing ability adequate enough to understand speech on the phone with the help of hearing aids, who, despite varying degrees of hearing loss, do not use sign language as their primary means of communication. They may use their voice and speech reading to communicate with hearing people (DeafSA, 2009; NID, 2010; Senghas & Managhan, 2002). The purpose of this study refers to deaf people who adapt to a hearing society through the use of a cochlear implant.

A statistical description of the society of silence nationally, yields the following picture: In 2001, 412 421 people were profoundly deaf and 1 237 264 were extremely hard of hearing (NID, 2010). On an international level, the picture, as constituted by a statistical description portrays the following. The American population has nearly 10 000 000 people who are hard of hearing and close to 1 000 000 people who are functionally deaf (Mitchell, 2006). This indicates the wide variation in degrees of hearing loss, some of whom may identify with the Deaf culture while others may identify with the Hearing culture. Where the society with silence is predominantly visual, the society with sound is predominantly hearing.

1.1.4 A “Society with Sound”

Where information is processed by the eyes in a society with silence, a society with sound processes information with the ears. A person hears sounds such as birds singing, trees rustling in the wind, busy streets filled with honking cars and running engines, sirens, alarms and musical notes chiming in the air. The most common form of sound is in the form of spoken language that is produced by the mouth, tongue and vocal chords (eDeaf, n.d.b). Within SA there are 11 official spoken languages, which include English, Afrikaans, Ndebele, Sepedi, Xhosa, Venda, Tswana, Southern Sotho, Zulu, Swazi and Tsonga. English is the spoken language that is generally understood across the country but it is not necessarily rated the highest in terms of being the home language. This indicates the linguistic and cultural diversity of the society of sound within SA, often referred to as the “rainbow nation” (SA-Venues.com, 2010; SouthAfrica.info, 2010).

Spoken language seems to enable people to be productive members in a predominantly hearing society with sound (Crouch, 1997). It has been argued that those who do not hear in a society with sounds, tend to have the lowest educational level and family income. Despite this outcome for the Deaf in a society with sound, SASL, as one of the many languages of SA, can provide one way of moving from a society with silence to a society with sound through the use of a SASL interpreter (Nunes, 2001; SouthAfrica.info, 2010). SASL interpreters, hearing aids, FM systems and ear implantations are described next in terms of how they may be used to move from a society with silence, to a society with sound.

1.1.3 From a “Society with Silence” to a “Society with Sound” through Technology

There are various ways for those who choose to move from a society with silence to a society with sound. These are through the use of SASL interpreters, hearing aids, FM systems and/or ear implants.

Firstly, the SASL interpreter can assist a deaf person to move from silence to sound through facilitating communication between the hearing person and the Deaf person

through the use of SASL skills and any of the spoken 11 official languages in SA (SASLINC, n.d). However, taking into consideration the variation in degree of hearing loss, moving from silence to sound through technology can enable a person to communicate independently to a larger degree than with the assistance of a SASL interpreter.

Secondly, the use of hearing aids may provide improved speech perception and better sound recognition. There are two different types of hearing aids which function differently, namely digital hearing aids and analogue hearing aids (Hear-it, n.d.a). These hearing aids can be either in the form of “completely-in-the-canal” hearing aids, “in-the-canal” hearing aids, “in-the-ear” hearing aids or “behind-the-ear” hearing aids. Appendix A includes a visual description of these types of hearing aids (Hear-it, n.d.b).

Thirdly, a device that works together with a hearing aid, but is also available for hearing people, is the FM system. The FM technology is a type of wireless system that helps people to understand speech more clearly in noisy situations. The person speaking holds the transmitter microphone or the transmitter is placed in the middle of a group of people where it picks up speech all around the room. It uses harmless radio waves to send speech signals to the listener, who wears a tiny FM receiver behind the ear (Phonak, 2008).

Lastly, some deaf or profoundly hearing impaired people may not benefit from using hearing aids. However, there is still hope for these deaf people to move from silence to sound. Technology provides another option called an ear implant, which is a device that is inserted surgically into the ear. There are four types of these ear implants, which include the middle-ear implant, inner-ear implant (also referred to as the cochlear implant), the bone-anchored hearing aid and auditory brainstem implant (Hear-it, n.d.c). It is specifically the inner-ear implant, referred to as the cochlear implant, that is the technology of focus in this study, with the aim of understanding adolescents’ experiences of moving from a society with silence to a society with sound through the use of this technology.

1.2 COCHLEAR IMPLANT

When one refers to a cochlear implant it is important, for the purposes of this research project, to distinguish between the terminologies of “cochlear implant” and “cochlear implantation”. Firstly, cochlear implant is used to refer to the inner-ear implant device and when referring to a person who uses such inner-ear implant devices, we refer to a cochlear implant recipient. Secondly, cochlear implantation is used to refer to the medical procedure of receiving a cochlear implant (W. Deverson, personal communication, October 23, 2010).

A definition of the cochlear implant is outlined so as to provide a basic understanding of what this inner-ear implant is and how it functions. However, the cochlear implant also has a past in its making, and its development over time is provided in terms of its history, consequently creating statistics in terms of the number of people implanted. However, there are certain criteria that need to be met before the deaf person can be a successful candidate for the cochlear implantation procedure, which is also outlined. Since this study is a narrative study, co-researchers who have done research on the outcomes of the cochlear implantation, are given a fourth voice in the narratives of the participants of this study, so as to remain true to the position of a narrative approach.

1.4.1 Description of Cochlear implantation

Hearing loss can occur as a result of damage to any one or more parts of the outer, middle or inner ear. More specifically, damage to the cochlea, hair cells or auditory nerves can result in inner ear deafness, often referred to as sensorineural hearing loss. Hearing aids usually do not provide any form of benefit for the deaf person with sensorineural hearing loss, so the cochlear implant, is an alternative electronic device that people with moderate to profound hearing loss can use to gain access to sounds. This access to sounds allows the deaf person the potential opportunity to develop spoken language and speech perception in order to communicate and interact with other hearing people more easily and more comfortably (Connell & Balkany, 2006; Hasenstab, 1989; Hearing Loss Education Center [HLEC], 2008b;

Kalat, 2004; Med-El, 2010; The Ear Foundation, 2010a; The Ear Foundation, 2010b).

The cochlear implant has a microphone that picks up sound from the environment and sends it to the speech processor to be analysed and digitalised into coded signals. The speech processor then sends the coded signals to the transmitter coil via a direct wire. More specifically, the external magnet linked to the internal magnet under the skin, enables the external transmitter coil to send the coded signals via a radio frequency signal to the aligned internal transmitter coil underneath the skin (Arts, Gerber & Zwolan, 2002; Connell & Balkany, 2006; Copeland & Pillsbury, 2004; Müller & Wagenfeld, 2003; The Ear Foundation, 2010a; Wilson & Dorman, 2008).

The receiver, also referred to as a stimulator, receives the signals and converts it into electrical energy which is then sent to the electrodes. The electrodes stimulate the remaining auditory nerve fibres as they send the electrical sound information through the auditory system to the brain where it is recognised as sound and produces hearing sensations (Arts et al., 2002; Connell & Balkany, 2006; Copeland & Pillsbury, 2004; Hearing Loss Education Center [HLEC], 2008c; Müller & Wagenfeld, 2003; The Ear Foundation, 2010a). A visual description of how the cochlear implant works is provided in Appendix B. This technology, as explained, unfolded over time to be where it is today and continues to develop. A brief overview of the history of the cochlear implant is provided next.

1.4.2 History of the Cochlear Implant

The history of the cochlear implant seems to have developed through various phases. The first phase was prior to the 1900's, when an Italian Physicist, Conte Alessandro Volta, discovered that electrical stimulation produced auditory sensation. The second phase was between the 1930's and 1950's, during which the first implant of a device for electrical stimulation of the auditory nerve was done by Djourno and Eyries in 1957. The third phase stretched from the 1960's to 1970's, with continued developments of cochlear implants with House and Simmons as prominent figures during this time. Other contributors during this third phase were Michelson, Eddington, and Hochmair. The fourth phase commenced in the 1980's

when the first paediatric cochlear implant programme was established and the first child, a nine year old boy, received a cochlear implantation (Arts et al., 2002; Connell & Balkany, 2006; Stinson, 1996; Willis, Lee & Yanagisawa, 1986; Wilson & Dorman, 2008).

The history of the cochlear implant, in SA specifically, seemed to have started in 1986, when the cochlear implant was first introduced at the Tygerberg Hospital's "Cochlear Implant Unit", at the University of Stellenbosch (US). The first cochlear implantation procedure in SA was done in 1988. Cochlear implants were then introduced in Johannesburg and Pretoria in 1991 and in Bloemfontein in 2003 (Müller & Wagenfeld, 2003; Wagenfeld, Loock, Müller, Perold, Kerr, & Kaltenbrunn, 2004). The two specific cochlear implant programmes which form part of this study are the "Johannesburg Cochlear Implant Programme" and the "Pretoria Cochlear Implant Programme". I shall refer to these two programmes in more detail in Chapter 3.

1.4.3 Statistics of the Cochlear Implant

Cochlear implants have continued to develop since the 1980's, so much so that by 2005 there were more than 80 000 people with cochlear implants worldwide, with a cumulative number of implantations exceeding 120 000 in 2008 (Connell & Balkany, 2006; Wilson & Dorman, 2008). Of these statistics, 260 children have received cochlear implants between 1988 and 2003 in SA (Müller & Wagenfeld, 2003). Although the number of candidates is increasing for cochlear implantation, successful candidacy for the cochlear implantation requires that certain criteria need to be met.

1.4.4 Criteria for Cochlear Implantation

There are five criteria that need to be met for deaf people to be successfully selected for the cochlear implantation. These include (1) audiological suitability; (2) medical suitability; (3) speech and language suitability; (4) educational placement, as well as (5) family context.

The first selection criteria to determine audiological suitability entails audiological tests administered to the deaf person to assess the audiological aspects of the hearing loss. The deaf person also needs to complete a three to six month hearing aid trial period to determine the benefits of amplification. This ensures that any potential functional residual hearing has been used to its full potential, to improve auditory skills through encouraging the deaf person to focus on audition, spoken language and listening, to encourage familiarisation with the device and to enable the deaf person and his or her family to experience the commitment involved. Successful audiological suitability requires that the deaf person's sensorineural hearing loss in both ears is severe to profound with limited benefits from hearing aids (Balkany et al., 2002; Discolo & Hirose, 2002; Hasenstab, 1989; Hear for Life, 2006; Hearing Loss Education Center [HLEC], 2008d; Kileny, Kemink & Zimmerman-Phillips, 1991; Müller & Wagenfeld, 2003; Stinson, 1996; Yaremko, 1993).

The second selection criteria to determine medical suitability is conducted by the Ear, Nose and Throat (ENT) surgeon and entails a medical history of the hearing loss, a history of hearing aid use, medical evaluations to determine various medical factors that could influence the deaf person's suitability, surgery and rehabilitation of the cochlear implantation as well as a determination of which ear is to be implanted (Balkany et al., 2002; Hear for Life, 2006; Kileny et al., 1991; Müller & Wagenfeld, 2003).

The third selection criteria for speech and language suitability includes an evaluation of the deaf person's abilities and skills in terms of his or her speech intelligibility, language and cognition as well as facilitation of speech and language development through speech therapy and encouraging the deaf person to focus on spoken language and listening (Hear for Life, 2006; Müller & Wagenfeld, 2003; Stinson, 1996; Yaremko, 1993).

The fourth selection criteria entails considering appropriate educational placement and facilities for the deaf child. It is essential that the educational environment is supportive and promotes oral language development (Hear for Life, 2006; Müller & Wagenfeld, 2003).

The last selection criteria entails an assessment by the social worker or psychologist. He/she discusses and uses evaluative tools with the deaf person and his or her family to assess the family situation, the deaf person and his or her family's ability to cope with the hearing impairment and to assess the availability of potential support and commitment to the deaf person after the cochlear implantation operation. Information is also shared with the family and the deaf person in terms of the various aspects associated with creating a supportive home environment (Hasenstab, 1989; Hear for Life, 2006; Müller & Wagenfeld, 2003; Yaremko, 1993). Once these criteria have been met, and a decision is made to go ahead with the cochlear implantation, there are several phases that the deaf person goes through.

1.4.5 Procedure of Cochlear Implantation

There are three phases pertaining to the cochlear implantation procedures. These are the (1) pre-operational phase, (2) the operational phase, as well as the (3) post-operational phase.

The first phase, which occurs prior to the operation, usually begins after the professional team has met with the parents/guardians and/or deaf person to discuss the outcomes and recommendations regarding the successful candidacy for cochlear implantation. If the professional team agrees to successful candidacy, the parents/guardians and/or the deaf person makes a final decision as to whether they will follow through with the cochlear implantation (The Ear Foundation, 2010b; Yaremko, 1993). If they agree to follow through, a surgery date is planned and any otological procedures that are required, are completed before the surgery. The deaf person's understanding and consent for the cochlear implantation procedure is ensured, since his/her motivation to use the cochlear implant is important for successful outcomes. A pre-operational medical examination is completed about two weeks before the date of surgery (Clark, Cowan & Dowell, 1997).

During the operational phase, the deaf person usually goes into hospital the day prior to a morning surgery or early in the day for an afternoon surgery. The surgery usually lasts approximately one to three hours and toward the end of the operation, the electrode array is tested to ensure proper functioning of the receiver-stimulator

and the electrode array. A post-operative x-ray of the position of the array within the cochlear is also taken. The cochlear implant recipient is usually discharged on the day of the surgery or the next day and the stitches are then removed about seven days later (Balkany et al., 2002; Clark et al., 1997; Hearing Loss Education Center [HLEC], 2008a; Müller & Wagenfeld, 2003; Yaremko, 1993).

The post-operational phase begins after the operation stage, where the cochlear implant recipient is reviewed by the visiting otologist or hospital medical staff. About two to three days following discharge from the hospital, the otologist reviews the cochlear implant recipient again and an appointment is made for the initial fitting of the speech processor (Clark et al., 1997).

About two to four weeks after the operation, when the wound has healed, the cochlear implant recipient visits the audiologist who then fits and programmes the speech processor. This mapping of the speech processor continues for several weeks according to the cochlear implant recipient's pace, ensuring that the loudness of the individual electrodes are balanced across the electrode array in order to ensure optimum, dynamic range (Clark et al., 1997; Discolo & Hirose, 2002; Hasenstab, 1989; HLEC, 2008a; Kileny et al., 1991; Müller & Wagenfeld, 2003; Willis et al., 1986; Yaremko, 1993).

An auditory learning programme is provided for the cochlear implant recipient to improve listening skills, spoken communication and learning and to reduce visual forms of communication. As well as improving speech reading skills through various activities, the cochlear implant recipient now has to relearn to hear. Consistent monitoring of progress, changing and programming according to the needs of the cochlear implant recipient is done at specified time periods on a continuous basis until a satisfied point of hearing is reached. Regular follow-up sessions with the audiologist is then expected to continue thereafter (Harrison et al., 1997; Hasenstab, 1989; HLEC, 2008a; The Ear Foundation, 2010b; Willis et al., 1986; Yaremko, 1993).

Post-operative rehabilitation aims to ensure that the cochlear implant recipient acquires skill in discriminating auditory input through the cochlear implant and focuses on maximising the potential for improved auditory comprehension and

speech production as well as development of language and communication skills (Clark et al., 1997).

Up until recently, research on adolescents is limited because the cochlear implantation is more often conducted on very young children or on adults (Wheeler, Archbold, Gregory & Skipp, 2007). Research on adolescents' experiences of the cochlear implantation is extremely limited. For these reasons, I have selected the limited researches that have been conducted on the outcomes of cochlear implantations in adolescents and young children. These co-researchers' findings, in terms of the outcomes, have been integrated into the participants' narratives in this particular research report, which can be found in chapter 5 to chapter 9.

1.5 QUESTION

Based on the above descriptions in 1.1 and 1.2, the research question for this project is, "How do adolescents within the South African context experience cochlear implantation?"

1.4 GOALS

1.4.1 General Goals

The general goal of this research project is to explore how deaf adolescents, within a South African context, experience cochlear implantation.

1.4.2 Specific Goals

The specific goals of this research project are:

1. To describe the research position of this research project.
2. To describe the research inquiry of this research project.
3. To conduct the research project in accordance with the guidelines set by the Postgraduate Committee of the Faculty of Humanities at the University of Pretoria (UP).

4. To conduct the research project in accordance with the ethical clearance set by the Ethics Committee of the Faculty of Humanities at the UP.
5. To write the research report.

1.4 MOTIVATION

1.4.1 Academic Motivation

The academic context is the Department of Psychology at the UP. The Department of Psychology offers three Master of Arts (MA) degrees in Psychology, which include MA (Clinical Psychology), MA (Research Psychology) and MA (Counselling Psychology). I am a MA (Counselling Psychology) student, who is being trained within the researcher-practitioner model, and this research project accounts for 50% of the MA (Counselling Psychology) programme. This is one of the reasons why I am conducting this research project.

1.4.2 Research Motivation

A literature search through the Academic Information Services (AIS) of the UP, on the Institute for Scientific Information (ISI) databases, revealed that there are various academic disciplines involved in studying cochlear implantations. Examples of these academic disciplines are Otorhinolaryngology, Neurology, Surgery, Paediatrics as well as Psychology. According to the ISI databases, 12 research projects were conducted in the field of Psychology in the past five years.

Of the 12 research projects conducted, two were conducted using both quantitative and qualitative approaches. The first of these 2 research projects focused on the long term impact of the cochlear implantation on educational placement, vocational outcomes and employment status of hearing-impaired adolescents and young adults (Huber, Wolfgang & Klaus, 2008). The other research project focused on the occurrence and potential effect of the Usher Type I (USH 1) gene and other factors on the therapeutic outcomes of the cochlear implant recipients with deaf-blind Usher syndrome (Liu et al., 2008).

The other studies were conducted quantitatively and focused on adolescents' psychological status as a determinant of speech perception outcomes (Yucel & Sennaroglu, 2007); the self-esteem level of adolescents with cochlear implant(s) compared to hearing adolescents (Sahli & Belgin, 2006); the self-esteem and social well-being of children with cochlear implant(s) compared to hearing children (Percy-Smith, Caye-Thomasen, Gudman, Jensen & Thomsen, 2008); the levels of depressive tendencies in adolescents with cochlear implant(s) compared to hearing adolescents (Sahli, Arslan & Belgin, 2009); the benefits of the cochlear implantation with regards to emotional perception in children and adolescents with cochlear implant(s) compared to hearing aid participants and hearing participants (Most & Aviner, 2009); quality of life in children with cochlear implant(s) (Warner-Czyz, Loy, Roland, Tong & Tobey, 2009) and adolescents with cochlear implant(s) (Loy, Warner-Czyz, Tong, Tobey & Roland, 2010); identification of poor outcome predictors in pre-lingually deaf adolescents with cochlear implant(s) in order to define reliable prognostic indicators in selecting patients for the cochlear implantation (Arisi et al., 2010); tolerance of ambiguity in pre-lingually deaf adolescents with cochlear implant(s) (Seifert, Kollbrunner, Montokoudis, Vischer & Kampis, 2008); and the development of speech, language and reading skills between primary and secondary school aged children who received cochlear implantations in their pre-school years (Geers, Tobey, Moog & Brenner, 2008).

None of these researches were conducted qualitatively on adolescents' experiences of the cochlear implantation within a South African context. As such, I will be using a qualitative approach to listening and making sense of adolescents' narratives about their experiences of the cochlear implantation.

1.4.3 Personal Motivation

My personal experience of hearing loss prompted my interest in other peoples' experiences of their hearing loss. More specifically, I was curious about my own experience of frustrations, feelings of not being understood or heard, sensitivity relating to the impact of my hearing loss on my interaction with other people, to how my experiences, feelings and attitude relating to my hearing loss had changed over time, since the age of 5 years through to my adulthood. My personal curiosity made

me curious about others' experiences of hearing loss to discover similarities and differences, as well as the uniqueness in our adaptation in a society of sound. This has also fostered a passion to want to specialise in working with deaf people in my practice as a Psychologist.

1.6 STRUCTURE

Chapter 1 provides an introduction to my research study and addresses the research context and the cochlear implant, introduces the research question, provides the research goals and motivation for the research study and describes the report structure.

Chapter 2 provides a description of the research position of this research project. The broad approaches to research in psychology are outlined, followed by a description of narrative research as a research position. Specific reference is made to the characteristics of the narrative research cycle, as well as the characteristics of narrative research.

Chapter 3 depicts the research inquiry of this research project. It focuses on the research context, research participants, research material, research quality and research ethics. The research inquiry is informed by narrative principles that are congruent with the research position.

Chapter 4 entails a pre-reflection of myself prior to conducting the interviews with the participants, on a professional level as a novice researcher, as well as on a personal level being a person living with hearing loss.

Chapters 5 to 9 focus on the research findings of the five participants, the cochlear implant recipients. These findings incorporate my understanding of the participants' narratives, their voices, my shared experiences of hearing loss, as well as those of the co-researchers found in literature.

Chapter 10 provides a brief summary of the research study, as well as the limitations of this research study and recommendations for future research.

Chapter 11 entails a post-reflection of myself after conducting the interviews with the participants, as a researcher on a professional level as well as autobiographically on a personal level.

Conclusion

In this chapter, I addressed the research context and discussed the cochlear implant. I then put forward the research question, goals and motivation for this research study. The next chapter will address the research position.

CHAPTER 2

RESEARCH POSITION

Introduction

In this chapter, I shall describe the research position of this research project. This will be done by giving a brief overview of the two broad approaches to research in psychology, namely quantitative and qualitative research. Thereafter, narrative research as a research position will be portrayed, with specific reference to the characteristics of the narrative research cycle, as well as the characteristics of narrative research.

2.1 RESEARCH

Research in psychology usually falls within two broad research approaches, namely quantitative and qualitative research.

2.1.1 Quantitative Research

Quantitative research is a deductive approach to research, which involves representative samples, structured data collection procedures, as well as precise measurement through statistics. The objective is to discover causal laws by means of hypotheses testing, which enable professionals to predict, control and explain human behaviour. Personal experiences are eliminated in favour of reified constructs, classes of events and systems of classification (Struwig & Stead, 2001).

2.1.2 Qualitative Research

Qualitative research is an inductive approach to research, which attempts to understand the world from the participant's point of view. It claims that no single truth is possible, since knowledge is constructed, both personally and socially. The material analysis is usually language-based, with the objective of establishing themes. There are various research approaches under the umbrella of qualitative

research, such as phenomenological research, grounded theory research, ethnographic research, as well as narrative research (Creswell, 2007; Struwig & Stead, 2001).

In this research project, narrative research informed the research position (Chapter 2) as well as the research inquiry (Chapter 3). Narrative research enables me, as well as the participants, to understand how adolescents make sense of cochlear implantations through the process of narrating their experiences (Broyand, 1992; Johnson, 1993; Langdridge, 2007; Murray 2008).

2.2 NARRATIVE RESEARCH

2.2.1 Characteristics of the Narrative Research Cycle

The narrative research cycle is depicted in the words that, “every story shares the common function of someone telling something to someone about something” (Kearney, 2006, p.5). This is also echoed by Carson (2004) who states that there are three important aspects of narratives. Firstly, if a narrative is told, it needs to be heard, secondly, if a narrative is heard it needs to be taken in and thirdly, if the narrative is taken in, it needs to be re-told. From this it is apparent that the narrative research cycle entails a narrator, a narrative and a receiver.

1. The “Narrator” in the Narrative Research Cycle

Within the narrative research cycle, the narrator constructs a narrative. On the one hand the narrative is an interpretive activity, while on the other hand it is a constitutive activity. These two aspects of narrative can be seen in the words of Andrews (2000, p. 77-78) who states:

“Stories are not only the way in which we come to ascribe significance to experiences ... they are one of the primary means through which we constitute our very selves. We become who we are through telling stories about our lives and living the stories we tell.”

a. Narrating as an Interpretive Activity

The first part of the above quotation states that, “stories are not only the way in which we come to ascribe significance to experiences ...” (Andrews, 2000, p. 77-78). From this part of the quotation it seems that narrative allows people to ascribe significance to their experiences and to interpret their experiences by attributing meaning to their experiences thereby allowing them to make sense of their experiences (Crossley, 2000; Johnson, 1993; Lock, Epston & Maisel, 2004).

b. Narrating as a Constitutive Activity

The second part of the above quotation states that, “... they are one of the primary means through which we constitute our very selves. We become who we are through telling stories about our lives and living the stories we tell” (Andrews, 2000, p. 77-78). From this part of the quotation it seems that constructing a narrative does not only allow people to interpret their experiences, it also constitutes their narrated identity (ies). Furthermore, the narrated identity (ies) is not only constructed, but is also lived (Anderson & Goolishian, 1988; Smith, 2008; Sclater, 2003).

2. The “Narrative” in the Narrative Research Cycle

a. Perspectives on Narrative

In this section three different perspectives to “narrative” are discussed. These three perspectives are depicted in the following quotation (Anderson, 1990, p.75):

“Three umpires are sitting around over a beer and one says, “There’s balls and there’s strikes and I call `em the way they are”. Another says, “There’s balls and there’s strikes and I call `em the way I see them”. The third says, “There’s balls and there’s strikes and they ain’t nothin’ until I call `em.”

In all three instances there is an “umpire” (narrator), “balls and strikes” (reality) and a “call” (narrative). However, they also differ from one another, which will be explained in point i-iii.

i. Narrative and “Objective Reality”

In the first section of the quotation, the first umpire states, “there’s balls and there’s strikes and I call `em the way they are” (Anderson, 1990, p.75). The focus here is on the balls and strikes (reality). The umpire (narrator) calls (narrative) the balls and strikes (reality) exactly as they are. This implies that the umpire’s (narrator) call (narrative) is reflective of the balls and strikes (reality).

This perspective on narrative can also be described as the positivist perspective to narrative. Within the positivist perspective to narrative, a narrative is seen as a reflection of an objective reality, that which is “out there”. Due to the external nature of reality it is there to be measured, labelled, and described. The narrative contains a unitary truth in its reflection of objective reality. Within the positivist perspective to narrative, language has a descriptive and passive nature, which merely fulfils the function of reflecting objective reality (Durrheim, 1997; Shaw, 2002; Smith, 2008; Taylor, 2001).

ii. Narrative and “Perceived Reality”

In the second section of the quotation, the second umpire states “there’s balls and there’s strikes and I call `em the way I see them” (Anderson, 1990, p.75). The focus here is not on the balls and strikes (reality), but rather on the umpire (narrator), and more specifically on the umpire’s (narrator) seeing (perception) of the balls and strikes (reality). The umpire (narrator) calls (narrative) the balls and strikes (reality), not as they are, but as he/she sees (perceives) the balls and strikes (reality).

This perspective on narrative can also be described as the constructivist¹ perspective to narrative. Within the constructivist perspective to narrative, a narrative is not seen as a reflection of objective reality, but rather it is seen as the reflection of people’s perception of the objective reality, and therefore depicts a subjectively perceived reality “in there”. Within the constructivist perspective to narrative, language has a

¹ I acknowledge that the term “constructivism” has many interpretations, but in this research report I shall follow the description by Patton (2007), as well as Roberts (2000), that this term refers to the “in there” world of people.

descriptive and passive nature, which merely fulfils the function of reflecting the subjective perception of people (Butchart, 1988; Cresswell, 2007; Gergen, 1988; Willig, 2001).

iii. Narrative and “Construction of Reality (ies)”

In the third section of the quotation, the third umpire states, “there’s balls and there’s strikes and they ain’t nothin’ until I call `em” (Anderson, 1990, p.75). The focus here is not on the balls and strikes (reality), nor is it on the umpire’s (narrator) subjective perception of objective reality, but it is on the umpire’s (narrator) calling (narrative) of the balls and strikes (reality). The calling (narrative) of the umpire (narrator) brings the balls and strikes (reality (ies)) to life.

This perspective on narrative can also be described as the social constructionist² perspective to narrative. Within the social constructionist perspective to narrative, a narrative is seen, not as a reflection of the objective reality, nor is it a reflection of people’s subjective perception of objective reality, but rather it is a construction of reality (ies). Therefore, the focus is not on the objective reality “out there”, nor is it on a person’s subjective perception “in there”, but it is on the constructed identities in the narrative that lie “in between” the narrator and receiver of a narrative.

Sclater states the following about narrative (Sclater, 2003, p.327):

It’s a way of integrating the inner and the outer. The story provides an intermediate or transitional area of experience in which the self continually negotiates its position in the world, inscribes itself in relation to available cultural scripts, integrates past, present and future through acts of remembering and telling.

Narrative is thus the “in between” place where a person’s inner and outer world meet (Magadla, 1996; Steyn, 1999; Willig, 2001), where the self is in constant

² I acknowledge that the term “social constructionism” has many interpretations, but in this research report I shall follow the description by Patton (2007), as well as Roberts (2000), that this term refers to the “in between” world of people.

conversation with itself, and with its world over time (Bakhtin, 1981; Burr, 1995; Gergen, 1985; Josselson & Lieblich, 1995). Within the social constructionist perspective to narrative, language is performative and active in nature and constructs reality (ies) (Durrheim, 1997; Jenkins, 2001; Kotzé & Kotzé, 1997; Smith, 2008).

If I translate the cricket metaphor to this research study it could be portrayed in the following way:

Five adolescents are sitting around having a conversation about their experiences of the cochlear implantation. One adolescent says, “There’s a cochlear implantation process and I call it as it is”. Another adolescent says, “There’s a cochlear implantation process and I call it the way I see it”. The third adolescent says, “There’s a cochlear implantation process and it ain’t anything until I call it”.

I have opted to conduct this research project from a social constructionist perspective, within a post-modern and post-structuralist position (Neukrug, 2011; Roberts, 2000; Weingarten, 1998). Therefore, I do not see the narratives of the adolescents’ experiences of the cochlear implantation as either reflecting the cochlear implantation (objective reality) “out there”, or reflecting their subjective perception of the cochlear implantation (perceived reality) “in there”. Rather I see the narratives of the adolescents’ experiences of the cochlear implantation as the meeting place where interplay is created between history and context, thereby constructing reality (ies)³. Therefore, the focus of this study will be on the narrated identities of the adolescents as they are constructed in their narratives.

b. Narrative as an Historical Product

As described in the above quotation by Sclater (2003) (See: 2.2.1 (2a)(iii)), narrative as an historical product implies that when people narrate their experiences, they do it

³ In this research project the “constructed reality (ies)” will specifically refer to constructed identities, also known as “narrated identity (ies)” and/or “storied identity (ies)”, within narrative research studies.

by taking past-lived experiences and possible future-imagined experiences into account and fuse the past and future into the present narrative (Larner, 1998). “Since all stories have a beginning (or a history), a middle (or a present), and an ending (or a future), the interpretation of current events is as much future shaped as it is past-determined” (White & Epston, 1990, p.10). The narrator of a narrative chooses from an unlimited array those moments that the narrator deems significant and arranges them in a coherent order, with the purpose of organizing the disorganized and giving it meaning (Broyand, 1992).

c. Narrative as a Personal-Contextual Product

As described in the above quotation by Sclater (2003)(See: 2.2.1 (2a)(iii), narrative as a personal-contextual product entails the meeting of subjective experience (self) and objective reality (world) in a narrative (Sclater, 2003). The meanings attributed to sequenced events across time do not occur in a vacuum, as there is always a wider context within which narratives form, evolve and become meaningful (Payne, 2000). In any culture, specific narratives will be louder than others, emphasizing customary ways of being, which create a community identity, visible in the rituals, symbols, behaviour and processes (Weisner & Millet, 2000; White & Denborough, 1998). Societies construct the ‘lenses’ through which their members attach meaning to the world, and “constitute” themselves (Freedman & Combs, 1996). Foucault (1979) emphasizes how norms permeate people’s lives at the deepest levels, including their gestures, desires, habits and so forth, and he refers to these as a form of “dressage”.

3. The “Receiver” in the Narrative Research Cycle

One of the characteristics of narrative research is that the researcher is professionally (as a researcher) and autobiographically (as a person) situated in the research. This is discussed in more detail in 2.2.2 (2).

a. Receiving as a Professional Activity

The receiver in the narrative research cycle is professionally (as a researcher) involved from a position of curiosity, also known as the “not-knowing” position

(Freedman & Combs, 1996). From this position the researcher observes the narrator, facilitates an interviewing process, transcribes the interview material, analyzes the transcribed material and writes up the findings from the research project (Kelly & Howie, 2007; Riessman, 1993).

b. Receiving as a Autobiographical Activity

Besides receiving a narrative professionally (as a researcher), the researcher is also autobiographically (as a person) involved in receiving a narrative. This suggests that the telling of a narrative can also have an influence on the person of the researcher. The person of the researcher needs to be open to the telling of a narrative, allowing the narrative to reflect on his/her own life. In this sense, narratives have their own way of generalizing themselves as the narrative has the potential to influence the life of each “open” receiver (Lindsay, 2006).

2.2.2 Characteristics of Narrative Research

In an article by Lindsay (2006), the model of Herron (1971) was used to indicate the differences between narrative research and interpretive phenomenological research. The following section focuses on these differences in terms of subject, agency, material, method and outcome. I shall conduct this narrative research project in accordance with these guidelines.

1. Subject in Narrative Research

The subject matter in narrative research focuses on the unfolding of experience over time. A narrative researcher will view experience in relation to where it has come (past), where it is now (present) and where it is going (future).

In interpretive phenomenological research, the researcher will focus on experience as it comes into being in the here-and-now. From an interpretive phenomenological position, an isolated event captures both the past and the future, in a present moment.

In this narrative research study, I shall focus on adolescents' experiences of cochlear implantations, with specific reference as to how these adolescents' interpreted the cochlear implantation thereby constituting their narrated identity (ies) through their narratives over time.

2. Agency in Narrative Research

On the one hand, agency lies with the researcher in narrative research. The researcher is autobiographically (as a person) and professionally (as a researcher) present in narrative research and approaches the subject matter from a position of curiosity. On the other hand, agency also lies with the participants, also called co-researchers, who tell and retell their narratives, and through this, interpret their worlds and constitute their narrated identity (ies).

In interpretive phenomenological research, the agency resides with the researcher who has knowledge about the subject that will be made explicit during the research process. The researcher, as an agent, is separate from the participants, and not autobiographically implicated in the research process. An interpretive phenomenological researcher approaches the subject matter from a position of being an expert interpreter.

In this narrative research study, I shall be present autobiographically (as a person) and professionally (as a researcher), and will allow the adolescents, as participants, to be co-researchers in the research project. This will be done by means of autobiographical (as a person) and professional (as a researcher) pre- and post reflections in the research report, as well as by establishing continuous involvement of the co-researchers.

3. Material in Narrative Research

In narrative research, various forms of material can be used, such as interviews, letters and pictures. The researcher, together with the participants, approaches the narratives as material to understand how the participants' experiences of a specific

phenomenon unfolded over time and within a specific context. In so doing the uniqueness of each participant's narrative is honoured.

The researcher working from an interpretive phenomenological position primarily makes use of interviews as research material. The material is approached by the researcher to uncover recurring themes in the material of the participants, and then to look for common themes amongst the participants. The uncovering of the recurring themes may also be presented to other researchers for input.

In this narrative research study, I will be engaging with the narratives as research material of adolescents, with the purpose of understanding how they interpreted their experience of the cochlear implantation, thereby constituting their narrated identity (ies) over time. The participants will be kept involved, not only in the interviewing phase, but also through a reflection phase.

4. Method in Narrative Research

In narrative research, the method requires that the researcher and the participants narrate their experiences of a specific phenomenon. Narrative research focuses on the backward-forward movement (past, present, future), as well as the inward-outward movement (person-context) within narratives. Furthermore, academic literature is seen as conveying shared experiences, which is interwoven as an additional narrative within the co-researchers' narratives.

In interpretive phenomenological research, interview texts are analysed and studied with the purpose of discovering recurring themes in these interview texts. These recurring themes are seen as central to the appearance, the coming-into-being, of the phenomenon that is being studied. Furthermore, academic literature is seen as challenging, affirming and/or extending the interpretations that come to the fore through the recurring themes.

In this narrative research study, I shall focus on the backward-forward movement (past, present, future), as well as the inward-outward movement (person-context) in the narratives of the adolescents. Furthermore, I shall view academic literature as a

form of shared experiences with the experiences of the participants, which will be interwoven as an additional narrative within the participants' narratives⁴.

5. The Outcome of Narrative Research

Based on the collaborative nature of narrative research, between the researcher and participants, both the researcher and the participants grow in their understanding of how their experiences unfolded over time and within various contexts. The outcome is therefore educative in nature by enhancing awareness for the researcher and the participants.

Through the uncovering of recurring themes, as well as common themes, in the research material of the participants, the outcome of interpretive phenomenological research leads to enhanced knowledge of the phenomenon that is being studied by the researcher. Therefore, the outcome is not an enhancement of awareness of the researcher and participants, but rather of the phenomenon being studied.

In this narrative research study, I shall endeavour that the research process will allow the adolescents, as well as myself, autobiographically (as a person) and professionally (as a researcher), to grow in our understanding of their narrated identity (ies) in relation to their cochlear implantation experiences.

Conclusion

In this chapter I have briefly stated my research position, by describing the two broad approaches to research in psychology, namely quantitative and qualitative research. Furthermore, I also described the characteristics of the narrative research cycle, as well as the characteristics of narrative research. In the next chapter I shall address the research inquiry.

⁴ Based on this characteristic of narrative research, no formal literature review is done in this project. The literature is seen as a conversational partner (Bakker, Eskell-Blokland & Ruane, 2010) with shared experiences that are interwoven into the research findings.

CHAPTER 3

RESEARCH INQUIRY

Introduction

This chapter describes the research inquiry in terms of the specific research contexts in which the research was conducted. This is followed by a description of the research participants, how they were selected and the various research materials that were used. This chapter then concludes by showing how the quality of this research was enhanced and the ethical guidelines that were followed in the research.

3.1 RESEARCH CONTEXTS

I shall describe two specific contexts relevant to this research, namely the academic context, which includes the Department of Psychology at the UP, followed by the community contexts, which include the “Johannesburg Cochlear Implant Centre” and the “Pretoria Cochlear Implant Centre”.

3.1.1 Academic Context

The UP was established in 1908 as the Pretoria campus of the Johannesburg based Transvaal University College (TUC). There were four professors, three lecturers and 32 students. In 1930 the TUC name was changed to the UP. At that time there were 900 students. Currently the university has more than 50 000 students and is comprised of nine faculties and a business school. Currently, it is one of the largest research universities in the country (University of Pretoria [UP], 2008).

The Department of Psychology, within the Faculty of Humanities at the UP, constitutes the academic context. Three MA-degrees in professional psychology are offered in the department, which include the MA (Clinical Psychology), MA (Research Psychology) and MA (Counselling Psychology) (Psychology, 2008). This research project was approved by the Postgraduate Committee (07 September

2009), as well as the Ethics Committee of the Faculty of Humanities (07 September 2009) at the UP. The research was done within the guidelines set by these two committees.

3.1.2 Community Contexts

Two different community contexts were approached in order to locate adolescent cochlear implant recipients.

One of these community contexts, the “Pretoria Cochlear Implant Centre”, is based in Pretoria within the “Speech-Language Pathology Centre” at the UP. The cochlear implant recipients have their hearing tested, receive their external cochlear implant device and have their external cochlear implant device mapped at the “Pretoria Cochlear Implant Centre”.

The other community context is based in Johannesburg at the private practice of Ms. Wendy Deverson who is the audiologist for the adolescent cochlear implant recipients of the “Johannesburg Cochlear Implant Centre”. Ms. Deverson is responsible for the hearing tests and the mapping of the external cochlear implant devices of the cochlear implant recipients of the “Johannesburg Cochlear Implant Centre”.

3.2 RESEARCH PARTICIPANTS

3.2.1 Cochlear Implant Recipients

1. Inclusion Criteria for Research Participants

The following criteria were set for inclusion in the research project:

- a. The participants needed to be adolescents (early and/or late adolescents) between the ages of 14-21 years.
- b. The participants needed to have had the cochlear implantation for six months or longer.

- c. The participants needed to be fluent with regards to verbal communication in either Afrikaans and/or English, as these are the languages that I, as a researcher, am proficient in and would prefer to communicate directly with the cochlear implant recipients without the assistance of a Sign Language Interpreter.

Although an attempt was made to include participants of different genders, hence at least two males and two females, and each participant of a different race (African European, Coloured, Indian), this was not possible because of the limited number of adolescents who fitted the mentioned criteria, as well as the limited number of adolescents who had cochlear implants at the time of the study. This can be seen as a limitation in this research project. It is likely, that in future, there will be more adolescents with cochlear implants due to more deaf candidates being implanted (Wheeler et al., 2007), and this may enable researchers to conduct research on this population group with equal distribution of males and females, as well as different races.

2. Sampling Method for Research Participants

A non-probability sampling technique, specifically purposive sampling, was used to select the adolescents that adhered to the above inclusion criteria (Rossouw, 2003), from the “Pretoria Cochlear Implant Centre”, as well as the “Johannesburg Cochlear Implant Centre”.

3. Adolescent Cochlear Implant Recipients as Research Participants

The following table depicts the characteristics of the adolescent sample group, all of whom had their cochlear implants for a period longer than six months:

Table 3.1

Adolescent Cochlear Implant Recipients as Research Participants

Participant	Gender	Age	Race	Language	Centre
FF	Male	15	White	Afrikaans	“Pretoria Cochlear Implant Centre”
AA	Male	15	White	Afrikaans/English	“Pretoria Cochlear Implant Centre”
MM	Male	17	White	English	“Johannesburg Cochlear Implant Centre”
BC	Male	20	White	English	“Johannesburg Cochlear Implant Centre”
SDV	Female	18	White	Afrikaans	“Pretoria Cochlear Implant Centre”

3.2.2 Postgraduate Student as Researcher

As the present study is a narrative research project, done from a post-modernist, post-structuralist position (Neukrug, 2011; Roberts, 2000; Weingarten, 1998), I am involved in this research project “professionally- as-a-researcher” (See: 2.2.1 (3a)), as well as “autobiographically-as-a-person” (See: 2.2.1 (3b)).

3.3 RESEARCH MATERIAL

The research material was generated according to the following process:

3.3.1 Phase 1: Prior to the Research Project

1. Institutional Permission

Prior to the research project, permission was obtained to conduct the research project from the Postgraduate Committee (07/09/2009) and Ethics Committee (07/09/2009) of the Faculty of Humanities at the UP.

See: Appendix C

2. Participant Permission

The parents were contacted via the “Pretoria Cochlear Implant Centre” and Ms W. Deverson of the “Johannesburg Cochlear Implant Centre”, in order to arrange a date to meet with the adolescents and their parents. This meeting entailed building rapport and providing the adolescents and their parents with the purpose, nature and procedures of the research study. These were also outlined in their assent and consent forms. Questions were answered and upon agreement, in terms of the participation, a second date was arranged for the interview process. The relevant assent and consent forms were also signed.

See: Appendix D, Appendix E, Appendix F, Appendix G

3. Researcher’s Position:

As mentioned in 3.2.2, the present study is a narrative research project, done from a post-modernist, post-structuralist position (Neukrug, 2011; Roberts, 2000; Weingarten, 1998). Therefore, I am involved in this research project “professionally-as-a-researcher” (See: 2.2.1 (3a)), as well as “autobiographically-as-a-person” (See: 2.2.1 (3b)). I address my researcher positions as a pre-reflection in Chapter 4.

3.3.2 Phase 2: The Research Project

1. Narrating: In a narrative inquiry, various forms of material can be used such as interviews, annals, chronicles, artefacts, photos, journals, diaries and letters (Clandinin & Connelly, 1994).
- a. Interview: An un-structured narrative interview was conducted in this study, in order to allow for openness and flexibility in the adolescents’ sharing of their narratives without “leading” them by pre-set questions (Rossouw, 2003). The narrative interview had three basic phases, namely: the period before the cochlear implantation, the participants’ experience of the cochlear

implantation and the period after the cochlear implantation (Ollerenshaw & Cresswell, 2002).

As described in 2.2.1 (1a) and (1b), narratives have a dual function. On the one hand they allow people to make sense of their experiences (Hurwitz, 2002; Josselson & Lieblich, 1995; Ollerenshaw & Creswell, 2002; Tsang, 2000), while on the other hand people constituted their identities, also called narrated and/or storied identities, through their narratives (Burck, 2005).

- b. Time: The duration of the narrative interview varied from participant to participant, ranging between 60 minutes to 90 minutes. The explanation of the research and its procedures, and any answering of questions, took about two to five minutes as it was already explained at the first meeting with their parents. The last five to fifteen minutes were used to conclude the interview.
 - c. Place: The first meetings, interviews and follow-up feedback meetings were conducted at the participants' homes. This context suited the needs of the participants in terms of eliminating the need to make transport arrangements to the community contexts as outlined in 3.1.2. The meetings could then take place after school and extra-mural activities without trying to fit in with the available time for office space at the community contexts.
2. Receiving: I received the adolescents' narratives during the narrative interview by adopting a position of curiosity (McNamee & Gergen, 1992), observing the participants' behaviour during the narrative interview (Ollerenshaw & Cresswell, 2002), asking various questions (Freedman & Combs, 1996; McNamee & Gergen, 1992) and giving feedback on my understanding of the participants' narratives (Ollerenshaw & Cresswell, 2002). This was my first receiving of the participants narratives, and can be

seen as a professional activity (Ollerenshaw & Cresswell, 2002) (See: 2.2.1 (3a)).

3. Transcribing: Where my first receiving of the participants' narratives were during the interviewing process, my second receiving of the participants' narratives was through transcribing the narratives personally. The reason for not using a professional person to transcribe the data was to allow myself to engage fully with the received narrative of the participants so as to enhance my analysis and writing of the findings. The transcribing of the narratives can also be seen as a professional activity (See: 2.2.1 (3a)).
4. Analysis: There are various ways to analyze narratives, for example, the "Problem-Solution Approach" (Ollerenshaw & Cresswell, 2002) and the "Narrative Analysis Approach" (Riessman, 2003).

The "Three-Dimensional Space Approach" of Ollerenshaw and Cresswell (2002) was used to do the narrative analysis. Using this approach to analyse the narratives enabled me to make sense of how the participants make sense of their experience of the cochlear implantation and how they created their narrated identities within a specific time and place in the telling of their narrative. This approach consisted of the following dimensions:

Dimension 1: Historical Analysis

Dimension 2: Person-Context Analysis

Dimension 3: Time/Place Analysis

5. Writing: The writing up of the research findings entailed four phases of writing:

Phase 1: The first writing of the narrative findings was based on my own interpretation of the given narrative of the participant.

Phase 2: The participant's voice was added to the narrative in the second writing by adding quotations from the narratives of the participants.

Phase 3: My own voice was added without taking away the dominant voice of the participant in the third writing. This allowed for an awareness of similarities and/or differences based on my own experiences of living with hearing aids.

Phase 4: Co-researchers' voices from the literature were added in the fourth phase, which highlighted the outcomes of the cochlear implantation based on their research studies and findings.

3.3.3 Phase 3: After the Research Project

1. Participant's Reflection:

After writing up the chapters of each participant, I visited each participant again, to discuss his/her experience of the research interview and the reading of their narrative chapter. This facilitated a discussion around their interpretation of their narratives, their fictitious names, the title of their chapter and their experience of reading their narrative.

2. Researcher's Position:

As mentioned in 3.2.2, the present study is a narrative research project, done from a post-modernist, post-structuralist position (Neukrug, 2011; Roberts, 2000; Weingarten, 1998). Therefore, I am involved in this research project "professionally-as-a-researcher" (See: 2.2.1 (3a)), as well as "autobiographically-as-a-person" (See: 2.2.1 (3b)). I address my researcher positions as a post-reflection in Chapter 11.

3.4 RESEARCH QUALITY

3.4.1 Supervision

Supervision with my supervisor, Prof. Lourens Human, guided me through the process of the research from the research proposal through to and including the research. Not only did it enhance the trustworthiness of my research material (Rossouw, 2003) but it also enabled me to learn and grow as a researcher, an individual and future practitioner.

3.4.2 Fellow Student Review

Regular meetings with my fellow student colleagues also enhanced the trustworthiness of my research material (Rossouw, 2003) and created a space for feedback, learning and growth.

3.4.3 Participant Involvement

Since the narrative is not my own, I kept the participants involved in their narratives by allowing them to provide credibility to their own narratives (Lindsay, 2006; Rossouw, 2003).

3.4.4 Material Engagement

Research quality was also enhanced through my engagement with the material. These specific materials included the narrative interview, the transcription of the narrative interview and the analysis of the narrative (Lindsay, 2006; Rossouw, 2003).

3.5 RESEARCH ETHICS

3.5.1 Information

To ensure that the adolescent participants and their parents could make an informed decision as to their willingness to participate, information was provided regarding the

nature, results and conclusions of the research in a language that could be understood. This information was attached to the consent and assent forms which were signed by the participants and their parents (Gravetter & Forzano, 2003; Health Professions Council of South Africa [HPCSA], 2008).

3.5.2 Participation

Voluntary participation was explained to the participants and their parents, by ensuring that they understood that they could choose not to participate or they could leave the research process at any time, without negative consequences (Gravetter & Forzano, 2003; [HPCSA], 2008).

3.5.3 Confidentiality

The participants and their parents were reassured of confidentiality by explaining that their anonymity would be kept through the use of a code name or fictitious name instead of their true names (Gravetter & Forzano, 2003; [HPCSA], 2008).

3.5.4 Material Storage

The material will be stored for a minimum of 15 years with my supervisor, Prof. Lourens Human at the UP, Humanities Building at the Psychology Department. The material will also be kept with me.

3.5.5 Institutional Permission

My research proposal was approved by the Postgraduate Committee and was used as a guiding tool for this particular research. Furthermore, the Ethics Committee approved my research proposal with regards to the ethical dimensions of the research.

Conclusion

In this chapter the research contexts were addressed. Furthermore, the research participants were described, and so was the research material. The Chapter was concluded by depicting the research quality and ethics. In the next chapter I shall portray me pre-reflections as a researcher, as well as a person.

CHAPTER 4

PRE-REFLECTION

Introduction

The goal of this chapter was to take a pre-reflective stance, prior to the research project, regarding my role as a researcher in psychology, as well as my personal experience of hearing loss.

4.1 PRE-REFLECTION AS RESEARCHER

My professional role as a researcher began prior to conducting this study as part of a requirement for my MA-degree in counselling psychology. As I graduated with a Bachelor of Arts (BA) in child psychology and was selected to continue with my Honours in Psychology, my interest in the deaf community increased. I decided to learn sign language and observed Deaf children in a classroom in a Deaf school. My interests got me wondering about the Deaf culture and deaf people of varying degrees of hearing loss, specifically from a psychological perspective. It was during my fourth year of study, in my Honours in Psychology, that I was able to do research in my field of interest.

During my Honours in Psychology in 2005, I was required to conduct research for a module in developmental psychology. By this time I had come to hear about, and become interested in, cochlear implantation. This stirred curiosity in me as to how the cochlear implantation impacted on the self-esteem level of the deaf person and with which culture he/she would identify. Consequently, I decided to do my research, from a qualitative approach, on the self-esteem and cultural identity of adult cochlear implant patients. This qualitative research was pursued from the discipline of psychology, using a developmental and narrative approach.

With the recommendation of an audiologist and a cochlear implantation surgeon, I was able to locate two adult cochlear implant participants. I decided to do a semi-structured interview with each participant partly based on “McAdams’ Life Story

Interview” (McAdams, Diamond, Mansfield & De St. Aubin, 1997, p. 683). After obtaining written consent and permission to use a digital voice recorder, the interviews took place at their individual homes in Gauteng. After the interview process, I made notes about my experience and observations during the interview process, and then analysed the material by sorting the sentences and words into categories and identifying dominant themes.

The outcomes of my research suggested that the cochlear implantation had a positive impact on the participants’ lives. Despite missing out on a lot in the hearing environment, in terms of hearing and communication, it seemed that their values, personality and previous experiences in their narratives contributed to their self-esteem. Both participants described the cochlear implantation as a positive experience which seemed to contribute to establishing hope, possibly increasing their self-esteem as they gained confidence in their ability to hear and become part of the hearing environment. Both participants were born with normal hearing and identified with the Hearing Culture, but experienced their hearing loss later in life. This may indicate that identification with a particular culture may influence one’s perception and attitude toward the cochlear implantation.

Having realised that my approach and title of my research in my Honours in Psychology was rather presumptuous of the outcomes, perhaps because of my own experience and curiosity about my own self-esteem and my experience of identifying with the hearing culture, I realised, with the guidance of my MA (Counselling Psychology) research supervisor, that a narrative approach allowed a person to let his or her voice be heard, with me as a researcher adopting an inquisitive and a not knowing approach. This was a humbling experience for me as a researcher as I pursued my MA (Counselling) Psychology research from a constructionist narrative research approach in psychology.

A pre-reflection of my personal experience prior to doing this particular research provide a glimpse into my experience of hearing loss.

4.2 PRE-REFLECTION AS PERSON

Before pursuing this particular research with the adolescents, I wrote my own narrative about my personal experience of hearing loss. This was quite a challenge for me as it brought back many memories that reminded me of how much I had struggled in terms of communication and being a part of the hearing culture. It also reminded me how I had adapted and developed despite my hearing loss, and nonetheless was still part of the hearing culture.

What I learnt from this process of writing my narrative and reflecting on it (through supervision) is that I became aware of the following which was important for the research:

Firstly, it has enabled me to empathise with people with varying degrees of hearing loss as I can relate to their experience from my own experience of hearing loss.

Secondly, it has helped me to identify specific abilities that I have as resources for coping, developing, learning, growing, persevering and being positive. This in turn enables me to assist other people to identify their own strengths and abilities as they adapt to a hearing society.

Thirdly, I became aware of my experience of living in a world of my own and not always being aware of everything that was happening around me. When I was at school, a child had said something hurtful about me, but I did not know about it until my friend told me. This is just one of many similar experiences which made me realise why I sometimes preferred not being able to hear everything. Although I could avoid being hurt by what others said, with the attitude of what I didn't hear would not affect me, the disadvantage to this is that I could also miss out on important information. This awareness enabled me to appreciate the quiet times yet to put in that extra effort to keep up to date with important information where I could, no matter how tiring or frustrating. Consequently, as a researcher, this could serve two purposes. For me to put in the extra effort to ensure that I heard and captured at least most of the narrative told, but also to be aware that other people with varying

degrees of hearing loss may also experience missing out on certain information and to be open to their experience of “not knowing”.

Fourthly, my own narrative includes parts of other people’s stories. For example, my parents told me that I did not respond to them when they called me from behind my back and only then realised I had a hearing problem. This narrative, amongst others, has contributed to me making sense of my experience of hearing loss, like fitting puzzle pieces together. It could be that other people with hearing loss may also be building puzzle pieces as they try to make sense of their experience of their hearing loss, with the help of various other stories complementing their narrative. As such, as a researcher, I look forward to building the puzzle pieces with them as we create a narrative from stories told.

The fifth aspect relates to how I had/have become skilled in reading non-verbal language as a result of not always hearing everything. This skill that I had developed made me aware of certain emotions or feelings that when, or if, I pointed it out to the other person, would be met with denial or disregard. As a researcher, this encourages me to be aware of my own non-verbal language in my communication with the participant to reveal an inquisitive and not-knowing approach that is congruent with my verbal language.

The sixth aspect relates to how my observation of people’s moods had a tremendous effect on me, to the extent that as a sensitive person, I would be hurt or upset by negative reactions toward me yet positive and calm when met with happiness or approval by others. This awareness has enabled me to work on not taking things personally and letting other people’s reactions affect me, but rather to be in control of my own emotional responses, which can have a significant impact on my various roles, more specifically for the purposes of this research, in my role as a researcher. Furthermore, my emotional response to others could contribute to others’ responses to me.

The seventh aspect relates to how my narrative helped me to understand the frustration and embarrassments I experienced, in not being able to hear in social or group situations, but also how I had come to understand and accept where I felt

comfortable and how I coped in social or group situations. As a researcher, this enables me to empathise with people who experience such situations and circumstances and to identify or listen for the times when dealing with certain situations were successful and what specific coping skills were used.

The eighth aspect relates to how my narrative made me realise that I am able to do the things that hearing people do, such as dancing and swimming. This awareness encourages me as a researcher to listen to the “normality” of adapting to a hearing society with hearing loss. After all, loss of hearing does not mean loss of physical ability.

Lastly, my narrative made me aware that my perception of how others’ saw my hearing aids or hearing loss may be distorted. People may perceive my hearing aids and hearing loss very differently. As a researcher, this encourages me not to make assumptions, as people have unique experiences and perceptions.

My goal to get involved in working with deaf people of varying degrees of hearing loss when I qualify as a psychologist also unfolded over time, where I started by wanting to help deaf people, but not being clearly specific about how I wanted to help. This unfolded to identifying with the deaf people and discovering emotional needs of the deaf individual that I could relate to. My experience of speaking to people who are deaf, professionals who work with deaf people and the wider social network who interact with the deaf person, has cultivated a growing curiosity about the outcomes of this research and a passion to work with deaf people in my professional role as a psychologist.

Conclusion

My experience of hearing loss as a researcher, as well as my personal experience of hearing loss, was outlined in this pre-reflection chapter. This has significant value as I realise that this past experience influences my role as a researcher and as a person in my interviews with the participants in this particular study, as a new narrative may be created between the participant and me, with each of us bringing our personal experiences into this newly created narrative.

CHAPTER 5

RESEARCH FINDINGS

The Narrative of AA

“Adapting to a hearing society creates hope for the future”

Introduction

AA is a male cochlear implant recipient aged 15 years, who lives in Pretoria with his father, mother and sister. As a scholar, he attends a high school in Pretoria.

The research question, as stated in Chapter 1, is, “How do adolescents within a South African context experience cochlear implantation?” It seems that from my engagement with AA’s narrative, he experienced the cochlear implantation as a way of adapting to a hearing society and this creates hope for the future.

In AA’s narrative, it seems that he constructs multiple narrated identities, such as the patient, scholar, son, brother, friend and athlete identities, which are in constant interplay with one another with the purpose of adapting to a hearing society which creates hope for the future.

BEING A “PATIENT”

The dominant narrated identity that comes to the fore in AA’s narrative is that of being a patient. This narrated identity unfolds over time, as it has its beginning in AA’s pre-school years and continues into his primary school years through to his secondary school years.

AA’s deafness began pre-school at birth, as he recalls, “When I was born, I got meningitis,” which his mother only picked up when he was 3 months old. He further explained that, “She told me that when she called me I didn't look at her.” As a researcher, with my personal experience of hearing loss, I could also recall being told that I did not respond to my parents when they spoke to me from behind. It was

at this young age, that AA remembered that, “When I was, I think 3 months old, I started getting hearing aids,” in both ears, with the right ear worse than the left ear. As he grew older and was able to pick up sounds, he relied more on his left ear and would sometimes leave the right ear’s hearing aid out because of the irritation of not being able to hear with his right ear.

Furthermore, AA struggled with his speech and with lip reading. He described his experience of people becoming impatient when he would ask them to repeat what they said, “If they tell me something, I say sorry can you repeat that and then they say it again and then I can't hear it again, and I ask and they tell me again, so its really embarrassing for me.” I, as a researcher, too, can relate to this experience as I also began to avoid asking people to repeat themselves so as to avoid embarrassment. AA didn’t really watch television as he couldn’t hear, and would preferably ride his bicycle, swim or play with balls. At the age of five or six years, he realized that he could hear something but, “It’s really hard, like it’s, it’s like difficult, like I don't know where the sound is coming from.”

By the time AA was ten years old and in primary school, he could hear almost nothing. His audiologist, since 3 years of age, began to introduce the idea of the cochlear implant. AA and his family researched it, spoke to another adult cochlear implant recipient and visited the cochlear implant doctor. According to AA, the doctor suggested, “Do the left ear, we said do the right ear,” as he could still make use of his hearing in the left ear. The day finally arrived. He lay in hospital, nervous, as he thought about the possibility of it not working, something going wrong or it resulting in his face going numb. The cochlear implant was for life, and waiting for the operation, “I felt nervous like I, I really don't like being in a operation, it's really the worst thing for me.” Similar findings were found by co-researchers Wheeler et al. (2007), that the operation itself could be experienced as a disadvantage.

AA’s doctor visited him in the patient room and explained the cochlear implantation operation to him. Soon his family and friend’s images faded as he fell asleep after drinking something the doctor had given him. The operation lasted about six hours, during which the audiologist also connected and programmed the coils of the cochlear in the cochlea. AA explained his experience on waking up after the

operation, “I didn't feel anything, no pain, no pain,” and although he should have stayed in hospital overnight, the doctor told him otherwise. He recalled, “I can go home now.” Missing two weeks of school, he spent the next six weeks with a bandage around his head, but also explained how nervous he was, “For me, it was, I didn't believe that it would work, I really didn't believe.” He was so bored in the last two weeks, he just wanted to go back to school.

The time arrived when they visited the audiologist, who explained how the cochlear implant and batteries worked, leaving AA feeling that this was a big responsibility. When he agreed that he was ready, the cochlear implant was switched on but, “I still didn't believe ‘cause it went like krrr.” The sound of crumpling paper was so loud he almost cried. The audiologist then programmed the sound on the computer and balanced the sound with the hearing aid sound output. This is similar to programming the digital hearing aids, which I, as researcher, experience as a hearing aid user. When I sit with the audiologist at the computer with my hearing aids connected by a wire to the computer, we set the sounds according to my hearing needs. It can sometimes be a challenge to try and describe what I am actually hearing, in order to “change the sounds” through the programming process. AA described that the audiologist recommended, “to try and go on with my cochlear, with the left ear out and walk around with my right ear on and the cochlear implant,” so he could practice identifying sounds with his cochlear implant. That evening, he put his cochlear implant in a dry box with his hearing aid, as had become the routine, and enjoyed the peacefulness of silence as he went to sleep. He described the morning after switch on as follows, “When I had the cochlear, um I wanted to switch it on but it was so hard, I was so nervous.” He then put it on for merely 30 seconds. This was the beginning of getting used to the cochlear implant, hearing more every day and practicing identification of sounds with the help of family who were ever so patient with him. The perspective of the cochlear implant changed about one to two months later as he expressed, “What a awesome thing.” He had made the right choice in choosing the cochlear implant. The power influence of his outer world on his inner world is apparent both before and after the cochlear implantation.

AA is currently in secondary school. Sounds of crumpling paper are heard if AA only has the cochlear implant on. He goes for mapping every six months and experiences

the cochlear implant as great, enabling him to be with friends, better identifying which side sounds come from, watch television with the subtitles on, enjoying playstation and listening to music with the earphones. As a researcher, I could relate to the experience of listening to music with the earphones. When I take my hearing aids out, I can almost feel the music as it plays through my ears. AA shared his experience of how other people perceived his cochlear implant as, “Like almost everyday people ask me what is this thing, is it like an MP3 player something?” AA was able to give his basic understanding of what the cochlear implant was to those people who asked him. Co-researchers Wheeler et al. (2007), have found that many children with a cochlear implant have a basic understanding of the way that the cochlear implant works and know what to do if something goes wrong in terms of changing the batteries, checking the possible places of fault and alerting their teachers and/or parents to the problem. Although AA still struggles in conversations and asking people to repeat what they have said, people talk to him like a “normal” person. He knows people of different hearing statuses and it has been asked and suggested that he learn sign language, to which he replied, “I say no, I can hear, that’s the best thing.” This indicates a significant change from difficulties with hearing and communication before the cochlear implantation to better identification of sounds and fuller participation in a hearing society after the cochlear implantation.

Due to AA’s hearing dilemma, he became a patient in the medical world. His narrated identity as a patient unfolds over time, from pre-school to primary school to secondary school, beginning with the experience of deafness as a baby and how he has adapted with hearing aids in both ears. When his hearing deteriorated, he and his parents were introduced to the option of having a cochlear implantation done, but had to decide which ear to implant. After the cochlear implantation operation, he started learning to identify sounds and getting used to the cochlear implant. Certain aspects, such as mapping and putting the cochlear implant in the dry box became routine and he experienced people talking to him like a “normal” person. The sequencing of events is strongly informing his identity.

AA continues to develop his hearing with the cochlear implant with the hope that his hearing will improve in the future. He said, “I think um, I’m gonna improve a lot of my hearing, like start hearing better.”

BEING A “SCHOLAR”

Besides AA constructing himself as a patient in his narrative, he also constructs the narrated identity of being a scholar. The patient identity seems to have a profound influence on the scholar identity in the narrative.

With Afrikaans as his home language, AA started attending an Afrikaans nursery school in SA. He then moved to East Africa with his family and attended an English school in Uganda, where he experienced great difficulty in communicating in English and understanding what was said. “I really struggled with my speech, I really, I couldn't like, I couldn't actually understand English that good.”

His difficulty in communicating in English during his primary school years was coupled with difficulty in hearing what was said, resulting in difficulty in concentrating, falling asleep in class and many days of asking the teachers to repeat what was said that he did not hear or understand. AA began to be more cautious about asking teachers to repeat what they said, as a specific experience of a teacher was described, “When a teacher like, like she would like um like when I go to her desk I ask her um, um I didn't understand could you please tell me again? She will like tell me no, I'm busy, I'll tell you later, but then she never told me. She like was impatient with me.” As a researcher, I too could relate to the tendency to avoid asking the teacher to repeat herself and would instead skilfully observe or “check” what the other children did, just to ensure that I was doing the right thing in class. AA seemed to improve his English with the move to Tanzania, as he met Afrikaans friends who taught him how to speak English. As his English language skills improved, his Afrikaans seemed to get worse. At the age of ten years, AA and his family moved back to SA. He excelled in his first English and Afrikaans tests. His hearing however got worse from there on, and so his marks dropped, only building up again once he had received his cochlear implant. After the cochlear implantation, AA described a different experience with school, “Like every time I heard, my teacher helped me a lot, I hear the instructions, I know what to do, ja, so the cochlear implant really helped me with my school work.” The interplay of his outer and inner worlds stands out prominently.

Currently, AA attends an English secondary school. He sits at the back of the classroom and describes his hearing as really good, “I can hear really, hear very, very good.” Although he may still need to ask teachers to repeat instructions, it’s not as embarrassing, as his teachers understand, know who he is and know about the cochlear implant. South African co-researcher Jessop (2005) found in her studies that although many of the children with cochlear implants had been enrolled in speech-language therapy, speech intelligibility tends to be higher in children with cochlear implants who attended mainstream pre-school than those who attended specialized education. However those in mainstream primary school developed normal or near normal speech intelligibility and high school children with cochlear implants had normal speech intelligibility.

The impact of the cochlear implant on his scholar identity in his narrative also unfolds over time from pre-school, to primary school through to secondary school, where he started as a hearing aid user. He struggled with his speech and English language, but despite having difficulty hearing what was said in class, he developed and improved his English language skills. However, with his hearing deteriorating, his school marks dropped and only improved again after the cochlear implantation. Considering his difficulty prior to the cochlear implantation, it made a significant difference after the cochlear implantation so that it resulted in improvement in his school work, the ability to hear really well and not experiencing as much embarrassment as he used to, at having to ask teachers to repeat what they said.

AA persevered through his struggles of developing the English language and being able to participate in a hearing classroom, in addition to adapting to a hearing society. His interest in subjects such as technology was highlighted as he expressed the hope of becoming a mechanical engineer in the future, within a hearing society.

BEING A “SON”

Another narrated identity that is constructed in his narrative, besides his narrated identities as a patient and scholar, is the narrated identity of a son. This narrated identity of a son reveals a close and balanced relationship with both his parents as

each play different roles at different stages of his development of hearing with the cochlear implant.

During his pre-school years, AA's experience of not hearing his parents were, "not nice," as "sometimes when my mom was calling me, I also didn't hear her or my dad." But the ability to understand their home language, Afrikaans, allowed him to communicate with someone at a time where communication at an English school was extremely limited. He explained, "There was no one who could speak Afrikaans, so at school I didn't really say a word." His parents taught him a bit of English but his experience of his mom helping him with homework seemed to be difficult for him because he couldn't do it himself and wasn't really learning anything.

His parents continued to provide support and guidance during his primary school years when big decisions needed to be made about the cochlear implant, during the operation and rehabilitation process. An example AA used was, "Like um sometimes I like take these things, like before my dad switch on the car, I like take my ear off, then he switch on, and then I know ok that is the sound of the car."

Although AA, currently in secondary school, struggles to watch television due to his hearing loss, his enjoyment of a particular programme that he watches "every day" makes him determined to know what is going on, even if it means that, "In the advertisement I will ask my mom and then she will tell me." I, as a researcher could relate to this experience, as I too would ask my parents what was going on in the movie or television program. This became a natural habit for me, as I too would sometimes struggle to follow when watching television.

AA's parents seemed to be aware of the impact of the cochlear implant on his adaptation to the hearing society in his narrative. As the constructed identity of the son unfolded over time from pre-school, to primary school through to secondary school, his parents have supported him from the time of his difficulty hearing as a hearing aid user, through the decision process, operation and rehabilitation process of the cochlear implant. AA's parents continue to play a significant role in providing support and guidance as he adapts to a hearing society.

BEING A “BROTHER”

Not only did AA construct his narrated identities as a patient, scholar and son, but he also constructed a narrated identity as a brother in his narrative. His development of hearing with the cochlear implant enables him to be a helpful brother to his sister in his narrative.

AA’s inability to hear made it difficult to distinguish where sound came from. He described his experience of not being able to hear his sister as, “It wasn't really nice.” He further described a particular experience of hearing his sister scream when she bumped her toe, “It was really hard for me because like I didn't know, like sometimes when I think something happening, like I have to run down or run down the stairs and find where it’s happening or something.” He only found her ten minutes later to help her. Despite the cochlear implant making it possible for him to find his sister as he hears where her voice was coming from, the cochlear implant introduced an option that his sister did not have.

The irritating noises that his sister hears at night are unknown to him, as he explains that, “It’s like I find it really nice for when I sleep because sometimes in the mornings I hear my sister, what’s this irritation noise coming from, like then I just sleep, I don't know where it comes from, so I really like that.” For AA, he has, and uses, the option of switching his cochlear implant off and sleeping peacefully. As a researcher I could relate to this particular experience of peacefulness at the option of switching off to a “silent mode”. The option of taking the speech processor off is available to those who prefer to relax or watch television or keep the processor off until later in the morning on weekends to enjoy the world of silence (Wheeler et al., 2007).

AA’s sister in his narrative seems to play a role in his adaptation to the hearing environment with his cochlear implant through his constructed identity as a brother that unfolded over time from primary school through to secondary school. He described the need to be able to identify where sound came from with his cochlear implant so he could offer help to his sister, but also describing when the option to switch off the cochlear implant could also be experienced as peaceful. Through his constructed identity as a brother, AA experienced change from difficulty in identifying

where sound came from, before the cochlear implantation, to AA being able to identify where sound came from as well as having the option of moving between the silent world and the hearing world after the cochlear implantation. This provided hope in adapting to the hearing society in the future.

BEING A “FRIEND”

Although AA had constructed his narrated identities as a patient, scholar, son and brother, he had also constructed an identity of being a friend in his narrative. AA leads a life with much support and playfulness from his friends as they contribute to his development of hearing with the cochlear implant.

Despite much difficulty in communicating with English children, AA had made friends through non-verbal play, “Um, I had friends, yes but I, I really struggled talking to them. We just, I just like played with them, I didn't really talk to them.” It wasn't until later that he met a friend who was Afrikaans but could also speak English. AA explained that, “He also taught me how to speak English 'cause he was friends with English people as well.”

A recent experience was described as pleasant when he explained, “Me and my friend living up here in the street, we went to swim, swim there at the townhouses and I took my ears off, while I swim I, I could actually hear something without my ears.” Although it wasn't much, it was something. I, as a researcher, could relate to the ability to hear something without my hearing aids on, although it's more difficult to distinguish what the sound is or what is being said.

AA's friends in his narrative seemed to make friendship possible regardless of whether he could hear or not. His identity as a friend unfolded over time from pre-school, to primary school through to secondary school. Here they were able to play without the need for verbal communication, with his friends helping him to develop the English language prior to the cochlear implantation, to sharing his experience with a friend of hearing something without his aids after the cochlear implantation. His experience of making friends regardless of whether he could hear or not seemed to provide hope as he adapted in a hearing society.

BEING AN “ATHLETE”

Another constructed identity as an athlete emerged in his narrative, besides the constructed identities of being a patient, scholar, son, sister and friend. AA was able to develop his hearing with the cochlear implant through the world of sports in his narrative.

Not being able to communicate in English did not stop AA and the other children from playing, as he described, “Basically I just played with my friends, like you know playing like soccer or something; they were just, they were just like show me the ball and I just said yes.”

Despite playing a friendly, safe, rugby game with his friends, AA chose against playing rugby as a sport to avoid damage to the cochlear implant. However, he enjoys playing other sports such as cricket, squash and hockey. “At least I can play sport,” he reasoned, as he explained that while playing sports, his hearing aid switches itself off when he sweats but switches on again after a while, while his cochlear implant continues to function, as it is water resistant.

AA’s constructed identity as an athlete in his narrative reveals from pre-school years, to primary school years and through to secondary school years. Despite not being able to play contact sports, so as to avoid potential damage to his cochlear implant, the cochlear implant still enabled him to play other sports where he could be part of a team in a hearing society. Not being able to hear prior to the cochlear implantation did not stop AA from enjoying sports, but water resistance as a feature of the cochlear implant contributed to adapting to a hearing society, after the cochlear implantation, in a way that hearing people may often take for granted. If technology improves as such, it certainly creates hope for the future.

Conclusion

AA’s experience of reading the research findings of my interview with him as well as his experience of the research interview was discussed at a follow-up feedback meeting that was arranged after writing this research findings chapter. AA described

his experience of the research interview as good and it was nice to talk about his experience and learn about himself. He described his experience of reading the research findings chapter as good and true about him, agreeing with the title that his, “Adapting to a hearing society creates hope for the future”.

CHAPTER 6

RESEARCH FINDINGS

The Narrative of FF

“Living my life with a cochlear implantation in a hearing society, despite my mother’s concerns”

Introduction

FF is a male cochlear implant recipient aged 15 years who lives in Johannesburg with his father and mother. He is one of triplets, the other two being a brother and a sister. As a scholar, he attends a high school in Johannesburg.

The research question, as stated in Chapter 1, is, “How do adolescents within a South African context experience cochlear implantation?” It seems that from my engagement in FF’s narrative, FF lived his life with a cochlear implant in a hearing society despite his mother’s concerns.

In FF’s narrative, it seemed that he constructed multiple narrated identities, such as the patient, scholar, friend, brother, son and athlete identities. These are in constant interplay with one another with the purpose of living his life with a cochlear implant in a hearing society despite his mother’s concerns.

FF’s mother sat in on the interview process to assist where FF could not hear or understand, which resulted in some prompting of memories that he could remember and others which he could not. It may be that his mother showed concern where FF seemed to be living his life to his full potential with his cochlear implant within a hearing society.

BEING A “PATIENT”

FF’s narrated identity as a patient seemed to be the dominating identity in his narrative. The narrated identity of a patient has its beginning in pre-school years through to secondary school years.

FF explained his deafness as the result of strong medication given to him as a very sick baby, “Toe het die dokter die sterk medisyne gegee, of iets het my doof gemaak.” As a researcher I could relate to this particular experience of FF, as my mother also suspected that I lost hearing as a result of too many antibiotics when I was sick at such a young age. At the age of two, FF received his first hearing aids, which he experienced as loud but provided the ability to hear although not clearly.

FF struggled as a hearing aid user as he entered primary school at a time when he had to learn to talk with the help of professionals. He described his hearing experience as, “Toe ek die ou aparate gehad het, toe was dit harder gewees, maar nie duidelik soos die cochlear nie.” He began to use a new technology, the FM system, in conjunction with his hearing aids. “Ek het hom 'n paar keer by die televisie gedra.” Although this FM system seemed to be better for him in terms of watching television, he never really listened and preferred instead to just watch and ask questions.

However, his hearing deteriorated even more as he became sick again and consequently was recommended for the cochlear implant. FF described the preparation phase before the operation as a bit of a scary experience, “Dit was ... was 'n bietjie scary gewees, want ek kennie mos nie al daai goed nie.” He had to undergo an X-ray to see what would be done and where they would operate, as well as visiting the doctor often. He also explained that as a family, they had to visit the psychologist who explained the operation to them, especially to his two siblings, who seemed to be funny about this. “Hulle het met ons gepraat omdat ek nou 'n operasie gaan kry en goeters en toe verduidelik hulle vir my suster hulle.” This was supported by co-researcher, Marlie (2003), who indicated that it was important to include siblings in such a process.

FF described the operation process, which finally occurred during his grade 4 year, as painful, as he described that it felt funny where they had drilled, “Dit was 'n seer operasie gewees en dit voel nogal snaaks vir my; omdat hulle geboor het.” He recalled having to get used to it, but that it got better later. Things started getting exciting when the time arrived for setting up and programming the cochlear implant. After the explanation of what to do and what not to do, the switch on resulted in sound that was loud and clear, but still had to be programmed according to his needs. “Ja, toe was dit duidelik gewees, hard ook, maar toe stel hulle dit vir my reg.” FF described hearing with the cochlear implant as clear every time, providing an example of when he would open the ‘fridge and hear the sound as noise and even hearing the sound of the engine of the car. He later had a very physically painful experience with the magnetic part of the cochlear implant which was set too strong. “Hulle het met die magneet, hoe hulle dit indraai, was dit te sterk gewees.” Another magnet was then put in which was experienced as being better. Even better prospects lay ahead as he entered secondary school which seemed to soften the dominance of the patient identity and to create the possibility of living life differently to being a patient.

As FF entered secondary school, the narrated patient identity became less dominant with the upgrade of his external device of the cochlear implant. The new external device was of a better technology, and provided him with clearer sounds and better hearing. Here he recalled hearing the car engine, and wondering whether it was faulty with all its sounds and noises, “Ek hoor net die engine hoe ek in die kar klim en hoor ek so klak; maar ek dink dis iets fout met die engine, huh?” I can relate to this experience of FF, as I, who wears hearing aids, experienced hearing the engine of the car as I received a newer technology range of the digital hearing aids. Watching television now seems to entail listening and understanding what is going on. “As ek fliiek kyk, dan luister ek.”

The cochlear implant became a natural part of his life as it was incorporated into his daily routine. Batteries were expensive, at R40-00 a box of six which lasted for four days, and as such, he used rechargeable batteries. “Ekke, hierdie een wat ek nou het, charge ek; en dan spaar ons bietjie geld want hy, hierdie battery is baie duur.” The rechargeable batteries seemed to help them save money as they last him for

one day and he would recharge them every second day. FF described his hearing experience when he took off his cochlear implant external device, “As ek dit nou uithaal kan ek niks hoor nie.” With music, he only heard the background sounds of very loud music. “Maar as ek musiek speel, dan hoor ek net die agtergrond.” This is another experience that I, as a hard of hearing person, can relate to when I take out my hearing aids. I experience this as a very pleasant experience when I listen to music through the headphones. When FF goes to sleep, he puts his cochlear implant external device into a machine. The next day, the routine begins again.

Due to FF’s deafness as a baby, his narrated identity as a patient unfolded over time from pre-school years through to secondary school years. His identity began with the experience of being a hearing aid user, who struggled in different areas and would use an FM system to assist him to hear “other” speech better, to further deterioration of hearing resulting in going for a cochlear implantation which enabled him to hear more after the cochlear implantation. As he adapted in the hearing society, he realized that with the upgrade of his cochlear implant external device, the better technology provided the opportunity to hear sounds more clearly. The cochlear implant, as one of the various options that FF tried to make hearing possible for him, has offered him the opportunity to live his life in a hearing society, despite his mother’s concerns. However, there are co-researchers who have found the opposite of FF’s experience, in that some children may perceive themselves as inadequate and vulnerable compared to what their parents or teachers report (Bat-Chava & Deignan, 2001; Filipo, Bosco, Barchetta & Mancini, 1999).

BEING A “SCHOLAR”

Besides narrating his identity as a patient in his narrative, FF also constructs a scholar identity. His constructed scholar identity in his narrative seemed to be strongly influenced by his patient identity.

As a scholar, preschool was not a pleasant memory that was shared too willingly and consequently faded away with the scholar identity. A quick glimpse into the vague memories of pre-school revealed that FF remembered the teachers talking to him. “Hulle het net met my gepraat, ek weet nie wat het hulle gepraat nie,” and described

the other children as also deaf like him, “Hulle was ook doof gewees.” FF’s vague memories of pre-school subsided as quickly as his narrative of his primary school years were introduced with its challenges and successes.

FF first began to use the FM system with his hearing aids in grade two which made hearing the teacher clearer when she stood so far away from him. “Die FM was baie duideliker gewees want die juffrou staan so ver dan kan ek nie mooi hoor nie.” He seemed to express a positive experience of the teachers, despite their anger at children talking. “Die onderwysers was nice gewees maar partykeer was hulle kwaai.” He also expressed a positive experience of the children as they spoke clearly to him and gave him a lot of support and help, even repeating what the teacher said, “Hulle herhaal vir my wat die juffrou gese het.” I can also remember my interaction with the teachers and children in my school days as being a positive experience. FF continued to go to school with the headband after the cochlear implantation, but was met by children asking him questions about his cochlear implant. He also struggled with headaches and did not enjoy singing a lot in class as he described, “Ek het net in die klasse baie gesing; ek is nie mal oor sing nie.” Co-researchers, Wheeler et al. (2007), found that children with a cochlear implant can experience headaches as a disadvantage of the cochlear implant. Experiencing no problems with children, teachers were experienced differently in secondary school by FF.

The change from primary to secondary school was experienced as normal with no problems with the teachers except one old teacher who spoke softly and difficultly, making attainment of good marks extremely difficult. “Ek het nie eintlik probleme gehad met onderwysers nie behalwe een, sy's baie oud, sy praat baie sag.” The times that she would talk loudly, he would try to take in the information and learn, otherwise he would ask the teacher and his peers and try to catch up the work at home. He further expressed a dislike for reading and felt that if he didn’t understand a word, there were other words that he did understand and he could just ask. “Ek vra maar net dan, want ek verstaan baie ander woorde behalwe dit.” His friends definitely were ones he asked first. These experiences raised interest in findings in other studies that indicated that a child with a cochlear implant who attended an inclusive mainstream education was more likely to use spoken language more fluently, which allows him/her to participate more and spend more time in the hearing

classroom, consequently becoming more hearing acculturated. However, the child with a cochlear implant also seemed to experience difficulty in understanding what the teacher and other children said, as well as difficulty communicating with hearing peers during break times where there was too much noise (Leigh, Maxwell-McCaw, Bat-Chava & Christiansen, 2009; Preisler, Tvingstedt & Ahlstrom, 2005; Schorr, 2006).

The impact of the cochlear implantation on his narrated identity as a scholar unfolds over time from pre-school years to secondary school years, beginning with a very vague but unpleasant memory of his pre-school, introducing instead his experience of hearing with the aid of an FM system and expressing his positive experience of the teachers and children overall, prior to the cochlear implantation. After the cochlear implantation he expressed receiving support from his teachers and peers despite an experience with a teacher who spoke softly and made hearing difficult for him. Despite his mother's concerns, FF was able to find a way to make learning work for him, in the school environment, with the support that was available to him as he lived his life with a cochlear implant in a hearing society.

BEING A "FRIEND"

Besides the narrated identities of patient and scholar, FF also narrated an identity as a friend. It seemed that FF's narrated identity as a friend developed and strengthened after the cochlear implantation.

During the waiting period, between having had the cochlear implantation operation but before the switch on, he explained that he went to his friends but realized he couldn't run because of the cochlear implant. His friends soon learnt and accepted that the cochlear implant should not get wet and that FF would not be able to play contact sport. "Hulle het nie eintlik 'n problem, hulle weet daarvan; hulle weet hulle mag nie nat word nie; hulle weet ek mag nie soos in kontak sport doen nie." Despite these physical considerations, the friend identity continued to grow as he entered secondary school.

Friendship became mutual as his friends assisted him when a stranger said something he did not hear. FF however helped them with their cell-phones. He described himself being at his happiest with his friends, “As ek saam met vriende is,” where he didn’t experience boredom as they played cricket, “As ek vriende kuier, speel ek krieket,” play-station and rode their bicycles together. Similar activities were enjoyed with other friends, who are his siblings.

The construction of the friend identity only began to reveal itself in his narrative from primary school years through to secondary school years. This began with his friends learning about what FF could or couldn’t do, and choosing to do the things they could do together. The friendship became mutual where, not only did his friends assist him, but he was also able to assist his friends. As the cochlear implant provided FF the opportunity to live his life in a hearing society, he was also able to be a friend within this, despite his mother’s concerns.

BEING A “BROTHER”

The narrated identity as a brother also emerged in his narrative among his other narrated identities as a patient, scholar and friend. Particularly, it would seem that his siblings in his narrative played a supportive role in his narrated identity as a brother.

His narrated identity as a brother in his narrative began to introduce itself during his primary school days as the cochlear implant provided improvement in hearing. FF felt better, as he was better able to hear what his siblings said more clearly. “Ek het duideliker gevoel, ook duideliker gehoor.”

Asking strangers to repeat what they had said, when he did not hear them, was somewhat difficult for him. FF would much rather ask his siblings or parents to repeat what the stranger said. However, he experienced his siblings as impatient, as they tended to get tired after a while of continually repeating what they said. “Partykeer is hy geduldig, maar partykeer is hy moeg vir herhaal.” As a person with hearing aids, I could relate to his experience of asking someone who knew about my hearing loss to repeat what the stranger said and I also experienced people’s impatience at having to repeat what they said.

FF's narrated identity as a brother unfolded in his narrative from primary school years through to secondary school years. In the beginning hearing his siblings more clearly with the cochlear implant allowed him to feel better, yet he still relied on the support of his siblings in situations where asking people to repeat what they said was difficult for him. FF seemed to feel at ease with his siblings, despite his mother's concerns, as he lived his life with a cochlear implant within a hearing society.

BEING A "SON"

The narrated identity of a son is another one of his other narrated identities such as being a patient, scholar, friend and brother that reveals itself. FF's narrated identity as a son seemed to predominantly share experiences as a cochlear implant recipient with his father.

The ability to hear better and more clearly with his cochlear implant seemed to make FF feel better, as he was able to share his experiences of hearing different sounds with his parents. "Ek hoor net die engine hoe ek in die kar klim and hoor ek so klank; ek het net vir my ma gevra hoekom klink die kar so; my ma het niks gesê nie, net dat dit die aparatuur is wat so goed is." FF shared an enjoyable experience of a different world of sounds with his father as they ventured into the wild side of life. "Ekke skiet teiken en ek jag; baie lekker vir my." Winter months were the best times of the year for FF and his father to go hunting together, as he told of how he had shot a buck. Although he could hear the animals, he seemed to see more than he heard. "Ek sien meer."

FF's narrated identity as a son unfolded over time from primary school years through to secondary school years, as the cochlear implant enabled him to enjoy time spent with his father in a different world of sounds. Despite his mother's concerns, the cochlear implant seemed to have enabled FF to enjoy a relationship with his parents as a son, as he lived his life in a hearing society.

BEING AN “ATHLETE”

Besides his narrated identities as a patient, scholar, friend, brother and son, FF also narrated his identity as an athlete. This athlete identity seemed to experience loss in one sport yet gain in other sports as he received his cochlear implant.

FF’s father introduced the idea of a cochlear implant to him as he explained to him that he could not continue with his rugby as a sport because he would be operated on using a type of hearing aid that has a magnet that can help him to hear better. Similarly, the speech processor falling off during energetic activities or restriction of certain activities because of the potential damage to the cochlear implant were found to be disadvantages in a study done by co-researchers, Wheeler et al. (2007). Despite crying, “Toe het ek gehuil,” he felt bad about not playing rugby. “Want ek wou nie rugby los nie.” FF knew he should choose the cochlear implant. That did not stop him from enjoying the world of sports, as he decided to do gymnastics. “Ek het ook gimnastiek gedoen.”

FF played cricket for the school and the club. In his club cricket, his team did not have any problems with him as he was a very good bowler in their A team. “By die klub is ek in die A span; ek is baie goed met bowl.” Curiosity builds as he tells of having heard from his aunt about a cricket helmet for children who have hearing problems. This is yet to be explored.

As FF’s narrated identity as an athlete unfolded over time, beginning from primary school years through to secondary school years, he gave up his rugby to choose the option of hearing with a cochlear implant, and decided to take up gymnastics and cricket instead, after the cochlear implantation. The cochlear implant enabled FF to enjoy the world of sports, despite his mother’s concern, as he lives his life in a hearing society.

Conclusion

A follow-up feedback meeting was arranged with FF to discuss the research findings of my interview with him. He had already read the chapter prior to the meeting. The discussion entailed his experience of reading the chapter as well as his experience of the research interview. FF described his experience of the research interview and reading the research findings as normal and interesting for him. His mother had sat in on the feedback meeting, and a discussion about the title of the research findings, which they were happy with, seemed to reveal that his mother's concerns was not extreme, but rather it was a natural concern for FF, especially when he was smaller. However, she also noted that FF coped well with his cochlear implant.

CHAPTER 7

RESEARCH FINDINGS

The Narrative of BC

“The technology that enabled participation in the hearing society with hearing people”

Introduction

BC is a male cochlear implant recipient aged 20 years who lives in Johannesburg with his father, mother and brother. He is unemployed and exploring options for his future career.

The research question, as stated in Chapter 1, is, “How do adolescents within a South African context experience cochlear implantation?” It seems that from my engagement with BC’s narrative, BC experienced the cochlear implantation as a way of enabling him to participate in the hearing society with hearing people.

In BC’s narrative, it seems that he constructed three identities, including the patient, friend and scholar, which are in constant interplay with one another with the purpose of participating in a hearing society with hearing people.

BEING A “PATIENT”

BC’s construction of the “patient” identity, within the medical context in his narrative, seemed to be the dominant identity that has been normalized through various experiences in order to be a part of the hearing society. This identity unfolds over time as it began in his pre-school years, to primary school years, to secondary school years and through to post-secondary school years.

BC’s mother contracted a virus during her pregnancy that resulted in him being born premature and sick. He explained the effect of the virus on his brain, “My brain is taken over on the one side, the creative side, so this side is controlling everything;

it's um amazing because I'm only using one side of my brain to function all the things that I need, for example running." BC had to go for therapy to help him use his muscles effectively and consequently only started walking at the age of four or five years. For the first five years of his life, when he could hear, he had developed good language skills but explained, "I went to speech therapy and all that as well." Although BC developed good language skills with his hearing aids, other co-researchers such as Berrettini et al. (2008); Wheeler et al. (2007), as well as Filipo et al. (1999), have found that children or adolescents with cochlear implant(s) generally improve their ability to communicate and develop communication skills, which consequently results in improved interaction with family and friends, improved modes of expression and better communication of their needs and wants.

At the age of five years, BC went deaf and couldn't hear, after which he underwent an operation, which he explained as, "The one with those needles, pins," to help restore his hearing. After this operation he received hearing aids for both ears, which he described as, "Wasn't that, um great," because it amplified sounds and made hearing people difficult with background noise. As a researcher, I could relate to BC's experience, also having gone deaf at the age of five years and struggling to hear people with background noise, with my hearing aids. He further described his first time with hearing aids, "the funny thing is when I was starting with the hearing aids, um it was like unusual for me, so what would happen is that I would go swim and jump in with my hearing aids."

This virus continued to affect him at the age of eleven years, resulting in deterioration in his hearing in the right ear. His parents looked into the option of a cochlear implantation and BC was confronted with the choice of getting a cochlear implant. It was at this point that he had to decide between sports and hearing, but decided, with the help of his parents, teachers, friends and the Doctor, "The cochlear is a good choice because hearing is obviously better than playing sport." The operation was experienced as painless. A check up to see if the cochlear implant worked took place during the healing process, and finally the day arrived to programme and tune the sounds on the computer. Worried that something more was coming, when the sound came on, it was different. He explained, "With this you know, this they can put hearing higher and higher to make the clarity better and all

that, so they sort of have a low one and it gets better gradually, so you build from it.” This cochlear implant, which he described as a “robotic ear”, allowed him to pick up the direction of sound and where it was coming from, to understand people and to talk to people in noisy areas. Co-researchers, Berrettini et al. (2008); Preisler et al. (2005), as well as Jessop (2005), have found that as a child gains access to a wide variety of environmental sounds, with the use of the cochlear implant, some of these children and adolescents want to be surrounded by these sounds. For some, these sounds function as warning signals to protect themselves and for others for the enjoyment of listening to music. These findings are similar to BC’s experience of enjoying listening to all types of music on the record player with his hearing aids on. Here too, I as a hearing aid user, also enjoyed the experience of listening to music, but it was also an enjoyable experience to “feel” the music without my hearing aids and with the headphones on. However, co-researchers Preisler et al. (2005) also indicate that other children with cochlear implant(s) may experience the noise as disturbing, frightening or irritating and consequently long for the silent world, which is similar to what BC experienced. BC experienced the sounds as a bit loud at times, and he could hear things he had never heard before, which although it was nice, it was also irritating, because he was not used to it. He nonetheless kept his cochlear implant on most of the time and explained that, “I had to go for speech therapy after I got the cochlear,” but he became used to the cochlear implant after about a month.

The choice for a second cochlear implant during BC’s secondary schooling was based on it being a benefit to him. He described the operation phase of the second cochlear implantation as, “It was kind of a concern for my mother, cause it was pretty stressful times.”

He also described his mother’s panic, “She started smoking again because apparently she was starting to panic,” worrying about the possibility of the operation going wrong. However, he reassured, “Luckily my process, my ears were first time successful.” Once again he went through the process of healing and checking if it worked.

The switch on was described as “hectic”, as if he was hearing for the first time in his left hear. He described it as, “It was kind of nice but irritating, irritating, you're not

used to it.” He expressed his response to the irritating sounds as someone making tea, “Stop with that tea.” If he got really irritated, he would take the cochlear implants off for a while. The problem was not the sounds, which he could at least remember from his first five years of life, but rather, “It was just getting used to the cochlear, you know, that was the challenge.” He nonetheless expressed that, “To get used to something you have to go through it.” Although the cochlear implant was experienced as a normal part of life for BC, his family was happy for him when he got both cochlear implants, and celebrated with a party, because after struggling to get him there, he could now hear properly.

Choosing to get used to hearing with the cochlear implants, by going through the process of hearing different sounds, enabled BC to continue enjoying his music. “I’ve liked music all my life.” Wanting to learn to play instruments, BC started to play the guitar, which he explained requires a lot of time to practice and commitment to play. One of the most important things that he expressed about his cochlear implants was, “I can hear music well.” He mentioned that making music would be something creative that he would do as a hobby. Although BC expressed, “I battle on the ‘phone sometimes,” he seemed to have discovered a specific ‘phone that worked for him and felt it was important to be able to hear on the ‘phone to interact with friends and people. This is an experience I, as a researcher with hearing aids, can relate to, in that, although I can hear the person on the ‘phone, hearing what the person says is something I really struggle with. He mentioned the other most important things about the cochlear implants, “I can hear properly, you know, I can have a conversation with people.” Not afraid of entertaining and being out there, BC felt he could interact with people and form relationships. For BC, being deaf is, “For me it, I don’t know, it’s the usual thing of life; that’s a normal part of life.”

Deafness at the age of five years was the start of the construction of a patient identity which unfolded over time, from pre-school, to primary school, to secondary school through to post-secondary school. It began at the age of five years where he received hearing aids in both ears. At the age of eleven years, BC’s hearing deteriorated and he underwent his first cochlear implantation which, after experiencing better participation in the hearing society, encouraged him to go for a second cochlear implantation. Both cochlear implantations were successful and

resulted in even better hearing and participation in the hearing society with hearing people.

Various challenges and successes experienced with the cochlear implants as he strived to adapt to the hearing society enabled him to participate in the hearing society with hearing people.

BEING A “FRIEND”

Besides BC constructing himself as a patient in his narrative, he also constructs an identity of being a friend in his narrative. BC’s patient identity seemed to have a significant impact on his identity as a friend.

BC seemed to experience his nursery school as non-supportive in helping him to get to know friends. As such, his brother became his friend in his pre-school days, where despite having fights like most children, they would go out and play, walk the streets where they knew the people from the other side, make friends in the neighbourhood and ride bikes. He described his brother’s perception of him, “He didn't see someone that was, hearing loss, you know, it was just BC, it's his brother.”

Although BC started to make a lot of friends as he entered primary school, where each individual in his school had some kind of disability, but yet understood each other, most of his friends did not have a disability. He explained, “I was the only person with my friends with hearing aids.” I can share my experience as a researcher with hearing aids where I had hearing friends and was the only one, among my friends, who had hearing aids. Yet, because I was able to communicate effectively with them, they would sometimes forget that I had a hearing loss. As BC told of how a lot of girls liked him, he recalled that he had a girlfriend from his primary school days.

Moving into secondary school, things started out well as he explained, “When I first came out it was pretty exciting to meet someone like me; they'd never seen a person like that before.” However, things seemed to get bad. He explained that he had both cochlear implants and, “People were mocking me.” With his popularity, he also

experienced other student's jealousy at his popularity as he explained, "There was where, you gonna take up spots, so I'm gonna try and put you down, or whatever, you know." He was even involved in a physical fight with this particular person. He explained that he continued to be nice to the person who later formed a bit of a friendship with him. However, fed up with the people and tired of the school being all about popularity, he expressed, "That's why, especially, I moved from that school to that school but then you become even more a main focus."

"To be the main focus is pretty hectic, you know, you don't ask for it, you don't," he explained. However, the environment at the second school seemed to be better with people trying to make friends with everyone else and the popularity seemed to be different in that it had a more comfortable vibe. BC expressed that the girls liked him for who he was, and he preferred that people treated him as a person and loved him for who he was. It was on these premises that he related to people and developed friendships. As a researcher with hearing aids who interacted with hearing people, I can relate to BC's experience, in that I decided that instead of worrying about whether someone liked me or not, people needed to accept me for the person that I was, which I concluded was what a true friend would do. BC explained that, "Having friends was important to me," because, "No one likes to be alone, ok, so everybody likes to have someone as a friend." However, this became more challenging when BC left Secondary school.

BC compared his constructed identity as a friend after school to his constructed identity as a friend in his school years. "When you're in a school environment, it's different. Why is it different? Because the people have to know you, they have to get to know you 'cause you're gonna be there the whole year, you'll be there maybe longer, whatever, and once they start understanding me, start justifying their acts." However, after school, BC realized that people were prejudiced and rejected him. "They just don't want to listen to you." Despite not liking the idea of being rejected, he argued that it was important to form friendships with people who were not cochlear implant recipients so that one didn't form a cocoon and get stuck. He further explained that, "Having social standards is important to me because there, to develop myself, and to know that, to, you belong somewhere as well." Studies conducted by Schorr (2006) and Marlie (2003) reveal differences in experiences of a

sense of belonging by different children with cochlear implant(s), such that some children who had the cochlear implantation done at an older age took longer to attain a feeling of belonging or experienced difficulty in feeling that they belonged at all. Whereas children who received the cochlear implantation at a younger age seemed to experience more positive psychosocial outcomes in adolescence and reported a general sense of support and feeling of inclusion. As a young adult, a feeling of inclusion seems evident as, despite not having seen one of his best friends in a long time, BC has been making a music project with a friend, which is done on the computer and recorded, which elicits amazement from people because they're so good at it.

The constructed identity as a friend in his narrative also unfolds over time from pre-school years through to post-secondary school years, where he first had his brother as a friend. They in turn made other friends so he became popular. Despite popularity causing issues of jealousy, he later valued the importance of developing friendships with people who treated him as a person and liked him for who he was. Although he experienced prejudice from other people, as well as some friends parting while others stayed in contact, he still placed importance on developing friendships with people who did not have cochlear implant(s). It seemed that, although prior to the cochlear implantation, BC had learned to make friends, after the cochlear implantation, his experience of popularity and making friends seemed to result in wanting people to like him for who he was.

The cochlear implant enabled BC to develop friendships with people who were hearing which enabled him to participate in the hearing society.

BEING A "SCHOLAR"

Not only has BC constructed an identity as a patient and a friend in his narrative, but he also constructed an identity as a scholar. The patient identity as well as the identity of a friend, seems to impact and influence the construction of the scholar identity.

BC attended a primary school for children with disabilities, cerebral palsy or learning problems. He was kept back because of immaturity for his age at the end of his first grade, and described his experience as, “It was kind of hectic hey, because all your friends are over there; your friends moved on and you stayed behind.” BC’s grade two teacher was the worst teacher of all his teachers as he explained, “Some kid said they, I was teasing him about his disability and the teacher came right up and started slapping me.” The teacher then put him in a corner. Despite these experiences, and forgiving the child later, the loss of another fellow pupil in his school was experienced as, “A very emotional topic,” when he was in Grade 6. A particular boy in his school would sell sweets and popcorn in order to make money to pay for a taxi to get home, and BC would see him once a day and go and talk to him and support him by buying from his goods. This continued, until early one morning, the boy was hit by a taxi and died on impact. People were sad, as they put flowers down where he had died, and his school had a funeral for him and paid tribute to him. Although he described the friendship as not tight, the narrative of the boy was an emotional topic. Entering into his final year at primary school, BC described his experience, “She took me and there were a couple of other students that were chosen and you were given a letter and your, your parents were spoken to as well, so from there, I went to grade 7. I did grade 7 in primary school, to our first grade 7 class.”

BC’s experience of entering secondary mainstream school with 35 children in a class was described as difficult, as his hearing had deteriorated and he had also received his cochlear implant. As a researcher, my experience as a hearing aid user was different from BC’s in that I moved from a primary school, with large numbers of children in a class, to a secondary school with smaller numbers of children in a class. This enabled me to receive individual attention and to hear better in a classroom environment, making learning somewhat easier. According to BC, “I think for the teachers, it was difficult, the mainstream teachers did not know how to handle children with hearing aids.” He continued to go to school and follow a normal process of going to class to learn. BC described his move to another secondary school in grade 11 as hectic, with people looking at him because of his cochlear implants. Similarly, co-researchers Wheeler et al. (2007), argued that generally, it would seem that children with cochlear implant(s) tended to move from mainstream primary

school to more specialized provision at secondary school, of which they found that the transfer to high school, and being bullied, was expressed as a negative experience. However, BC also mentioned strengths that he used in his secondary schooling which included his ability to do speeches that maintained the children's attention, as well as his ability to sing and make music that elicited amazement from the children in his class. Academically, BC coped, as he explained, "I would say, it was sometimes, I scraped through the years and sometimes I did better; and then I passed matric, not bad, but I could have done better."

Having passed matric, BC felt that his life had stopped with no progress or moving forward. He described his experience of the stop point, "It's nice, sometimes you play games for two hours, you rest at home, you don't do anything; but on the other side is, ja, I would like to move away from the stop point 'cause you don't have the social side." Deciding that he would like to explore what he really wanted to do through voluntary work, where he could help people, the stop point seemed to have allowed him to think about possibilities for the future. Such possibilities seemed to include psychology as he explained, "You can help people with their emotional needs, you can understand children who are about to get cochlears and you can help them while getting the cochlear 'cause you understand how they feel." He also considered audiology where he could help with, "Developing a new cochlear, having ideas for people with cochlears." His interest in psychology and audiology seemed to come from a need to help people because he understood what it was like to go through a cochlear implantation. Co-researchers, Haensel, Engelke, Ottenjann and Westhofen (2005), as well as Wheeler et al. (2007), found that the majority of the children in their studies would undergo the cochlear implantation procedure again and in terms of offering advice to another person in need of a cochlear implant, these children recommended that it should be considered after careful assessment in order to do what was best for the child. Alternatively, BC considered other possibilities such as becoming a public relations administrator because of his good public speaking ability or becoming a lawyer to help prove people innocent.

BC's constructed identity as a scholar unfolds over time from primary school years through to post-secondary school years, as he began with various experiences mostly related to his social relationships with hearing teachers and pupils.

Academically, he coped, and despite being kept back, he was one of the few selected children to attend his primary school's newly introduced grade 7 class. After the cochlear implantation, although secondary school was experienced as hectic with his cochlear implants, he also revealed areas of strength. As he found himself at a stop point, he considered various options for his future career, some for the very reason of being able to relate to the experience of a cochlear implantation.

The cochlear implant not only enabled BC to engage in social interaction with hearing people in the hearing school environment, but also enabled him to participate academically in a hearing society's academic context.

Conclusion

A follow-up feedback meeting was arranged with BC, where we discussed BC's experience of reading the chapter of the research findings of my interview with him as well as his experience of the research interview. Agreeing with the title of his chapter, BC described reading the chapter of the research findings as visualising himself as if he were watching himself on television, and experienced it as different, as he had not done something like that before. BC further explained that reading the chapter was like, "De-je-vu." When asked about his experience of the research interview, BC explained that it was nice, comfortable and easy-going.

CHAPTER 8

RESEARCH FINDINGS

The Narrative of MM

“Hearing colours with cochlear implants enables participation in the hearing society”

Introduction

MM is a male cochlear implant recipient aged 17 years who lives in Johannesburg with his father, mother and sister. As a scholar, he attends a high school in Johannesburg.

The research question, as stated in Chapter 1, is, “How do adolescents within a South African context experience cochlear implantation?” It seems that from my engagement with MM’s narrative, MM experienced the cochlear implantation as enabling him to hear colours which consequently resulted in participation in the hearing society.

In MM’s narrative, it seemed that he constructs multiple identities, such as the patient, family member, scholar, athlete and friend, which are in constant interplay with one another with the purpose of participating in a hearing society where colours can be heard.

BEING A “PATIENT”

MM’s construction of the patient identity in his narrative seems to be the dominant identity that influences, and is influenced by, all the other constructed identities. The constructed patient identity has its beginning in the pre-school years through to primary school years and to secondary school years.

MM described the discovery of his hearing loss at the age of 18 months, “We were just like looking at this helicopter and apparently I didn’t react to the helicopter; and

my gran was like, I think you have to take him for a hearing test, um ja that's when I, that's when they found out I was deaf." He was deaf in both ears and got hearing aids, which he would wear for five minutes and then take them off. Hearing with the hearing aids enabled him to pick up and learn different sounds and to communicate with people and have a conversation, despite not hearing the cars or hearing on a telephone. Just like MM, I as a researcher could relate to his experience of the hearing aids, as I too wore hearing aids in both ears and could hear some sounds while not hearing others.

MM's hearing began to deteriorate when he was in grade 1 which prompted his mother to find out about the option of a cochlear implant. "My mom went like to the doctor, I think like every night, to speak about cochlears and what we're gonna do and what's like advantages and disadvantages." His mother also spoke to another girl who had a cochlear implant who went to the same nursery school as MM. Although he was nervous about the possibility of the operation being unsuccessful, after finding out about a lady who had experienced her cochlear implantation as unsuccessful, he had seen other people who had had cochlear implant(s) that were working and so he considered the option. He went through a preparation phase that entailed checking that he didn't get sick and that he was ready for the operation. As well as being scared, he described his experience just before going in for the operation, "My mom took me like to the room and then I was, was it there, ja, and then they took me and then my mom came in and they put that mask on and then they'd count like 1 2 3 and then like I was gone." He remembered waking up, feeling sore and dizzy with a bandage on his head. "Afterward I came out and I didn't know what happened, I felt I was hit like a train, by a train." The pain stopped, and as his mother came in, they went into the ward where his family and au-pair waited. He recalled his drip had started leaking and they had to redo it.

After four weeks of waiting for the wound to heal, the day finally arrived for MM to have his cochlear implant switched on. He described the long process, "When that switch on came, it was like a long time 'cause you really have to do it right to suit you, your hearing." This process entailed audiological tests and feedback on the loudness or softness of the sounds, which the audiologist would program on the computer, according to his needs. As a researcher with hearing aids in both ears,

this is a similar process that I go through when I visit my audiologist to adapt the settings on my hearing aids via the computer. They then realized that MM couldn't hear, to which the audiologist responded that they had missed something and had to fix the problem on the computer. He described hearing a noise, fine and clear, "I could hear but it was different because the first thing I could hear, the car; I was like, what's that noise? She was like no it's cars." Initially he couldn't really understand it but then it became better. The hearing aid was used as a backup with the cochlear implant and enabled him to hear more. Two years later his device stopped working, and while that went in for repairs, he had to wear an external device with an attached box and described his experience, "It stopped like working and I remember having that box thing; and I had to make sure that it didn't fall out the pocket or anything." He then realized the advantage of having the behind-the-ear external device, as he didn't have to worry about the box device falling or dropping out of his pocket. Similarly, in their studies, co-researchers, Schorr (2006); Schorr, Roth and Fox (2009), as well as Wheeler et al. (2007), found that although there seemed to be a low level of concern about problems associated with wearing the cochlear implant, children or adolescents with cochlear implant(s) have become dependent on the cochlear implant(s) to the extent that, should they experience a problem and cannot use the device, they feel bereft.

However at the age of 13 years, MM's hearing in the right ear began to deteriorate so that he couldn't hear with the hearing aid. He became aware of his hearing loss and questioned why he was losing his hearing, which was confirmed by the audiologist during an audiological test. Although he was initially against going for the second cochlear implantation, because of the expenses of the batteries, and not wanting to go through the drilling in his head and the throbbing pain, he then explained, "I was told that I'm only hearing black and white. If I have to, I'd be hearing colour," which seemed to motivate him to go for the second cochlear implantation, thinking it would be the right thing to do.

MM described the hospital experience in terms of his concern for his parents, "I think they didn't want to go through this trauma and everything again; and we've just been through all this, all that time and it doesn't want to work and then I don't know." After the operation and the healing took place, he went for his switch on, which, as well as

having a new program, he said, “It wasn’t as bad as the first time,” as it was shorter and they knew what to do. As a researcher, I can relate to the familiar routine of setting the sounds according to my hearing needs at follow-up appointments with my audiologist, where it seems to be easier on the audiologist to have a client who knows what to do. Although MM could hear better and clearer with both cochlear implants, he also mentioned that therapy had changed his right ear to be the better ear.

MM expressed concern about whether his parents could afford the batteries which only lasted three or four days. “We weren't gonna get it, I was like against doing the second one, well I don't know, for some reason, I think it's gotta do with batteries; batteries are expensive back then.” However after the second cochlear implantation, the batteries became cheaper even though he had to buy double batteries. MM wears his cochlear implants from six in the morning until nine in the evening every day and describes his hearing with both cochlear implants, “I could tell the difference because it was so much better and everything and so much clear; than what it was before.”

The cochlear implants enabled MM to hear people on the ‘phone, which he explained that, after talking on his friend’s ‘phone, he realized that that specific ‘phone was much clearer and he could hear better on it. He described his communication on the ‘phone, “It’s nice, sometimes I don’t hear what the people are trying to say so you like ja, mm; ja I get the point and then ja, it is nice to hear people but I like to like talk to people face to face.” He prefers instead to send short message texts to people or to talk to people face to face. This is an experience I, as a researcher, can also relate to, where I prefer to talk to people on the ‘phone where need be, yet conversation face to face is an even better option for me. If MM misses what was said, he sometimes just listened to hear what the overall conversation was about. If he still didn’t know what was said, he would ask and people would tell him. However, he also described people’s responses to him asking them to repeat what they said more than once, “Sometimes when I like meet new people, meet new friends and like sometimes I don’t hear them, so I think afterwards they get like cross. I’m like sorry, what did you say and then they say it again. I still can’t hear you, what did you say? Some people can like really get irritated like in small things; but

then afterwards they realise that I am deaf.” Co-researchers, Bat-Chava and Deignan (2001), found in their study that, although children or adolescents with cochlear implant(s) may experience problems in communicating with children who were impatient, there is potential for improvement in social relationships with hearing peers.

The cochlear implants have given MM a sense of direction of sound, so much so that if someone greets him, he can say where the person is standing. It has also given him the option of choosing to switch to the silent world, which he describes as nice, as he can have a good rest, with the best sleep ever without anyone bothering him.

MM became a patient in the medical world as a result of his hearing loss. His identity as a patient unfolded over time from pre-school through primary school then to secondary school. It started with the discovery of his deafness at 18 months and getting hearing aids. However, as his hearing deteriorated, he then received his first cochlear implant in his left ear, using the hearing aid in his right ear as a backup. But deterioration in his right ear later led to getting his second cochlear implant for the right ear. With both cochlear implants, MM was hearing much better and clearer than prior to the cochlear implantation, and was able to participate in the hearing society.

Hearing with both cochlear implants enabled MM to hear “colours” rather than black and white, and consequently enabled him to participate more fully in the hearing society.

BEING A “FAMILY MEMBER”

Besides constructing his identity as a patient in his narrative, he also constructed an identity as a family member, which encompassed his experiences with his parents, sister and grandmother.

MM’s hearing aids only seemed to provide him access to hearing certain things whereas when he had the cochlear implant and the hearing aid, it was better because he could hear his family, interact more with them, understand what they were saying and engage in a conversation with them. After his second cochlear

implantation, he realized that it was different. “I quickly saw that it was different and that I could hear them and that and we could like talk properly like on normal level.” His family were amazed that, with the cochlear implant technology, he could hear so much more. For MM, the cochlear implants really made a difference.

MM’s observation of the effort that his family put in to help him, even with school work, enabled him to experience his family as supportive, caring and willing to do anything to help him. He explained, “They’ll support me and you know whatever I decide to do, they will be there for me.” As a researcher, this triggered my memory of my own observation of my parents helping me wherever they could, as they seemed to understand and support me in a way that I realised that hearing people, who have not lived with a deaf person, would never understand or begin to relate to.

The impact of the cochlear implants on his constructed identity as a family member unfolds over time from primary school years through to secondary school years, beginning with hearing only certain things with his hearing aids. After his first cochlear implantation, the cochlear implant enabled him to hear better with the hearing aid as a backup. However, once he received the second cochlear implant, he was able to have a proper conversation with his family, who all made it possible, through their support, care and willingness, to help him.

Two cochlear implants enabled MM to hear the “colours” in his conversations with his family members, and consequently enabled him to participate in the hearing society with his family.

BEING A “SCHOLAR”

Besides constructing himself as a patient and family member in his narrative, MM also constructs an identity of being a scholar. Hearing loss and deterioration had a profound impact on his constructed scholastic identity.

At the age of five years, MM went to a school for children with hearing impairments. There were children who were, like him, using hearing aids and other children who had cochlear implant(s). He described his nursery school experience, “I remember

we did like read books and like you have to say a word out and like draw pictures and um, ja, but I remember and listening and then like listening.” MM stayed back a year in nursery school, and then moved to grade 0 at another school. He recalled his experience, “I just went from like a small group to like a class of 25 all of the sudden, that was like different than um I don’t know, like in grade 0, we used to like line up and I always used to go like to the front and I was supposed to be in the middle; ‘cause like in nursery school, I always used to go to the front; then eventually I started seeing now, this is where I am supposed to be.” He nonetheless coped with his hearing aids in grade 0 and made friends.

Up until about June in his grade 1 year, MM was able to hear with his hearing aids. However, his hearing began to deteriorate, and as he explained, “I then just basically used to lip read the teacher the whole time.” Although he was good at it, it was difficult because he could not hear as well as he used to. His grade 1 teacher was a very good teacher, as she knew about his hearing loss and spoke slowly so he could pick up what she was saying and consequently, “I only just passed grade one by lip reading.” As a researcher, I can relate to mastering the skill of lip reading. The response of the children to his hearing loss varied, as he explained, “Some then were like ha, ha, ha, whatever and some of them were like ja, some of them were with me.” MM described his hearing after the cochlear implantation as different, because he could hear what all the people and the teacher in his class had said, better and clearer. Based on studies done by co-researchers, Leigh et al. (2009), as well as Schorr (2006), it was found that a child with cochlear implant(s) who attends inclusive mainstream education is more likely to use spoken language more fluently, allowing him or her to participate more in the hearing classroom. Consequently a child with cochlear implant(s) becomes more hearing acculturated as opposed to children with cochlear implant(s) who attend schools for the deaf. MM indicated that he improved academically. “I think my marks like changed like from 40s to 60s.” The cochlear implant opened new doors in his school work and interaction with people. Studies have shown that having the cochlear implant benefits academic performance and helps with understanding the lessons, despite the need for additional reliance on support for understanding (Schorr, 2006; Schorr et al., 2009; Wheeler et al., 2007).

As MM started grade 8, and started playing rugby, the children who had laughed and been disinterested in his hearing loss, were in his class for two years and had become friends with him. MM felt he needed to work hard and put in more effort in his work, as he explained, “I wanna be like in the middle, not like at the bottom, like in the middle you know, like there’s top, middle, bottom, I’m there.” The cochlear implants have enabled MM to realise, “I just see that I can do it, you know, I can go to varsity, get my degree.” Although he was confused about his future and didn’t know what he wanted to study, he did mention wanting to do IT or a business degree.

As MM’s identity as a scholar unfolded over time, from pre-school years through to secondary school years in his identity, he expressed a sense of hope in furthering his scholarly identity with success after his secondary schooling. The constructed scholar identity begins as a hearing aid user who moved from a small class to a bigger class in another school, where he nonetheless coped and made friends. However, as his hearing deteriorated in first grade, he began to rely on lip-reading, resulting in varied responses from the children. After the cochlear implantation, there was a marked improvement, not only in his ability to hear other people, but also in his academic marks. Striving to improve academically, he expressed hope in going to study at a university to get a degree.

The cochlear implants enabled MM to be a part of the hearing academic context, as hearing colours made it possible for him to learn.

BEING AN “ATHLETE”

Not only did MM construct an identity as a patient, family member and scholar in his narrative, but he also constructed an identity as an athlete, which unfolded over time from primary school years through to secondary school years.

MM enjoyed his sports, because he was able to hear people, play with them and play freely in the team. Since he had to do sports in his Primary school, he played touch rugby, soccer and did swimming. He explained that with touch rugby there was no contact, as he had to put the ball down if the person touched him. He didn’t like

soccer as he expressed, “You can’t get a score the whole game; you have to like pass to like other people.”

As MM explained, “You could like prove like your time in like your swimming without all the other people.” Swimming was different without his cochlear implant. He would lip read and watch his coach, who, knowing that he was deaf, would show him what to do, such as using his arms to indicate to him to kick his legs. At the swimming galas, people were aware that he was deaf and because his cochlear implant would be on the stand, he would lip read a lot as they sorted themselves into their teams. People would indicate to him where to go and he would use a permanent marker to write on his hand as to where to go. Besides being able to hear the start gun to know when to dive in, he also added, “I used to watch other people. If they dive in, I would dive in.” MM went to try out for the School Trials but didn’t make it, and since then has stopped swimming. As I reflect on how MM explained doing different sports and finding one that he enjoyed, I, as a researcher could also relate to this trend, as I tried netball and tennis and eventually settled on dancing, where I took part in competitions, concerts and exams.

As MM entered Secondary school, he decided to play tennis instead of doing swimming, which he did in the first year. He was then approached by a coach, who knew he couldn’t play rugby or hockey. “He said to me, so why don’t you wanna be like, like team manager and like sort out everything for me; you know like do the teams and you know like do background work while I do the practice. So then I did that for like the whole season.” MM began to score in the rugby games, and enjoyed it because he could still be part of the team. When he was replaced during the rugby season, it was suggested he learn how to score in cricket, which he did for two teams in the summer sports. However, he did not fulfil the requirements needed to do some kind of sport or exercise to get fit. Despite this, he thought out loud, “I think I’m gonna take swimming in the third term, no 4th; I want to start swimming and I’ll still do cricket scoring.” He noticed at the swimming galas that there was a new system for deaf people, where there was a big button that made a noise and the light came on, and the deaf person could see the light to indicate when to go. Although he doubted whether he could swim a lot, seeing the other people swimming, made him realize, “If they can do it, why can’t I?”

The constructed athletic identity unfolds over time from primary school years through to secondary school years in his narrative, where he starts as a successful deaf swimmer who is able to swim without his cochlear implant on but decided to stop after not making it for the School Trials. As he moved into secondary school, he was also given the opportunity to be a team manager and to score rugby games as well as cricket games. However, there seemed to be a hopeful dream to start swimming again. It seemed that after the cochlear implantation, MM was able to explore and take part in different sports and find ways to make them work for him.

Hearing colours with his cochlear implants enabled him to participate with the hearing sport team in some sports, and he was also able to choose a sport where he could succeed without his hearing.

BEING A “FRIEND”

MM’s narrative included another constructed identity, as a friend, that unfolded over time from primary school years through to secondary school years, besides his constructed identity as a patient, family member, scholar and athlete.

MM described his conversations with his friends prior to the cochlear implantation, “Before I felt one level down; and they would like become one level down as well.” His friends didn’t seem to have a problem speaking to him on a lower level as they knew he had difficulty hearing. Consequently, they would also talk slowly to him, especially when he couldn’t hear so well. Once MM had the cochlear implant, he could hear his friends and could communicate with them. “They like responded, like wow, ok, ja, we don’t have to like you know step a level down; we can just talk you know like on a normal basis.”

MM explained that he had different groups of friends, some of whom were from other schools. This brought me to a finding by co-researchers, Preisler et al. (2005), who argued that often a child with cochlear implant(s) who attended inclusive education tended to have hearing peers at home and was likely to use text telephone with friends who were deaf or had cochlear implant(s). Referring to his attendance in the bottom class of the three academic achievement class levels of bottom, middle and

top, MM described the children in the bottom class, “They don’t wanna work, they just wanna play all the time.” He only had two or three friends in his class that he could work with, but felt he needed more than that. He described his friends, “They were my good friends last year and they like worked with me and we did everything.” As a researcher, I could relate to the experience of having good friends, and despite being able to interact and build friendly acquaintances with people in general, I had a preference for having only a few close friends. Although MM experienced it as different not seeing his friends, because they all did different subjects, he suggested that if he worked, he would be able to move up to the middle class where his friends were.

MM constructed his identity as a friend in his narrative that unfolded over time from primary school years through to secondary school years. Here he was able to move from his experience as a hearing aid user, who engaged in conversations with his friends on a lower level prior to the cochlear implantation, to hearing his friends speaking to him as they would any other hearing person after his cochlear implantation. Despite this, his friends were good friends who were aware of his hearing loss.

The cochlear implants enabled MM to hear the colours in his friends’ conversations consequently resulting in better participation in the hearing society with his friends.

Conclusion

The follow-up feedback meeting arranged with MM entailed a discussion of the research findings of my interview with him. He had already read the chapter prior to the meeting. The discussion pertaining to his experience of reading the chapter indicated that it was different, but nice for him as it described “him”. He also expressed that the title was linked to how he described his hearing during the interview process in terms of hearing black and white.

MM described his experience of the research interview as different, as he had to think to remember, and had realised that he had experienced both bad times and good times with his cochlear implant.

The approach to go back to the research participant for his input of the findings of the results remain true to my position from a narrative approach, where the participant remains an active contributor and creator of his own narrative.

MM's mother sat in on the feedback meeting, and recalled a particular experience of MM as an athlete, which MM had not included in his narrative. This indicated the uniqueness of each person's narrative about a particular person's experience of the cochlear implant. It is an area for further research, where parents of the adolescent cochlear implant recipient can be interviewed from a narrative approach to determine the parents' experience of their adolescent's cochlear implant. This is discussed in Chapter 10.

CHAPTER 9

RESEARCH FINDINGS

The Narrative of SDV

“The privilege of an opportunity to hear with a cochlear implant”

Introduction

SDV is a female cochlear implant recipient aged 18 years who lives in Pretoria with her biological mother, step-father and biological brother. On alternate days of her choice she lives with her biological father, step-mother and step-brother. As a scholar, she attends a high school in Pretoria.

The research question, as stated in Chapter 1, is, “How do adolescents within a South African context experience cochlear implantation?” It seems that from my engagement with SDV’s narrative, SDV experienced the opportunity to hear with her cochlear implant as a privilege.

In SDV’s narrative, it seemed that she constructed multiple identities, such as the patient, friend, family member, scholar and athlete identities. These were in constant interplay with one another with the purpose of using the privileged opportunity to hear with her cochlear implant to participate in a hearing society.

BEING A “PATIENT”

The dominant identity that comes to the fore in SDV’s narrative is that of a patient, as it unfolds over time, from pre-school years, as well as primary school years through to secondary school.

SDV’s hearing loss was picked up before the age of four years when people would speak to her and she would sometimes respond and at other times not. “Want wat my ma vir my gesê is, ek het partykeer, dit was voor die cochlear implanting, wat ek net partykeer gereageer wanneer 'n mens met my praat en ander keure het ek glad

nie gereageer nie, so of ek kon hoor, of ek kon nie hoor nie.” As a researcher, I could also relate to this experience of sometimes hearing people and reacting, and at other times not. Although she could hear a little, her hearing started deteriorating and after undergoing audiological tests, she was recommended for a cochlear implant. Since she was too young to make a decision, and her parents wanted to give her the opportunity to hear, they decided to let her go for the cochlear implantation. Co-researchers, Wheeler et al. (2007), found in their study that the majority of the children's parents made the decision for them to have a cochlear implant and the children seemed to be grateful for the choice their parents made.

SDV remembers lying in the hospital bed in a lot of pain, and her parents explaining the cochlear implant to her after asking her parents what the headband was for. “Ek het so kop band om my kop gehad, ek het so in die bed gelê en ek het my pa en my ma gevra wat is die ding om my kop.” SDV’s memories of the operation were triggered by photographs that her mother took at the time. They would often go to the doctor, who would check to see if the cochlear implant was fine, until the day arrived for the switch on, when her parents sat on either side of her. As they put the cochlear implant on, it was as if she heard nothing then suddenly heard everything at an incredibly loud volume. She described her reaction of crying and taking the cochlear implant off and putting it on the table. “Ek het gehuil en ek het hom afgehaal en ek het hom daar op die tafel neergesit en dit was vir my soos vir enige ander mense, jy hoor niks en volgende oomblik hoor jy skielik, soos die soort mense, jy kan nie sien nie en dan volgende oomblik dan maak jy die oë oop en dan kan jy alles sien.” Realising the uniqueness of children with cochlear implant(s) experience of sounds, a study by co-researchers, Preisler et al. (2005), found that some children and adolescents want to be surrounded by these sounds for protection or enjoyment of listening to music. Others may experience the noise as disturbing, frightening or irritating and consequently long for the silent world. SDV had to wear the external box device, with a wire attached from the magnet to the ear piece, to a box with an on and off switch kept in pieces of clothing or a rucksack. As she started going to speech therapy, learning to talk and pronounce words properly, she began to wear it more and explained that it changed her life, “Dit het my lewe ongelooflik baie verander.” As a researcher, I remembered also going to speech therapy which

helped me to pronounce words properly, so much so that people often told me that they would never have thought I was deaf because I spoke so clearly.

SDV's father started projects to raise funds to help other deaf children who couldn't afford the cochlear implantation. "In die Kaap motorfiets gery en hy't 'n klomp mense gehad en hy't almal saam gery en na soveel plekke gestop en hulle het geld ingesamel vir mense wat soos kinders wat doof is wat dit net nie kan bekostig nie." The financial costs involved were extensive and if the cochlear implantation was unsuccessful, it was a lot of money to lose. Besides the good intention of the projects, people would 'phone her parents to ask how SDV handled the cochlear implant and wasn't embarrassed about it because girls tend to be sensitive about it. For SDV, new technology had changed her life a lot.

By the time SDV had reached grade 4, the external box device that held all the wires and inner parts for the cochlear implant to work, was now in a little ear piece that could fit behind the ear, where no one could really see it. "Toe kry ek hierdie ding sonder die tou, dis nou net die ding wat oor my ore is; dit was vir my baie lekker gewees om te, van iets ontslae te raak." Although it initially felt as if something was missing, not needing to carry something extra every day, it was also nice to be able to get rid of this box and change to better technology that enabled her to wear clothes she could not wear before. Every three months she would go for mapping to ensure that the sounds she heard were set according her needs. She further explained that she could hear very well what other people said. "Ek is doof, ek kan hoor en ek speel saam met doodgewone kinders."

The ear that had the cochlear implant was completely deaf yet the other ear enabled her to hear very low sounds like the drum or a man's deep voice if she took her hearing aid out. "As 'n man praat; stem baie diep maak, kan ek hulle, ek kan hulle hoor maar ek kan nie uitmaak wat hulle sê nie." As a researcher who wears hearing aids, I could also relate to this experience of hearing low sounds when I take my hearing aids out, yet it's sometimes difficult to make out what people are saying." Although SDV can hear the voice without her hearing aid, she cannot make out what is being said. This interested her as she realized that she was not completely deaf in that ear.

Although she struggled to follow what was being said in a movie, she described a setting on her cochlear implant which enabled her to minimize background noise so she could hear a specific person talking, “Soos daar's nog 'n setting wat die geraas sagter kan maak en dan is dit net toe baie sagter maar die ou se stem is nog steeds dieselfde; so die cochlear implanting help jou nie net om te hoor nie, maar dit help jou op verskillende maniere om, om dit beter te maak vir jou.” Other co-researchers have argued that, although the cochlear implant enables the child to hear better, with the majority feeling safe in everyday situations, he or she may experience problems when noises are at extremes of either too quiet or too loud. When there are background noises, situations involving many people or where people do not understand the needs of the child with a cochlear implant, it makes effective and confident communication difficult (Bat-Chava & Deignan, 2001; Haensel et al., 2005; Sahli & Belgin, 2006; Wheeler et al., 2007). To make it easier for herself, and perhaps reacting like a deaf person, SDV puts the subtitles on so that she can read about what is going on instead of asking the person next to her every five minutes. This same setting on her cochlear implant has also made communication in a restaurant somewhat easier for her and more comfortable.

SDV had been given the choice of a second cochlear implantation for the ear with the hearing aid, but felt that if she got a second cochlear implant, she would have to switch on both and not just one. She also argued that if technology improved to the point of possibly only putting a “thing” in your ear or implanting in the ear, she would be sitting with the second cochlear implant of the older technology. “Ek hoor almal sê ja, dit is, dit help baie en jy kan beter hoor en ek het maar gesê maar ek hoor goed genoeg myself, hoekom wil ek nog een hê, ek meen dis nie of ek niks kan hoor nie.” She also felt she could hear enough with her hearing aids and if she needed another one, she’d get one for herself.

SDV’s experience of the cochlear implant, as an opportunity to hear and be part of the hearing world, meant a lot to her and changed her life. She felt that she would not want to go back to the deaf world, as she would not use her abilities to the best of her potential. “As 'n mens 'n cochlear implanting, dit voel, dit verander jou lewe so omdat jy deel is van 'n horende wereld; ek dink net omdat ek die geleentheid het om te kan hoor, om dit, hoekom wil ek terug gaan na 'n dowe, dowe wereld toe?”

However, the choice to switch off from the hearing world and enjoy the peace and freedom of the deaf world, is available to her. She chooses this option when she goes to sleep at night, swims, doesn't feel like hearing for the day or when her brother irritates her. These are definitely peaceful experiences that I, as a researcher can relate to. This can frustrate other people when they are trying to tell me something and I try to follow the conversation initially only to tell them after a while that I need to put my hearing aids in because I could not hear what they were trying to say. Co-researchers, Wheeler et al. (2007), highlighted that the option of taking the speech processor off is available to those who prefer to relax or watch television or keep the processor off until later in the morning on weekends to enjoy the world of silence.

Although SDV describes herself as deaf, she also says that with the cochlear implant, she can live like a normal person and if she didn't have the cochlear implant, she would not have been the person that she is now. She sees it as a privilege to be able to hear. "Maar eintlik is ek ook doof maar ek het 'n cochlear implanting gehad en nou kan ek soos enige gewone mens lewe, en dit was vir my baie interessant gewees en ek sê ons moet dankbaar wees." Young cochlear implant recipients' experiences of the cochlear implant are unique, as is revealed in the study by co-researchers, Wheeler et al. (2007), where they found that some children with cochlear implant(s) identify themselves as hearing, where others may see themselves as deaf while others see themselves as deaf and hearing.

As a result of her hearing deteriorating at such a young age, SDV became a patient in the medical context. This constructed patient identity unfolded over time from pre-school years through to secondary school years, where it started with her being deaf and going for a cochlear implantation in one ear at the age of four years. As she learned to get used to hearing with the cochlear implant, she was also able to experience various improvements in the technology of the external cochlear implant device which contributed to her participation in the hearing world. She also enjoyed the option of being able to move in and out of the hearing world.

The opportunity to hear with a cochlear implant was considered to be a privilege which SDV felt had made her the person that she is.

BEING A “FRIEND”

Besides constructing an identity as a patient in her narrative, SDV also constructs an identity as a friend. The cochlear implant seemed to have influenced her identity as a friend in such a way that she was treated as a hearing person within the hearing society.

SDV described the people from primary school years through to secondary school years as treating her the same as any other hearing person and not differently because of her cochlear implant, which is what she prefers. She was able to ask people to speak louder because she was deaf in a manner that indicated to people that they should not feel sorry for her. This usually left people feeling comfortable, as they understood that she didn't experience it as a problem.

The mutual understanding between SDV and her friends, that she was not sensitive about her cochlear implant, enabled her to enjoy a type of friendship with her friends where they could enjoy jokes such as her friends shouting at her, or talking softly as they pretended that her batteries were flat. She responded by asking whether her batteries were flat or if they were just not talking. “Dit is 'n rede hoekom mense van my hou, omdat ek dit as 'n joke vat en ek sien dit as 'n geleentheid vir my.” Knowing that SDV could lip read very well, her friends would also tend to ask her to read a particular person's lips from far and tell them what the person was saying. Her friends often forgot that she was deaf, especially when they went swimming and they started talking to her as though she were hearing. “Baie keer as ek swem met my vriende of wat ook al, dan's hulle actually vergeet ek is doof, dan as hulle met my praat, dan is ek soos in van hoor hier, ek kan nie hoor nie.” I, as a researcher also experienced people forgetting that I am hard of hearing, and I would need to remind them sometimes when I hadn't heard what they said. She explained that people liked her for the person that she is, and preferred that people forget that she was deaf, as she didn't want to be remembered as the girl who could not hear.

Although it was not a problem for people to repeat what they said, because she often did not hear them the first time, she and her friends decided to play a game where she had to learn to hear and listen to what was said the first time. “Dan het ek ook

geleer om soos te luister, soos wanneer iemand praat, of nie dat ek nie luister nie maar om te reageer of te fokus as iemand praat, dan hulle nie hoef om twee keer iets te sê nie, maar mens het nie 'n probleem om dinge vir my twee keer te sê nie want dis al 'n gewonte vir hulle.” However, she was very inquisitive, and because she hadn’t heard the first time, she would ask her friends what they said and they would not repeat themselves because of the rule to hear the first time. “Ek is baie nuuskiering, ek is ongelooflik baie nuuskierig; so ek sal, as iemand vir die eerste keer vir my ietsie sê dan sal ek, sê hulle vir my nee ek kan nie dit weer sê nie, dan sal ek aanhou tot die volgende dag tot die ou vir my sê, hoor hier wat het jy gesê.” She insisted on asking until they told her, which they found very funny and they would laugh at her. Although it was a challenge for her, SDV felt that it would be an experience to hear the first time so that people did not have to repeat themselves twice. However, hearing what was said in a movie was difficult for her and she usually asked her friend to tell her what was going on in the movie.

The constructed identity as a friend in her narrative unfolded over time from primary school years through to secondary school years, where people felt comfortable and at ease adapting to certain ways of communicating with her because of her hearing difficulty in certain situations. People liked her for the person that she was, when they could enjoy good clean fun with her, even if it was related to her hearing loss or cochlear implant without her being sensitive about it.

The privilege of being able to hear with a cochlear implant has enabled SDV to be the person she is with her friends.

BEING A “FAMILY MEMBER”

Not only has SDV constructed her identity as a patient and a friend in her narrative, but she has also constructed an identity as a family member. It encompasses her parents and her biological brother. SDV’s hearing loss and cochlear implant does not seem to have influenced her family in treating her any differently from a hearing family member.

SDV did not feel for a moment that she was deaf. “Nee, ek het nie gevoel vir een oomblik ek is doof nie,” as she could hear, talk, sing and do anything. Her parents treated her like a hearing child and brought her up “normally”, not fussing over her hearing loss. “My ma'le het my nie behandel asof ek doof is nie; my ma het, my pa het my behandel soos 'n gewone kind, hulle het my groot gemaak soos 'n gewone kind.” As a researcher, who wore hearing aids since the age of five years, I too experienced being raised as a “normal” hearing child by my parents, and consequently did not feel different from my hearing family. SDV expressed that if they had treated her differently she would have become sensitive about her hearing loss and cochlear implant and would have found it a problem.

SDV felt that her parents played an important role in her life. As her parents brought her up and treated her “normally”, this enabled her to be the person she is, who is able to stand her ground and not be sensitive about the cochlear implant. SDV described her relationship with her brother, “Hy sal my, baie keer sal, hy sal my uit help, as ek nie kan hoor nie sal hy so sê SDV, het jy gehoor; en dan is ek so ja ek het gehoor dankie, ja so hy gee om vir my, hy hanteer my ook as 'n gewone sussie, ja want almal hanteer my as gewone mens.” She and her brother are just like any other brother and sister who fight, love and care for each other, and he often helped her if she couldn't hear but treated her like a “normal” sister.

Choosing not to treat her any differently, the constructed identity of a family member unfolded over time from pre-school years through to secondary school years, as she was brought up like a hearing child who got “hidings” to treating her as a hearing family member who was capable of standing her ground and not being sensitive about the cochlear implant.

SDV considered the opportunity to hear with a cochlear implant as a privilege that enabled her to be the hearing family member that she is.

BEING A “SCHOLAR”

Not only does SDV construct her identity as a patient, friend and family member in her narrative, but she also constructs her identity as a scholar. Although the children did not really focus too much attention on her cochlear implant, SDV seemed to experience a significant change as a scholar as the cochlear implant technology improved.

From pre-school years through to secondary school years the children in her classroom didn't really pick up on her cochlear implant and hearing loss, as she would not always react as if she were deaf. “Hulle het nie eintlik agtergekom ek is doof nie en ek sal nie altyd reageer om te maak of ek doof is nie.” As a researcher I could relate to this experience as a hearing aid user who seemed to fit in at a hearing school in the hearing classroom, where children saw me and treated me as a hearing peer. Similarly, academic co-researchers argue that since the cochlear implant provides the potential to develop good speech and languages skills, some children with good spoken language skills have been perceived by strangers as hearing (Schorr, 2006; Wheeler et al., 2007). However, wearing the box device, with additional clothes to support the carrying of the device on her body, made her feel uncomfortable. She shared an experience of doing a show where they dressed up in mermaid dresses, where she had to wear an extra piece of clothing to carry her box device. Feeling uncomfortable she realized that she also wanted to be like the other children and look nice without the device. “Ons het mermaid so sulke mooi rokkie aangehad; ek moes 'n sportbra nogsteeds daarby aangetrek het; en dit maak eintlik my, die look van die dresses nie leliker nie maar net, dit was net vir my bietjie ongemaklik gewees want ek wil ook soos enige ander mens nie dit gedra het en mooi gelyk het sonder dit.” Her parents spoke to her and explained that she could hear and did not need to be embarrassed about it. She then decided that it didn't matter what other people said to her. As technology improved, and she began to wear the behind the ear device, her parents asked her if she would like to cut her hair in a style that would hide her device. She responded with a question asking why she would want to do that. SDV preferred to tie her long hair into a side pony on the opposite side of her cochlear implant, which although it was visible to others, was not a problem for her.

SDV's parents would inform the teachers and the head of the school about her deafness and cochlear implant, and the teachers would inform the children. Sitting in front of the class so she could hear, sometimes a teacher would stand at her table to ensure that she heard. At other times she had a bit of fun with her cochlear implant, using it as an excuse if she hadn't done her homework. "Ek hoor, maar eintlik hoor ek ook nie, eintlik nie want ek wil verskoning of wat ook al; en dan kom ek in die klas volgende dag, sorry juffrou ek het nie geweet dit was huiswerk nie." If the batteries went flat, she informed the children that she was deaf and they would pretend she was physically disabled and would take her to the teacher to inform the teacher.

The choice to switch off from the hearing world was available to her as she took them off if she wanted to learn, with nothing bothering her. "As ek leer en goed dan haal ek hom af en dan is dit nou soos ek leer, maar seker want niks kan my pla om my nie." SDV felt she did well at school because she had not made the cochlear implant a problem for herself. As a researcher, I could relate to this experience in that the hearing aids did not stop me from achieving academically, participating in school activities and making friends. As a prefect she introduced herself to the students alerting them to the fact that if they thought she was ignoring them, she was actually not. It's just that she was deaf. She explained this in a manner that elicited laughter from the other children without making a joke of her hearing aid or cochlear implant.

SDV expressed that she didn't really want to leave high school as she really enjoyed being with good friends. "Ek wil nie eintlik hoerskool verlaat nie want dit is vir my baie baie lekker maar ek dink dis vir 'n mens lekker, 'n groot stap wat voor jou le; en ja, ek is baie, ek is baie opgewonde." She did however look forward to a future outside school where she would like to study at university. Although she was not sure what to study, she had mentioned that she thought she would like to study BCom Accounting. She mentioned that it would be fun to study with her father, who said he would study an MBA degree with her after her fourth year. She pointed out that it would be a challenge for her, but also realized, upon reading about a deaf girl who was busy with her Masters, that doors would open and other people could also look at her and see her as having achieved something despite her circumstances. The challenge may be good as it could help her to become a stronger person. "Ek dink dit

sal 'n uitdaging vir my wees vir wat ek wil doen of, of as ek deel van 'n maatskappy wil word of wat ook al want dit is nou soos vir my mense sal soos in kyk, daai meisie het gehoorstuk, sy is ,sy het 'n cochlear implanting, of kyk wat kan sy bereik deur middel van haar omstandighede; so dit is nogal vir my ek dink sal 'n uitdaging vir my sal wees vir my en ander mense en ek dink dit sal, ek dink dit sal baie goed wees vir my, dit sal my half sterk maak as 'n mens vorentoe.”

The impact of the cochlear implant on her constructed identity as a scholar unfolded over time from pre-school years through to secondary school years. It began with experiencing the changes in her life with improvement in technology, from a box device to a behind the ear device. This impacted on her feelings about her physical appearance such that she did not concern herself about what other people thought of her cochlear implant or hearing loss. She began to enjoy her life with the cochlear implant, as she would use hearing loss as an excuse to get out of trouble, or choose to switch off from the hearing world to enjoy the quiet to study. Despite her awareness of various challenges with her hearing loss, her successes have created the hope that she can go to university to study further.

Hearing with a cochlear implant was a privilege that enabled her to experience success within a school environment as a scholar.

BEING AN “ATHLETE”

Besides constructing an identity as a patient, friend, family member and scholar in her narrative, SDV also constructed an identity as an athlete. The cochlear implant has enabled SDV to participate and enjoy the world of sports in the hearing society.

SDV did athletics and played netball and softball in Primary school, achieving Gauteng colours for softball. “Toe ek in die laerskool was het ek netbal gespeel, ek het sagtebal gespeel, ek het atletiek gedoen.” She continued in these sports as she moved into secondary school, excelling in netball, where she played centre for the first team. She argued that if she were in a deaf school, she would’ve been treated differently and been in a team with deaf girls. She had watched a team of deaf girls play netball, and how the coach would get their attention to point out what they did

wrong. She noted that this was so different from the way she played netball with the hearing girls.

SDV also spoke of how some deaf children didn't play sports because of fear of their hearing devices possibly falling off. She opposed this perception by saying that the cochlear implant was not a problem for her, and she would try to solve the problem in order to make it work for her. "Ek sal enige iets probeer doen vir my sport en goedes, ek sal ek, soos 'n wat eintlik vir die babies bedoel is sulke baby clip ding; sit ek hom agter in my pony vas; dit was nooit vir my 'n probleem gewees nie, so ek sal die probleem oplos en ek wil dit doen." She gave an example as she explained that she used a clip that was meant for babies to fasten her cochlear implant to her pony to keep the cochlear implant from falling. Although she preferred to be in the business world in the future, she felt that she would still do her sports. With her parents talented in sports and sports being in the genes in the family, she would like to make use of sport in the future.

SDV's constructed athletic identity in her narrative unfolded over time from primary school years through to secondary school years. With the use of her cochlear implant, she began with various sports, excelling in one during her primary school years to excelling in another sport in her secondary school years. She would like to continue after her matric year.

The opportunity to hear with a cochlear implant was a privilege that has enabled SDV to participate and excel in sports with hearing children.

Conclusion

A follow-up feedback was arranged with SDV to discuss the research findings of my interview with her. She was provided with a copy of this chapter which she read and we then had a discussion pertaining to her experience of reading the chapter. If there were any changes to any parts of the chapter, that she would have liked to have made, she was welcome to do so. We also had a discussion pertaining to her experience of the research interview.

SDV was very happy with the research findings pertaining specifically to my interview with her, and felt it was very good, as it described her. Although SDV was very happy with the title, she asked to change her fiction name from SD to her real name. However after a discussion around maintaining confidentiality as to her true identity, she agreed and asked to change her fiction name from SD to SDV. She noted that as she read the chapter, there had been a change, which was possible since a narrative has a past, present and potential future. It is this potential future that SDV explained that she had done a career guidance assessment after the interview process, and was recommended to do Educational Psychology. Consequently she will not be doing BCom Accounting. She explained that when she thought about it, she realized that, because she loves to help older children and young adolescents, she decided to study education or teaching and then specialize in Educational Psychology.

SDV described her experience of the research interview as very good, as the questions I asked made her think about the things that she did and how people responded to her. Normally she would not have thought about her actions and behaviour. She further commented that it would be interesting to know what her parents, friends, and other significant people in her life thought about her. This is perhaps an area for further research from a narrative approach, which was discussed in detail in chapter 11.

My approach to go back to the research participant for her input in terms of the findings of the results remains true to my position from a narrative approach. Here the participant remains an active contributor and creator of her own narrative.

CHAPTER 10

CONCLUSION

Introduction

This chapter is the concluding chapter that provides a summary of the research findings, followed by an outline of the shortcomings and recommendations.

10.1 SUMMARY OF RESEARCH FINDINGS

Five adolescents agreed to participate in this research study about their experiences of the cochlear implantation. The adolescents constructed multiple identities in their narratives which had unfolded over time from pre-school years through to the time and space telling of their narrative during the interview. These adolescents are FF, AA, BC, SDV and MM.

10.1.1 The Narrative Findings of FF

Firstly, FF was a male adolescent cochlear implant recipient who constructed multiple identities, such as the patient, scholar, friend, brother, son and athlete identities in his narrative. These constructed identities were in constant interplay with one another with the purpose of living his life with a cochlear implant in a hearing society despite his mother's concern.

As a patient, FF went deaf as a baby and had used hearing aids as well as an FM system to assist him in hearing. However, further deterioration in his hearing resulted in his first cochlear implantation in grade four. The cochlear implant enabled him to hear clearer, yet with the upgrade of his cochlear implant external device, he was able to hear sound more clearly with more advanced technology. His scholar identity revealed a positive experience with the teachers and children, except for one teacher who made hearing difficult for him because she spoke so softly. Leigh et al. (2009); Preisler et al. (2005), as well as Schorr (2006) found that children with cochlear implants who attended mainstream schools may experience difficulty understanding

the teacher and children, and may experience difficulty communicating with hearing peers during break times where there was a lot of noise. FF's constructed identity as a friend portrayed friendships that entailed helping one another and also enjoying various activities together. They took into consideration what FF could and couldn't do with his cochlear implant. As a brother, hearing his siblings more clearly, enabled FF to feel better, despite his reliance on them to repeat what someone else had said that he might not have heard. Consequently, after repeating themselves repeatedly, he experienced their impatience, which is something, I as a researcher can relate to with my own experience of hearing loss in both ears. The cochlear implant also enabled FF to feel better as a son who could hear better and more clearly. He shared his experience of hearing different sounds with his parents and even went hunting with his father. Although FF had to give up rugby because of the cochlear implant, he rechannelled his sporting interest to gymnastics and cricket. More specifically, his strength in cricket lay in his ability to be a very good bowler in their A team.

In answering the research question from the narrative of FF, it would seem that the cochlear implantation enabled FF to live his life with a cochlear implant in a hearing society, despite his mother's concern.

10.1.2 The Narrative Findings of AA

The second participant, AA, was a male adolescent cochlear implant recipient, aged 15, who also constructed multiple identities, such as the patient, scholar, son, brother, friend and athlete identities in his narrative. These constructed identities influenced one another as he adapted to a hearing society, thus creating hope for the future.

AA went deaf as a baby and adapted, with hearing aids in both ears, from the age of three months. His difficulty with speech and lip-reading, followed by an experience of hearing almost nothing by the age of ten, the cochlear implantation became an option and reality. AA's nervousness and experience of an operation as the worst thing for him correlated with a finding by Wheeler et al. (2007) who argued that the operation could be experienced as a disadvantage. Nonetheless, after the switch on

and much practice in identifying sounds with the cochlear implant, he experienced the cochlear implant as great. AA's constructed identity as a scholar revealed that as a hearing aid user, he struggled with speech and the English language. However, with help, he was able to improve on his English language skills. Deterioration in his hearing resulted in his school marks dropping, which only improved again after his cochlear implantation. AA's parents supported and guided him from the time of his difficulty in hearing as a hearing aid user through the decision process, operation and rehabilitation process of the cochlear implant. His sister also seemed to play a role in his adaptation to the hearing environment with the cochlear implant. Firstly, his ability to identify where the sounds came from enabled him to locate his sister more easily. Yet, where his sister may have heard irritating noises, he had the opportunity of enjoying peace and quiet after switching off his cochlear implant. This is an experience that I, as a researcher, could relate to, enjoying the peace and quiet when I switched to "silent mode" by taking my hearing aids out. Regardless of whether AA could hear or not, he was able to make friends who taught him how to speak English and were there to share his experience of hearing. Despite not being able to play contact sport with the cochlear implant, AA continued to play other sports, which enabled him to be a part of the team.

In answering the research question from the narrative of AA, it would seem that the cochlear implantation enabled AA to adapt to a hearing society which created hope for the future.

10.1.3 The Narrative Findings of BC

The third participant, BC, was a male adolescent cochlear implant recipient, aged 20. His narrative included three constructed identities, namely his patient identity, friend identity and scholar identity. These identities seemed to be in interplay with one another as they enabled him to participate in a hearing society with hearing people.

BC went deaf at the age of five years and received hearing aids in both ears. I, as a researcher, could relate to his experience of going deaf at five years of age and receiving hearing aids in both ears. One of my own struggles was trying to hear people in conversation when there was background noise. However, for BC, a virus

continued to affect him at the age of 11 years when he experienced further hearing deterioration in his right ear which consequently resulted in him undergoing a cochlear implantation. The cochlear implant enabled better participation in the hearing society which motivated him to go for a second cochlear implantation. This resulted in better hearing and participation in the hearing society, and BC continued his enjoyment of music. BC shared his experience of his brother as his friend during his pre-school years, who saw him as BC, his brother, and not as someone with a hearing loss. His constructed identity as a friend also told of how he had friends and became popular, yet also experienced jealousy, prejudice and rejection by others. Schorr (2006) and Marlie (2003) found that children who had the cochlear implantation done at an older age took longer to attain a feeling of belonging in comparison to children who received the cochlear implantation at a younger age who may have experienced more positive psychosocial outcomes in adolescence. For BC, having friends was important to him. Furthermore, he placed importance on developing friendships with people who did not have cochlear implants. Academically, BC seemed to cope and despite being kept back one year at the end of his first grade, and experiencing secondary school as hectic with the cochlear implant, he was able to reveal some of his areas of strength. At the time of the interview, he was at a stop point, considering possible options for his future career. Helping other potential recipients of the cochlear implant was also mentioned.

In answering the research question from the narrative of BC, it would seem that the cochlear implantation enabled BC to participate in the hearing society with hearing people.

10.1.4 The Narrative Findings of SDV

The fourth participant, SDV, a female adolescent cochlear implant recipient, aged 18 years constructed identities such as the patient, friend, family member, scholar and athlete identities in her narrative. These constructed identities influenced one another with the purpose of using the privileged opportunity to hear with her cochlear implant to enable her to participate in a hearing society.

SDV had been deaf since a very young age and received her cochlear implant at the age of four. She experienced improvement in the technology of the external cochlear implant device, such that she moved from carrying a box device to wearing a device behind the ear. The option to switch her cochlear implant off enabled her to enjoy moving in and out of the hearing world. SDV preferred not to be sensitive about her cochlear implant, and consequently people liked her for who she was, as they felt comfortable in adapting their way of communicating with her to make hearing them easier for her. They also felt that they were able to have fun with her. Wheeler et al. (2007), as well as Schorr (2006), found that since the cochlear implant provided the potential to develop good speech and language skills, some children with fluent spoken language skills had been perceived by strangers as hearing. As a hearing aid user, I could relate my experience of being perceived by other children in my school years as a hearing peer. SDV's parents and brother did not treat her differently because of her cochlear implant, and consequently she grew up as a hearing family member who was capable of standing her ground and not being sensitive about her cochlear implant. The improvement in the technology of the cochlear implant device, as she moved from the box device to the behind the ear device, impacted on her feelings about her physical appearance. She decided not to concern herself with what other people thought of her cochlear implant or hearing loss, and began to enjoy her scholar identity as an adolescent with a cochlear implant. This created hope as she noted that she would like to study further at university after her matric year. SDV excelled in her sports from primary school through to secondary school. More specifically, SDV achieved Gauteng colours for softball in primary school and excelled at netball in her secondary school where she played centre for the first team. SDV noted that she would like to continue with her sport after her matric year.

In answering the research question from the narrative of SDV, it would seem that the cochlear implantation provided SDV the privilege of an opportunity to hear with a cochlear implant.

10.1.5 The Narrative Findings of MM

Finally, MM was a male adolescent cochlear implant recipient, aged 17 years who constructed multiple identities of being a patient, a family member, scholar, athlete and friend in his narrative. These constructed identities constantly influenced one another with the purpose of participating in a hearing society where he could hear colours with his cochlear implant.

Deaf in both ears at the age of 18 months, MM received hearing aids which enabled him to hear some sounds to enable communication and conversation. Yet there were other sounds that he could not hear. As a researcher who wears hearing aids, I can relate to hearing some sounds and yet not hearing other sounds with my hearing aids. However, his hearing deteriorated further in the beginning of his primary school years, which prompted the option of a cochlear implant in his left ear, and later his second cochlear implant in the right ear. Consequently he experienced hearing with both cochlear implants as much better and clearer. Although he could hear better with his first cochlear implant, after receiving the second cochlear implant, he was able to have a proper conversation with his family, who provided support and care, and were willing to help him. His scholar identity revealed that he coped and was able to make friends, despite various responses from the children about his hearing loss. However, after he received the cochlear implant, his hearing improved so that it was better and clearer, consequently resulting in academic improvement and the ability to interact with people. Studies done by co-researchers, Schorr (2006); Schorr et al. (2009), as well as Wheeler et al. (2007) revealed that the cochlear implant benefits in terms of academic performance and in helping to understand lessons, despite a need for additional reliance on support for understanding. This created hope for wanting to study further at university when he completes his matric year. As an athlete, MM was a successful deaf swimmer during his primary school years and experienced the opportunity to participate as a team manager and to score rugby and cricket games during his secondary school years. However, he mentioned wanting to start swimming again. MM moved from being a hearing aid user, who engaged in conversations with his friends on a lower level, to being a cochlear implant recipient whose friends spoke to him as they would to a hearing person. He

highlighted that his friends were good friends, who knew he had difficulty hearing and who worked with him.

In answering the research question from the narrative of MM, it would seem that the cochlear implantation allowed MM to hear colours with his cochlear implants which enabled him to participate in the hearing society.

10.2 SHORTCOMINGS AND RECOMMENDATIONS

10.2.1 Sessions

The participants in this particular research study, as co-participants and researchers, were only able to construct knowledge from reconstruction of their experiences (Lindsay, 2006) to a limited degree because of time constraints. Ideally, the co-participants should have had more interactive involvement in the writing of their own narrative from the interview with me as a researcher. Although a follow-up feedback meeting was arranged, after I had written their research finding chapters, more scheduled sessions could possibly have provided the potential for valuable changes and insight from the co-participants' side. Future research may consider expanding this research by engaging the co-participants on a long term basis by keeping the co-participants involved in the writing of their narratives over a continuous, period of time (Rossouw, 2003). This is likely to reflect more clearly the person's reconstruction of knowledge from his or her reconstruction of experiences, with continuity in the discovery process (Lindsay, 2006).

10.2.2 Participants

It would be interesting to explore deaf people's experiences of hearing loss, by focusing on specific age groups such as young children, adolescents and adults, as separate studies. The findings of these researches may be interesting from the perspective that people experience hearing loss at different stages of their lives, and to explore their experience in terms of when they lost their hearing. This may provide interesting narratives in terms of how they make sense of their experience of hearing loss at the time of the hearing loss and where they may be at that point and time of

the interview session with the researcher. It would be interesting to explore what these narratives tell us about the person sharing his or her narrative through exploring his or her identities.

10.2.3 Family as Participant

Further research may also explore, from a constructionist narrative approach, the experiences of significant other people in the adolescent cochlear implant recipient's life narrative. More specifically, one could explore these significant others' experiences of the adolescent's cochlear implant. This research may also need to be conducted over a longer period of time to keep the participants involved in the research process, by having continuous meetings with the participants as they continue to reflect on, and re-write, their narratives (Rossouw, 2003).

Conclusion

In Chapter 4, I portrayed a summary of each participant's narrative findings followed by a brief discussion of some of the shortcomings and recommendations that emerged in this research. As a researcher, my personal experience of hearing loss has been outlined briefly in chapters 4 and 10. To conclude this chapter 11, I will provide a brief summary of how this research has impacted on my professional role as a practitioner.

CHAPTER 11

POST-REFLECTION

Introduction

A post-reflection on the effect of this particular research on my researcher narrative as well as my personal narrative, is outlined.

11.1 POST-REFLECTION AS RESEARCHER

Adopting specifically a constructionist, narrative research approach in this research study required a shift in my thinking as I had been trained to think predominantly from a positivistic approach and a constructivist approach, with the constructionist approach whispering in the background. However, this research gave me the opportunity to experience doing research from a constructionist approach, to think predominantly from a constructionist approach and consequently made the constructionist approach's voice louder and clearer. As such, I strived to be inquisitive and to stand from a position of "not knowing," which took away a need to be in control. Instead it gave me a sense of reward as the narrative teller became empowered in making his or her voice heard. The constructionist approach also gave me freedom in knowing that it was acceptable if I tended to influence the new narrative being created between myself and the participant, as we could not separate our experiences from the narrative that we created in the process. As I reflected on the narratives created, I was able to see more clearly some of my own experiences and influences in the process.

The narrative teller's voice was the dominant voice to be heard, and as I adopted the inquisitive and "not knowing" approach, the participants shared their narratives in a way that would not have been possible if I had decided to ask specific questions and probe in a specific direction. I must mention that, as a researcher, adopting an inquisitive and "not knowing" approach, was not always an easy task. Many times it was easy to slip into the assumptive way of thinking because I could relate to certain experiences. However, it helped to be consciously aware of my way of thinking, and

to re-channel that thinking that different people have different experiences of similar incidents, and consequently create unique narratives to make sense of their experiences. Consequently, adopting an inquisitive and “not knowing” approach is a habit to be practiced daily.

The unstructured interview with one open ended question enabled the participants to share their narrative, which told me a lot about who they were as people. This became so much more valuable as we began to see how, over time, they adapted as people with identities in a hearing society. As a researcher, I had the privilege of hearing so much more and consequently received so much more information that I would not have known about otherwise. Not only was their narrative valuable for me as a researcher, but upon publication, could be valuable for other cochlear implant users, people with hearing loss, and professionals who work with people with hearing loss.

The opportunity to meet the parents of these adolescents also made me realise that there are many other narratives to be told about the experience of the adolescent’s cochlear implant. These other voices seemed so eager to make their voices heard too. I realised that by allowing many different voices to be heard, it had the potential to create a narrative that could have tremendous value for other people who experienced hearing loss and/or the cochlear implantation, important people in the lives of people with hearing loss and/or cochlear implant(s), as well as professionals working with people with hearing loss or cochlear implant(s).

This is only the beginning of many more research areas of focus, as I realise that not only can research focus on the voice of those people who have experienced the cochlear implant, but research can also focus on making the voices heard of deaf people with varying degrees of hearing loss, who may have varying assistive technological devices.

Not only did this research study influence me as a researcher, but it also influenced me personally.

11.2 POST-REFLECTION AS PERSON

This particular research study influenced me personally, such that as an adult who has hearing loss in both ears, and has worn hearing aids since the age of five years, I had many personal experiences that enabled me to relate to the research participants of this particular research. Since a glimpse of my personal experiences are outlined in chapter 4, I will not elaborate on these experiences in this chapter, but rather I will focus on how this particular research influenced me personally after the research process.

As I reflected on the participants' narratives, I came to realise that each narrative had an influence on me in some way. Being able to hear with hearing aids is also a privilege, as it provides hope in many areas of my life. This hope has enabled me to persevere in all that I do, and to see life as a journey. It also enabled me to experience challenges as tests of my faith and opportunities for growth. Although my own mother showed a lot of concern, which is a natural concern to have the best for your child, I became aware of her tendency to become protective. Yet I coped as I adapted in the hearing society, not letting go of the support of my parents, yet persevering to be able to be independent and self-sufficient. At some stage in my life I wondered what it was like to have "normal" hearing, and this whispered voice became louder again as I reflected on the metaphor of hearing black and white versus hearing colours. I then wondered how different it was to hear with a cochlear implant versus hearing with hearing aids. Yet again, there are people who do not hear with any assistive devices. I only know what I can hear, and consequently feel that despite various challenges, the hearing that I do have has enabled me to adapt well in the hearing society. This is a privilege and a blessing. Consequently, each person makes sense of his or her experience differently in terms of adapting in a hearing society with their assistive hearing devices, where some may value certain ways of adapting yet others may prefer it to be different.

Through this experience of the research, I have come to realise that perhaps we all would like to have our voices heard by someone who is willing to listen. I didn't quite realise the impact that being a willing listener could have on someone who would like to share his or her narrative with me, until I asked them about their experience of the

research interview and of reading their chapter findings. Furthermore, based on my own experience of wanting someone to willingly listen to my narrative and voice, without judgement or interruption, I could empathise with these participants as I realised that I could be that willing listener to other people, so that they could experience the empowerment of having their voices heard. If I continue to live this on a personal level, it is bound to play out in my professional role, as I strive to be a non-judgemental listener with the purpose of empowering soft voices to be heard.

Conclusion

Post-reflection of the impact of this research on my researcher narrative and personal narrative was outlined. Although it influenced both my narratives, these two narratives also influence each other in a hopeful future as a psychologist.

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APPENDIX A

TYPES OF HEARING AIDS

Appendix A

Types of Hearing Aids



Obtained from

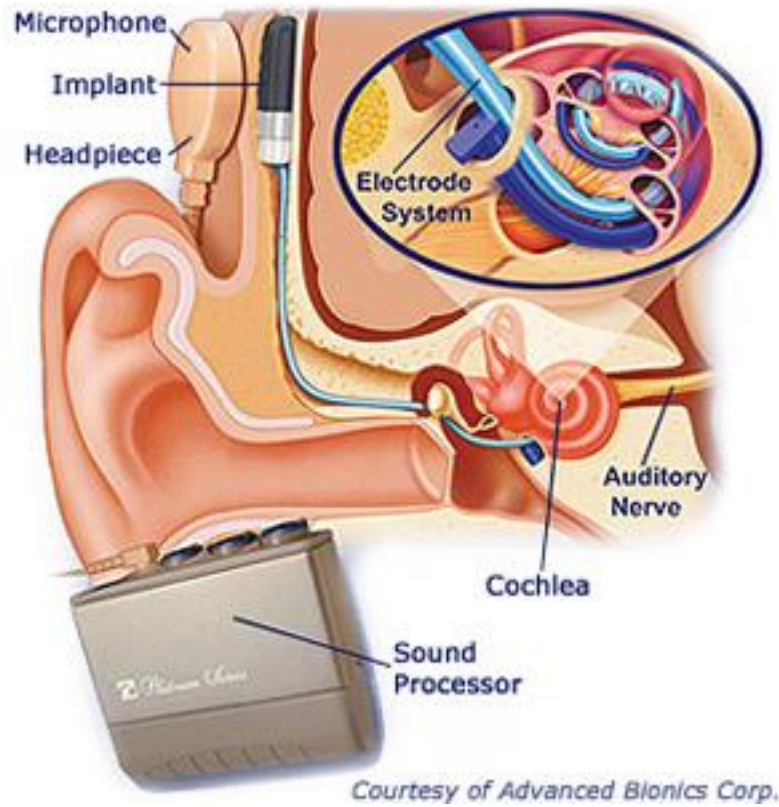
The Society of Hearing Aid Acousticians of South Africa (SHAA), 2009.

APPENDIX B

FUNCTIONING OF THE COCHLEAR IMPLANT

Appendix B

Functioning of the cochlear implant



Obtained from Central Speech and Hearing Clinic inc. (2010),
an affiliate of Victoria General Hospital.

APPENDIX C

INSTITUTIONAL PERMISSION LETTER



14 September 2009

Dear Dr Human

Project: Adolescents' experiences of cochlear implantation
Researcher: R Fick
Supervisor: Dr L Human
Department: Psychology
Reference Number: 28030860

Thank you for the application you submitted to the Postgraduate Committee of the Faculty of Humanities.

I have pleasure in informing you that the Postgraduate Committee formally **approved** the above study on 7 September 2009. The approval is subject to the candidate abiding by the principles and parameters set out in her research proposal in the actual execution of the research.

The Committee requests that you convey this approval to Ms Fick.

We wish you success with the project.

Sincerely

Prof. David Medalie
Acting Chair: Postgraduate Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: david.medalie@up.ac.za

Postgraduate Committee Members: Prof S Africa; Prof PJ Botha; Dr C Carbonatto; Prof E Dreyer; Dr A Gildenhuis; Prof AE Goslin; Ms H Kirstein; Prof L Kriel; Prof D Medalie (Acting Chair); Dr S Ouzman; Prof I Pikirayi; Prof MMME Schoeman; Prof JS Sharp (Chair); Prof GJ Swart; Prof R Vally; Prof H van der Mescht; Prof A Wessels, Ms P Woest

APPENDIX D

PERMISSION LETTER FROM THE PRETORIA COCHLEAR IMPLANT CENTRE



30/07/2009

Section A
Research Information

Dear Prof. B. Louw,

I have a particular interest in the adolescent cochlear implant patients' experiences of cochlear implantation that stems from a personal experience and interest in how deaf adolescents make sense of their world and create meaning for themselves within a South African context. I would like to request your permission to ask some of your selected adolescent cochlear implant patients to participate in the research. I would prefer that the adolescent participants be between the ages of 14 to 18 years of age, who can speak and have had the cochlear implant for at least three to six months. Furthermore, it would be preferable to interview the participants of different genders, hence at least two males and two females, and each of a different race, so that it creates opportunities for different voices to be heard. I would also like to request that the research process in terms of the interview be conducted at your venue.

The following information is important regarding the research project "Adolescents' experiences of cochlear implantation". Please read through the information.

Information: I, Roxanne Fick, am currently registered for my Masters degree in Counselling Psychology at the University of Pretoria (UP), where I am required to do a dissertation. I am interested in understanding adolescents' experiences of cochlear implantation. This is the topic of my dissertation. Dr. Lourens Human from the Department of Psychology at UP is the study leader of my research.

The study is qualitative in nature, and entails an interview with the adolescent participant, who will be the storyteller about his or her own experiences with regards to cochlear implantation.

Title: Adolescents' experiences of cochlear implantation.

Purpose: This interview is conducted for research purposes, and to understand and describe the adolescents' experience of the cochlear implantation.



- Procedures:** The adolescent will be required to play the role of a storyteller about his or her own life. Specifically, I will begin by asking him or her to tell me about his or her experience of the cochlear implantation. The content of the story can be selective, therefore there is no need for him or her to tell me everything but rather to concentrate on information about him- or herself and his or her life which says something significant about him or her and how he or she has come to be who he or she is. I would like to voice-record the interview process for the purpose of transcribing the interview accurately for the process of analysing it. After the interview, I will transcribe the story told and will contact the adolescent again to make an arrangement to meet with him or her to engage in a feedback conversation as to whether he or she agrees with the transcription. If any relevant changes are to be made, it will be done and he or she will be notified of the changes. At the end of the research process, I will also provide feedback about the outcome of the research to him or her.
- Risks:** There are no perceived physical risks for the participant while participating. However, should the participant feel overwhelmed by sharing his or her experiences, appropriate professional concern will be provided.
- Benefits:** There are no financial gains for participating in the research, but the participant may benefit personally in terms of sharing his or her experiences.
- Rights:** Participation is voluntary. The participant may withdraw from participating at any time and without negative consequences for doing so.
- Confidentiality:** All information will be treated as confidential. Anonymity will be assured and the data will be destroyed if the participant wishes to withdraw his or her participation.
- Material:** After completion of the research, the material will be stored in the Department of Psychology at UP. The participant will need to grant permission to do so, subject to the same conditions as the above.
- Researcher:** If any clarity or more detailed information is needed, my contact details are as follows:
- Name: Roxanne Fick
Cell no.: 079 696 2629
E-mail: mrsroxannefick@gmail.com



If you agree to allow me to use your cochlear implant patients as participants as well as to use your venue for the interview process, please could you state the permission in writing and sign it on your standard letterhead. This is a requirement that needs to be attached to my research proposal for approval.

Once my research proposal has been approved by the Ethics Committee of the Faculty of Humanities at the University of Pretoria, I will provide you with a copy of the letter of approval that I may proceed with the research study.

Researcher: *R. Fick* (Mrs. R. Fick)

Head of the Department: *M. Marchetti-Mercer* (Prof. M. Marchetti-Mercer)

Study leader: *L. Human* (Dr. L. Human)

Approved

Please let the Pretoria Cochlear Implant Program know what your ultimate findings are. I wish you well.

Prof J.G. SWART

11/8/2009

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APPENDIX E

PERMISSION LETTER FROM THE JOHANNESBURG COCHLEAR IMPLANT CENTRE

Wendy Deverson
B.A. (Speech and Hearing Therapy) Wits.

PR. NO.8207496
STA 0007021

P.O. BOX 871
Honeydew 2040

Tel: 484-3408 / 782-6407
Cell: 082 482 0855

3 August 2009

Mrs Roxanne Fick
mrsroxannefick@gmail.com

Dear Roxanne

Further to our e-mail correspondence and discussions I would like to confirm that you may interview some of my adolescent cochlear implant recipients, subject to their agreeing to participate in the study. These interviews may be conducted at my premises – the exact venue will have to be confirmed closer to the time of the interviews. Please remember that some of the participants may be writing their Grade 12 exams and take this into consideration when planning your interview schedule.

I would like to take this opportunity to wish you success with this interesting study and look forward to feedback on your findings.

Yours sincerely



Wendy Deverson

APPENDIX F

CONSENT LETTER AND FORM



Human Science Building 11-32
Department of Psychology
Faculty of Humanities
(012) 420-3685

30/01/2010

SECTION A RESEARCH INFORMATION

Dear Parents/Guardians,

The following information is important regarding the research project "Adolescents' experiences of cochlear implantation". Once you have read through the information and are willing to allow your adolescent to participate in the research project, please complete Section B.

Information: I, Roxanne Fick, am currently registered for my MA (Counselling Psychology) degree at the University of Pretoria (UP), where I am required to do a dissertation. I am interested in adolescents' experiences of cochlear implantation. This is the topic of my dissertation. Prof. Lourens Human from the Department of Psychology at UP is the study leader of my research.

The study is qualitative in nature, and entails interviews with your adolescent, in which he/ she will be the storyteller about his/her own experiences with regards to cochlear implantation.

Every attempt will be made to provide an accurate reflection of your adolescent's story, and this will be verified with him/her through feedback sessions at different stages of the analysis of his/her story.



Title: The title of the study is: “Adolescents’ experiences of cochlear implantation”.

Purpose: The purpose of the research is to understand adolescents’ experiences of the cochlear implantation.

Procedures: Your adolescent will be required to play the role of a storyteller about his/her cochlear implantation. The total time duration in terms of interviews is not specified so as to allow your adolescent the time he/she needs to tell his/her story.

The interviewing process will be video-recorded for the purpose of transcribing the interview accurately for the purpose of analysis. After the interviews, I will transcribe the story told and will meet with your adolescent again to engage in a feedback conversation as to whether he/she agrees with the transcription. At the end of the research process, I will also provide feedback about the outcome of the research to him/her. The video data will be destroyed by deleting the video recording after the research process.

Should your adolescent prefer not to be video-recorded, an audio-recording can be made of the interviewing process for the purpose of transcribing the interview accurately for the purpose of analysis. The audio data will be destroyed by deleting the audio recording after the research process.

Risks: There are no perceived physical risks for your adolescent while participating. However, should he/she feel overwhelmed by sharing his/her experiences, he/she may feel free to speak to Prof. Lourens Human, a professional psychologist, at (012) 420-3685.



Benefits: There are no financial gains for participating in the research, but your adolescent may benefit personally in terms of sharing his/her experiences. The story told by your adolescent can also benefit other people who receive cochlear implantations, as well as assist professionals in understanding people's experiences of cochlear implantations.


Rights: Participation is voluntary. Your adolescent may withdraw from participating at any time and without negative consequences for doing so.


Confidentiality: All information will be treated as confidential. Anonymity will be assured and the data will be destroyed if your adolescent wishes to withdraw his/her participation.

Material: After completion of the research, the transcribed material will be stored in the Department of Psychology at UP for a period of 15 years.

Researcher: If any clarity or more detailed information is needed, my contact details are as follows:

Name: Roxanne Fick
Cell no.: 079 696 2629
E-mail: roxannefick@gmail.com

Researcher:  (Mrs R. Fick)

Study Leader:  (Prof. L. Human)

Head of the Department:  (Prof. M. Marchetti-Mercer)



Research Consent

We, (Full name and surname of mother/guardian) and (Full name and surname of father/guardian) hereby acknowledge that we have read and understand the above-mentioned research information. We hereby agree to allow our adolescent to participate in the above-mentioned research project. We accept and agree with the conditions as stated above.

Mother/Guardian:

Date:

Father/Guardian:

Date:

APPENDIX G

ASSENT LETTER AND FORM



SECTION A RESEARCH INFORMATION

Dear Participant,

The following information is important regarding the research project "Adolescents' experiences of cochlear implantation". Once you have read through the information and willing to participate in the research project, please complete Section B.

Information: I, Roxanne Fick, am currently registered for my MA (Counselling Psychology) degree at the University of Pretoria (UP), where I am required to do a dissertation. I am interested in adolescents' experiences of cochlear implantation. This is the topic of my dissertation. Prof. Lourens Human from the Department of Psychology at UP is the study leader of my research.

The study is qualitative in nature and entails interviews with you, in which you will be the storyteller about your experiences regarding cochlear implantation.

Every attempt will be made to provide an accurate reflection of your story, and this will be verified with you through feedback sessions at different stages of the analysis of your story.

Title: The title of the study is: "Adolescents' experiences of cochlear implantation".

Purpose: The purpose of the research is to understand adolescents' experiences of the cochlear implantation.



Procedures: You will be required to play the role of a storyteller about your cochlear implantation. The total time duration in terms of interviews is not specified so as to allow you the time you need to tell your story.

The interviewing process will be video-recorded for the purpose of transcribing the interview accurately for the purpose of analysis. After the interviews, I will transcribe the story told and will meet with you again to engage in a feedback conversation as to whether you agree with the transcription. At the end of the research process, I will also provide feedback about the outcome of the research to you. The video data will be destroyed by deleting the video recording after the research process.

Should you prefer not to be video-recorded, an audio-recording can be made of the interviewing process for the purpose of transcribing the interview accurately for the purpose of analysis. The audio data will be destroyed by deleting the audio recording after the research process.

Risks: There are no perceived physical risks for you while participating. However, should you feel overwhelmed by sharing your experiences, you may feel free to speak to Prof. Lourens Human, a professional psychologist, at (012) 420 3685.

Benefits: There are no financial gains for participating in the research, but you may benefit personally in terms of sharing your experiences on your cochlear implantation. The story told by you can also benefit other people who receive cochlear implantations, as well as assist professionals in understanding people's experiences of cochlear implantations.

Rights: Participation is voluntary. You may withdraw from participating at any time and without negative consequences for doing so.

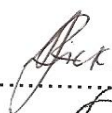
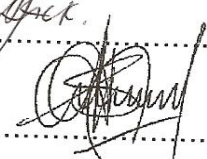
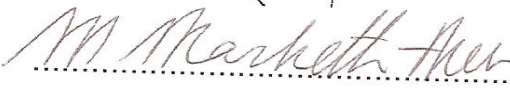
Confidentiality: All information will be treated as confidential. Anonymity will be assured and the data will be destroyed if you wish to withdraw your participation.



Material: After completion of the research, the transcribed material will be stored in the Department of Psychology at UP for a period of 15 years.

Researcher: If any clarity or more detailed information is needed, my contact details are as follows:

Name: Roxanne Fick
Cell No: 079 696 2629
E-mail: roxannefick@gmail.com

Researcher:  (Mrs. R. Fick)
Study Leader:  (Prof. L. Human)
Head of Department:  (Prof. M. Marchetti-Mercer)



SECTION B
RESEARCH ASSENT

I, (Full name and surname) hereby acknowledge that I have read and understand the above-mentioned research information. I hereby agree to participate in the above-mentioned research project. I accept and agree with the conditions as stated above.

Participant:

Date: