SUPPORT GROUPS FOR ADULT COCHLEAR IMPLANT USERS: NEEDS AND PERCEIVED OUTCOMES

by

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ABSTRACT

Purpose: To describe the need for and perceived outcomes of group meetings for adult cochlear implant recipients (ACIR).

Method: The research study was conducted in two phases, namely a quantitative descriptive phase where data was collected by means of a questionnaire, and a qualitative deepening phase where data was collected by means of focus group discussions. Thirty-six ACIR completed questionnaires in order to determine the need for and specific requirements for group meetings. The outcomes of phase one contributed to the establishment of group meetings for ACIR. After four consecutive group meetings, focus group discussions were conducted (nine participants) in order to describe the perceived outcomes of group meetings.

Results: Participants expressed an evident need to attend group meetings and logistical requirements and preferences were established. After participation in group meetings, benefits in terms of psychological and emotional support, acceptance, understanding and improvement in social skills and confidence were reported. The opportunity to offer and receive support created a sense of empowerment for participants.

Conclusion: The establishment of much needed group meetings benefited ACIR to a great extent. ACIR reported positive outcomes with regards to improved assertiveness and self-perceived quality of life as a result of their group meeting attendance.

KEY TERMS

Hearing loss, adult, cochlear implant, support groups, self-esteem, qualitative research, focus groups.

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ABBREVIATIONS

UP CIU: University of Pretoria Cochlear Implant Unit

ACIR: Adult Cochlear Implant Recipient

CI: Cochlear Implant

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CHAPTER 1: INTRODUCTION AND RATIONALE FOR STUDY

1.1 Introduction

The sense of hearing supports the symbolic function of language and communication and provides constant environmental contact (Hallberg & Ringdahl, 2004). Hearing loss results in impairment in everyday communication and for the individual with a severe to profound hearing loss, this often leads to the deterioration of relationships (Heydebrand, Mauze, Tye-Murray & Binzer, 2005). Reduced social interaction and restriction in activities of daily living, in turn, could lead to depression, social anxiety, introversion, stress, social and emotional coping difficulties, reduced quality of life, loneliness and also negative changes in self-image and confidence (Hétu, 1996; Trychin, 2002; Preminger, 2007).

A cochlear implant (CI) is available as a prosthetic aid for individuals with congenital or acquired moderate to profound sensorineural hearing loss who do not obtain useful benefit from appropriately fitted hearing aids (Hallberg & Ringdahl, 2004; Olze, Szczepek, Haupt, Förster, Zirke, Gräbel & Mazurek, 2011). Unlike traditional hearing aids that amplify sound acoustically, cochlear implants provide hearing-like sensation by directly stimulating the auditory nerve (Pederson, Jochumsen, Madsen, Koefaed-Nielsen, Johansen, 2000), resulting in improved ability to hear sounds and speech.

The benefits of a cochlear implant cannot be described adequately if the outcomes of the procedure are not measured to a certain extent. Various variables contribute to cochlear implant outcomes, and most studies report on aspects such as communication and speech sound recognition (Heydebrand et al., 2005; Rembar, Lind, Arnesen, Helvik, 2009), auditory performance (Stacey, Fortnum, Barton & Summerfield, 2006), and quality of life (Olze et.al.,

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2011; Hogan, Giles & Stewart, 2002; Sanches-Cuadrado, Lassaletta, Maria Perez-Mora, Zernotti, Fernanda Di Gregotio, Boccia, Gavilan, 2013). Outcome studies of adult, post-linguistically deafened cochlear implant recipients demonstrate that most recipients experience at least a reasonable improvement in everyday communication and, in many cases, show significant gains in speech sound recognition (Heydebrand et al., 2005, Rembar et al., 2009). There are also indications that psychosocial outcomes among adult cochlear implant recipients (ACIR) include significant personal, social, and vocational gains compared to pre-surgical levels (Hallberg & Ringdahl, 2004; Hogan, Giles & Stewart, 2002; Sanches-Cuadrado, 2013; Fazel & Gray, 2007). These findings suggest that the psychological harm that results from acquired deafness is reversible (Heydebrand et al., 2005). Some researchers have proposed that improved hearing as a result of cochlear implantation has a salutary psychological effect that influences activities of daily living (Knutson, Schwartz, Gantz, Tyler & Hinrichs, 1991). However, cochlear implant recipients experience improved psychological well-being mostly due to non-auditory factors such as attitude, social involvement, and support (Heydebrand et al., 2005). Psychological and psychosocial issues associated with severe to profound hearing loss may not only have an impact on outcomes, but may also be responsive to intervention (Heydebrand et al., 2005).

Individuals with cochlear implants could experience an improved quality of life when, in addition to providing sensory aids and facilitating communication skill building, hearing health professionals also facilitate the development of insight, assertiveness, social identity and the self-confidence that is required for effective communication (Heydebrand et al., 2005; Hawkins, 2005; Binzer, 2002; Hétu, 1996; Hogan, 2001). For ACIR this could typically be achieved during a support group situation as part of the aural rehabilitation process. In a systematic review of the evidence of the effectiveness of counselling-based adult group aural rehabilitation

programs (Hawkins, 2005), it was concluded that structured adult audiological rehabilitation groups for cochlear implant recipients are effective in improving assertiveness and communication skills as well as reducing social withdrawal associated with hearing loss, which in turn leads to improved self-perceived quality of life (Hawkins, 2005; Preminger, 2007). Unfortunately, support groups are not currently part of the aural rehabilitation process at University of Pretoria Cochlear Implant Unit (UP CIU). Hearing rehabilitation programs for individuals with a hearing loss also tend to focus, usually within a didactic model, only on teaching communication tactics and instruction on how to manage communication breakdown (Hawkins, 2005). As this has been demonstrated to be insufficient (Hawkins, 2005), another component needs to be incorporated into hearing rehabilitation programs.

As audiological rehabilitation groups for ACIR are proven to be an effective means of intervention (Hawkins, 2005; Preminger, 2007), the establishment of group meetings should be considered a critical element of any auditory rehabilitation program (Luterman, 2004). Support group meetings are settings in which individuals with a hearing loss are understood, where common experiences can be validated, and help can be offered and received (Hétu, 1996; Binzer, 2002; Hogan, 2001; Luterman, 2004). Support groups reinstate the feeling of belonging (Hétu, 1996 in Preminger, 2007) and are a straightforward way to deal with the stigma and the loss of social identity that is often associated with hearing loss (Preminger, 2007). The primary focus of support group meetings is on emotional support, practical support and information exchange in a safe and welcoming space (Hétu, 1996; Binzer, 2002; Luterman, 2004). In a group meeting setting individuals with hearing loss can learn that others have undergone the same discomforting and frustrating experiences, and have had the same feelings and reactions to those experiences (Binzer, 2002). These painful feelings experienced by hearing-impaired individuals

can often be validated by professionals, but professionals lack the credibility that members of a support group have (Luterman, 2004). Furthermore, the benefits experienced when attending support group meetings can be ascribed not only to the content of the discussions, but to the many unspoken factors intrinsic to the group experience (Ross, 1987).

Support groups can maintain contact in the form of face-to-face contact sessions, through printed newsletters, and by means of telephone chains, internet forums, and mailing lists. Since 1982 or even earlier, the internet has provided a new and successful venue for support groups (Potts, 2005). Mail and internet bulletin boards have become popular methods of communication for peer-to-peer self-help groups and among facilitated support groups (Fox & Fallows, 2003). Several studies have shown the importance of the internet in providing social support (Potts, 2005; Fox & Fallows, 2003; Horrigan, 2001). The internet can create community and understanding, as well as the sharing of knowledge, in spite of great geographical distances (Potts, 2005; Fox & Fallows, 2003; Horrigan, 2001).

1.2 Rationale

Group meetings were demonstrated to be one of the more hopeful developments in aural rehabilitation for individuals with hearing loss (Ross, 1987 in Binzer, 2002). Recently, improved cochlear implants and methods of surgery have led to a broadening of criteria for cochlear implantation candidacy. For adults, this applies not only to implantation at an advanced age, but also to implantation in patients with more residual hearing than was previously the case (Olze et.al., 2011). Due to the broadening of selection criteria, more diverse needs from ACIR have evolved, therefore, a higher level of need for support groups and extended aural rehabilitation exsists.

On the African continent, cochlear implant units have only been established in South Africa and Egypt (Muller & Wagenfeld, 2003) and ever since, cochlear implantation is steadily increasing in South Africa. Since the first cochlear implant was performed in 1986, more than 1000 cochlear implants have been performed countrywide (SACIG annual reports, 2012). Currently, there are eight independent cochlear implant programs throughout South Africa.

The South Africa health care system is divided into private and public sectors, with the majority (approximately 85%) of South Africans relying on the public health care sector for health services, (National Treasury Department, Republic of South Africa, 2007). Recently, private medical aids have begun to contribute towards CI (Swanepoel, 2006) and four public sector driven (government funded) cochlear implant units have been established. As a result, there will be larger numbers of ACIR in South Africa in future who will have the need for aural rehabilitation and support after implantation.

The importance of comprehensive rehabilitation and support after receiving a cochlear implant cannot be over-emphasised, and the benefits have been well documented (Zeng, 2004; Kerr, Tuomi & Müller, 2012). Currently, none of the eight programs except the University of Stellenbosch-Tygerberg Hospital Cochlear Implant Unit has an established support group for ACIR. At the time of data collection for this study, no form of structured group meetings existed at UP CIU. As group meetings have been demonstrated to enrich aural rehabilitation for individuals with hearing loss, it would be sound practice to consider group meetings as part of the standard aural rehabilitation services for individuals with cochlear implants in the South African context.

Accountable aural rehabilitation services and evidence-based practice in any setting require trustworthy research data. It is therefore essential to investigate the need for and value of support group meetings for ACIR as a necessary component of a rehabilitation program.

The question thus arises: **What is the need for and what are the perceived outcomes of support group meetings for ACIR?**

CHAPTER 2: METHODOLOGY

2.1 Research aims

This study aimed to investigate the need and specific requirements for support group meetings for ACIR within a specific South African context as well as the perceived outcomes of such groups. The research aims were formulated as follow:

1. To determine to what extent ACIR experience the need to attend support group meetings.

2. To determine the requirements of ACIR with regard to the design, functioning, and logistics of support group meetings.

3. To describe the perceived outcomes of support group meetings as reported by ACIR.

2.2. Research design

2.2.1 Selected Research Design

A descriptive design was utilized with questionnaire surveys, followed by focus group discussions. The research approach that was followed was a mixed methodology design model (Creswell 1994 in De Vos, 2002). This approach uses the advantages of both quantitative and qualitative paradigms, as aspects of both paradigms were mixed (De Vos, 2002). In order to improve the validity and reliability of the acquired results, quantitative and qualitative approaches were combined for the purpose of this study by means of methodological triangulation (Duffy 1993 in De Vos, Strydom, Fouche & Delport, 2002). The research study was conducted in two phases, namely: Phase one (quantitative descriptive phase: data collection

by means of a questionnaire) and phase two (qualitative deepening phase: data collection by means of focus groups).

In the first phase of the research study, the researcher aimed to determine the need for support group meetings in adult cochlear implant recipients. This was done in order for support group meetings to be established and administered in accordance with the requirements expressed by ACIR.

The qualitative deepening phase (phase two) of the research study aimed to describe the actual outcomes of group meetings as perceived by adult cochlear implant recipients.

2.2.2 Research phases

The researched study was conducted in two phases, namely:

- Phase 1:   Quantitative descriptive phase (data collection by means of a questionnaire)
- Phase 2:   Qualitative deepening phase (data collection by means of focus group discussions)

The chronological sequence of the above mentioned phases were as follow (compiled from van der Spuy, 2006):

1. Design and construction of a questionnaire for adult cochlear implant recipients. (See *Appendix C* for questionnaire)

2. Conduction of a pilot study to evaluate the effectiveness of the questionnaire.

3. Collection of quantitative data by means of the questionnaire.

4. Processing of raw data and statistical computer analysis of questionnaire data.

5. Information session on support group meetings where results of questionnaires were discussed and a plan of action was formulated was led by an experienced rehabilitative audiologist.

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6. Conduction of several support group meetings. (Amount of sessions was determined by needs analysis and information session held)

7. Planning of focus groups. (See *Appendix D* for proposed focus group guide)

8. Conduction of focus groups and collection of qualitative data.

9. Processing of raw data by means of analysis, open coding strategy and categorization of qualitative focus group data.

10. Recording of results.

2.3 Phase 1: Quantitative descriptive phase

The initial phase of the research study followed a quantitative, descriptive approach. Quantitative research is a form of conclusive research involving collecting representative samples and carrying out structured data collection procedures (Struwig & Stead, 2001). This study therefore aimed to collect information which enabled the researcher to describe the need for support group meetings as indicated by adult cochlear implant recipients. It also attempted to describe the specific requirements of ACIR with regard to support group meetings.

Descriptive studies examine a situation as it is (Leedy & Ormrod, 2005). The main use for descriptive studies is to give service providers information that will help them in the design of services (Katzenellenbogen, Joubert & Abdool Karim, 1999). The needs of ACIR with regard to support group meetings was described in order to contribute to the design of the establishment of support group meetings for ACIR of the UP CIU.

2.3.1 Participants

Adult cochlear implant recipients of the University of Pretoria Cochlear Implant Unit (UP CIU) were used for the purpose of this study. The adult cochlear implant recipients who participated in this study will be referred to as participants.

Assistance was sought from the UP CIU in selecting the participants. A letter was sent to the coordinator of the UP CIU, requesting the permission to conduct the study using clients from the UP CIU (*Appendix A1*).

Non-probability, consecutive sampling was used to select the participants for this study. Non-probability sampling is referred to as any technique in which samples are not chosen based on the probability theory (Babbie, 2004). Convenience sampling is a method of non-probability sampling and was used. In convenience sampling, researchers use participants who are easy to get hold of and are readily available and willing to participate in the study (Gravetter & Forzano, 2008). Due to the limited number of individuals with cochlear implants, this type of sampling was used to ensure that the maximum possible number of participants was reached. Participants were selected through the Pretoria Cochlear Implant Program (UP CIU).

In consecutive sampling, individuals are selected should they match the set criteria and agree to participate in the study. Participants are selected until the desired sample size has been reached. This type of sampling method was selected in order to ensure that the set goals were achieved. The main goal of this study specified that the sample group should be adult cochlear implant recipients of the UP CIU.

The sample size for this study was selected in order to overcome the constraints of low response rates with questionnaires, as well as the limited number of available subjects who met the selection criteria. The desired sample size was 60 adults with cochlear implants. The sample size

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has been increased, from the actual size expected, to account for lost mail and non-responders (Salkind, 2006).

2.3.1.1 Participant selection criteria

The participants were selected according to the following criteria; as summarized in table 1:

Table 1. Participant selection criteria

Criteria	Motivation
Participants should be cochlear implant recipients, between the ages of 18 to 59 years.	The research objective was to describe the need for and perceived outcomes of support groups for adult cochlear implant recipients.
Participants should be adult cochlear implant recipients who were implanted in collaboration with the UP CIU.	Due to the nature of the sampling technique used in the study, participants were selected from the UP CIU. All participants were therefore required to be receiving services from the UP CIU of the University of Pretoria at the time of the study.
Participants should be competent in either Afrikaans or English.	The questionnaire was formulated in English and Afrikaans and the participants were required to comprehend and answer the questions of the questionnaire adequately.
Participants should be literate and able to read and complete a questionnaire in writing.	Participants should have had the ability to accurately complete the questionnaire, having full understanding of the questions asked, and be able to complete the questionnaire accurately.
Participants must be willing to participate in the study.	Participants were able to make a voluntary and reasoned decision about their possible participation (De Vos, 2002).

The age of diagnosis, the age of cochlear implantation, the duration of cochlear implant usage, speech perception abilities as well as the type of communication approach followed, were not considered as determining factors or taken into account when participants were selected.

2.3.1.2 Selection procedure

The participants were selected through the following procedure:

1. The UP CIU of the University of Pretoria was contacted and the aim and practical implementation of the study were discussed with the head of the program. Permission was obtained to conduct the study and gain access to the contact details of participants (See *Appendix A1*).

2. Since adult cochlear implant recipients refer to individuals between 18 and 59 years, individuals with the birth dates from the year 1992 and who were currently receiving services at the UP CIU at the University of Pretoria, were selected and their contact details were obtained.

3. Participants who met the sampling criteria were considered to be participants and were contacted telephonically or via e-mail. Permission to be included in the study was obtained during the telephonic conversation or electronic communication. Participants were asked to indicate the preferred method of receiving the questionnaire (i.e. via e-mail or fax).

4. Cover letters (See *Appendix B*) and the questionnaire (*Appendix C*) were then e-mailed or faxed to the participants following the telephone conversations or e-mail correspondence. It was clearly stated on the questionnaire that participants gave consent, which confirmed that they were willing to participate in the study, when completing and returning the questionnaire.

2.3.1.3 Description of the participants

Seventy-two ACIR complied with the criteria and were considered for phase one of the research study. Of these, 17 were excluded as 13 of the ACIR declined to participate and four could not be contacted due to incorrect contact details. The remaining 55 prospective participants were

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provided with an information letter and the questionnaire. Of the 55 prospective participants, 65.45% (36/55) completed and returned the questionnaires.

Questions A1 to A5 (Section A) of the questionnaire consisted of questions relevant to the biographic information of the participants. Biographic information about the participants is given in Table 2. The responding participants' age distribution (represented in Table 2) predominantly represented the 18-30 years (30.56%) and are furthermore fairly equally distributed across the spectrum of the other age groups, with least respondents in the age group 51-59 years (11.11%). The largest group of responding participants (77.78%) was English speaking. Male (47.22%) and female (52.78%) respondents were almost equally represented as shown in Table 2.

More than half (54.54%) of these participants have their cochlear implants between 6 and 10 years. Thirty four (94.44%) respondents have a unilateral cochlear implant and only two respondents (5.56%) have bilateral cochlear implants. It also became apparent from table 2 that the vast majority of respondents are employed (78.13%). Due to item non-response, analyses including employment are reduced to 32 participants.

Table 2. Demographic data of participants (n=36)

Variables	Participants (n=36)
Average age (yrs.)	40.69 SD15.06 (21 – 70)
Gender (M:F)	17:19
Language (English: Afrikaans)	28:8
Marital status (n=36)	
Single	8
Engaged	1
Married	16
Divorced	5
Widowed	2
In relationship	4
Occupation (n=32)	
Employed	25
Unemployed	2
Student	2
Pensioner	3
Duration of CI use (yrs.)	7.42 SD4.39 (1 – 21)
Cochlear implant(s) (Bilateral : Unilateral)	2:34

2.3.2 Material for data collection

For the purpose of the first phase of the study, a cover letter (*Appendix B*) and a questionnaire (*Appendix C*) were used as research material.

2.3.2.1 Motivation for the use of questionnaires as method of data collection

Structured questionnaires were the selected method for data collection in the first phase of this study. A questionnaire is a data collection tool which is comprised of standardized questions relating to the proposed research topic used to gather information which cannot be obtained through observation, and does not require direct personal contact with participants, (Bless & Higson-Smith, 2000).

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Structured questionnaires translated the research objectives of the first phase into specific questions, ensuring that all the set objectives were achieved (Venter & Viljoen, 2008). In this way, the results of this phase of the research were easily quantified and interpreted.

Questionnaires are relatively inexpensive in comparison to other methods for data collection. Advantages of using questionnaires may include time and cost efficiency, less interview bias, more time for the respondent to answer questions than in an interview and the fact that more participants can also be reached in a shorter space of time (Bless and Higson-Smith, 2000).

However, a limitation of using a questionnaire as method for data collection is that questionnaires generally have low return rates (Leedy & Ormrod, 2005). In order to compensate for this limitation, the participants were regularly reminded telephonically and via e-mail to complete the questionnaires and send them back to the researchers.

2.3.2.2 Cover letter and Letter of consent

The questionnaire contained a cover letter in which the aim and nature of the study were briefly explained (see *Appendix B*). According to Trochim and Donnelly (2006), prospective research participants should be fully informed about the procedures and risks involved in research. Therefore, a cover letter was also given to the head of the UP CIU (see *Appendix A1*).

In the study, the cover letter clearly stated the risks and benefits of participation. Participants were instructed to indicate that they understood that the study was conducted anonymously, that information provided would be treated as confidential, and would be used solely for research purposes.

2.3.2.3 Questionnaire design

The questionnaire was designed and constructed in order to achieve the stated sub-aims relevant to phase one of the study.

The questionnaire comprised of closed-ended questions. Closed-ended questions provided the researcher with data that is factual and easily quantifiable. Closed-ended questions that were used in this study's questionnaire (see *Appendix C*) included checklists. Checklists require participants to select the most appropriate answer from a list of options (for example, Questions A2; A5; A7 A9 and A10 in Section A, B1- B6 in Section B, as well as questions C1- C20 in Section C). Other closed ended questions included in the questionnaire required a simple yes or no answer, (for example, Questions A8 and A11 in Section A, and B7 and B8 in Section B).

Thus, the following types of questions were included in the questionnaire:

- **Factual Questions** (used to obtain specific and objective information regarding the participant, for example personal information.)
- **Structured Questions** (these took the form of multiple choice questions and contingency questions.)

Questions were short and simple, they were not be ambiguous, but clearly stated, jargon was avoided and questions were asked in a logical sequence, formulated according to the guidelines as stated in Bless and Higson-Smith (2000).

2.3.2.4 Questionnaire content

The questionnaire was compiled in English and Afrikaans to accommodate the language preference of the subjects. The questionnaire consisted of 40 questions and it was divided into 3

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sub-sections. The content of the questionnaire was finalised once the pilot study had been completed.

The content of the questionnaire was drawn from the following:

- The need for specific information in order to answer the research question as well as the sub-aims of the study.

- A pilot study questionnaire was applied prior to the commencement of the study. This was done to determine whether the questionnaire was feasible, practicable and effective in achieving identified aims of the study (Leedy & Ormrod, 2005).

- The pilot study was carried out on two participants who met the criteria. The participants used for the pilot study did not participate in phase one of study. The participants of the pilot study were asked to give feedback in terms of how the questionnaire should be changed. Their comments were taken into account, and relevant changes were made to the measurement instrument.

The content of the questionnaire included questions on the following topics:

- Section A: Background Information

- Section B: Logistical arrangements for group meetings

- Section C: Topics to be covered during group meetings

The final questionnaire that was sent to participants has been included as *Appendix C.*

2.3.3 Research Procedure

2.3.3.1 Pilot Study

Prior to conducting the research, a pilot study was carried out. In this case, a pilot study was performed to evaluate the effectiveness of the measurement instrument (namely the compiled questionnaire), testing its reliability and validity. According to Converse and Pressor (1987, in Ter Poorten, 2001) a minimum of two participants are required for a pilot study. Only the minimum number of participants was used for the pilot study in order to maintain the maximum number of participants who met the criteria to take part in the study. As mentioned above, the participants of the pilot study did not complete the questionnaire used as method of data collection in phase one.

2.3.3.2 Data collection procedure

Data was collected by conducting the following:

1. The UP CIU of the University of Pretoria was contacted and the aim and practical implementation of the study were discussed with the head of the program. Permission was obtained to conduct the study and gain access to the contact details of potential participants (See *Appendix A1*).

2. Consent and approval to conduct the study were obtained from the Ethical Research Committee of the Department Communication Pathology (See *Appendix A2*). A research proposal was submitted to the committee in order for the study to be considered for ethical clearance.

3. The participants were contacted telephonically or via e-mail, first requesting their permission to take part in the study.

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4. Cover letters, together with the questionnaires, were then e-mailed or faxed to the participants. The participants were clearly informed that consent is given when completing and returning the questionnaire. Thus, when participants returned the completed questionnaires, they confirmed that they were willing to participate in the study.

5. A time period of one week to complete the questionnaire was given. This aimed to prevent the misplacement or neglect of the questionnaire. High response rates are crucial in ensuring the maximum number of responses possible, increasing the validity of the study. Response rates were increased through making use of telephonic (sms) reminders.

6. Data analysis commenced once all the questionnaires were completed and collected.

2.3.4 Data Analysis

The data collected for the initial stage of the research were analysed descriptively to yield percentages and frequency distributions and to provide an overall, coherent summary of the information collected.

The following tasks were performed in the statistical analysis of data:

1. The questionnaires were read carefully and thoroughly. Information was first organised in a chronological order, followed by categorization of the data.

2. To organize the information, data was tabulated in Microsoft Exel.

3. The next step taken was to convert the data into information which carries meaning and is interpretable (Struwig & Stead, 2001), in the form of graphs, tables and summarized figures.

4. Closed-ended questions were analyzed by using mainly descriptive statistics (Crabtree & Miller, 1992 in Maxwell & Satake, 2006).

2.3.5 Validity and reliability

The validity of this study was increased by the fact that a pilot study was carried out. This ensured that the measurements that were made truly measured the concept (i.e. needs) that it intended to measure. According to Struwig and Stead (2001) there are two types of validity to take into account when conducting quantitative research. These two types are described below and related to this specific study:

- External Validity: refers to the extent to which the results of a study can be generalized to other populations (Struwig & Stead, 2001).   The external validity of this study is adequate, as the demographic distribution of participants is in accordance with a general population of ACIR. This study only involved participants from the UP CIU so this study needs to be supported by similar studies from other cochlear implant centres to make it more applicable to other populations.

- Internal Validity: Extraneous variables can influence the validity of the results, and must be controlled in order to avoid this from taking place. In terms of this study, the factors not taken into account when selecting participants could be viewed as variables which could influence the internal validity of the study. These factors are age of diagnosis, the age of cochlear implantation, age of participants, the duration of cochlear implant usage, speech perception abilities, whether the participant have received aural rehabilitation as well as the type of communication approach followed.

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Reliability should be determined ideally on representative samples of 200 or more participants, but smaller sample studies should still provide reliability coefficients (Struwig & Stead, 2001) . Therefore, even though this study was a relatively small research project, reliability was ensured as far as possible. To this effect, it was ensured that the participants understood the questions asked, and the reasons for asking them, as changed and guided by the results of the pilot study. Sufficient explanations in the cover letter were therefore also important.

2.4 Establishment and administration of Group Meetings

Participants in phase one who indicated a need to belong to a support group were contacted in order to confirm a date and venue for an initial group meeting. A group of experienced rehabilitative audiologists facilitated the initial meeting which consisted of an information session followed by break-away discussion group sessions, during which the participants discussed the requirements for group meetings. After the initial meeting, the second in a series of four support group meetings was scheduled according to the input and requirements as stated by the participants (refer to table 6 in *Results* for description of logistical arrangements for meetings). The content of the support group meetings was also planned according to the established aims and topics of interest as determined by the participants in the questionnaire and the discussions during the initial meeting. A summary of the content of the four support group meetings is presented in table 3.

Table 3: Summary of the content and structure of support group meetings

Support group meeting	Structure	Content
Initial Meeting	Presentation by speaker (expert audiologist in the field of cochlear implants) followed by a presentation by the researcher Break-away discussion groups Social interaction (informal)	• Information sharing: cochlear implant components; device troubleshooting, bilateral cochlear implantation, advice on assertive behaviour. • Feedback about results obtained in phase one of the study. • Discussion and establishment of structure, format and goals for future support group meetings.
Second meeting	Presentation by speaker (Professor in bio-engineering working in the field of cochlear implants) Group discussion and sharing of personal experiences Video conference call (Skype) with an established support group in Cape Town, South Africa Social interaction (informal)	• Information sharing: recent cochlear implant research, music perception with cochlear implants, advice on the use of assistive listening devices • Discussion of the objectives, composition, structure, projects, logistics and on-line component of support group. • Informal sharing of personal experiences.
Third meeting	Informal get-together: picnic	• Sharing of personal experiences and informal social interaction
Fourth meeting	Presentations by representatives from three different cochlear implant companies Demonstration of various assistive listening devices Social interaction	• Information sharing and practical demonstration: assistive listening devices and recent technologies associated with cochlear implants. Tips on telephone use. • Informal sharing of personal experiences

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The second phase of the study commenced after four consecutive support group meetings. As this phase of the research aimed to describe the perceived outcomes of support group meetings as reported by ACIR, focus group discussions were conducted to explore and record their experiences.

2.5 Phase 2: Qualitative deepening phase

In the second deepening qualitative phase, focus group discussions were conducted with selected adult cochlear implant recipients to elaborate on the need for and specific requirements with regard to group meetings and to establish actual outcomes of group meetings as perceived by adult cochlear implant recipients. A focus group design was adopted to generate maximum data via participant interaction used to encourage the generation of participant views (Docherty, 2004). The aim of focus group discussions therefore was to explore the amount of consensus about a certain theme by eliciting different views and emotional processes within a group situation (Gibbs, 1997 in van der Spuy, 2006).

2.5.1 Participants

Participants who were selected for the focus group discussions (phase two) had to attend all four of the consecutive support group meetings. In order to prevent the contamination of data (Docherty, 2004), focus group members did not participate in the quantitative descriptive phase (phase one) of the research study. Nine ACIR were selected to participate in focus group discussions. Participants were divided into two separate focus groups according to home language, namely an Afrikaans and an English focus group. The two groups consisted of four and five participants respectively. A description of the participants of the focus groups is provided in tables 4 and 5:

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Table 4. Focus Group 1 (English speaking participants)

Participant	Occupation	Unilateral/ bilateral CI	Duration of CI use (months)	Congenital/ Acquired Hearing Loss
Participant 1	Pensioner	Unilateral	39	Acquired: Adult
Participant 2	Radiographer	Unilateral	70	Acquired: Child
Participant 3	Pensioner	Bilateral	130	Acquired: Adult
Participant 4	Communication Manager	Bilateral	95	Acquired: Child

Table 5. Focus Group 2 (Afrikaans speaking participants)

Participant	Occupation	Unilateral/ bilateral CI	Duration of CI use (months)	Congenital/ Acquired Hearing Loss
Participant 1	Technician	Unilateral	77	Congenital
Participant 2	IT Technician	Unilateral	48	Congenital
Participant 3	Pensioner	Unilateral	81	Acquired: Adult
Participant 4	Lecturer	Unilateral	80	Acquired: Child
Participant 5	IT Consultant	Unilateral	79	Acquired: Child

The majority (77.8%) of the focus group participants were post-lingually deafened adults implanted unilaterally.

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2.5.2 Purpose of and motivation for focus groups as method of data collection

As this phase of the study aimed to describe the actual outcomes of support group meetings as perceived by adult cochlear implant recipients, focus groups were utilised as a method of data collection. Focus groups can effectively be used to determine the outcomes of service delivery in a program (Kritzinger & Barbour, 1998 in van der Spuy, 2006).

Data obtained in a setting of group dynamics are comprehensive and can be effectively applied in a descriptive study. Thus, participant's perceptions of the outcomes of support group meetings could have been described holistically if qualitative data analysis was used (Duffy, 1993 in De Vos et.al, 2002). This deepening qualitative phase aimed to complement phase one by elaborating on the specific needs for support group meetings, as well as indicating the perceived outcomes of the support group meetings for which the participants indicated a need. This, in turn, indicated whether or not needs was met and in this manner, it contributed to triangulation.

2.5.3 Research material

2.5.3.1 Focus group guide

A focus group guide was compiled which consisted of specific formulated open questions. These served as a structure and agenda in which members could engage in conversation (Steward & Shamdasani, 1990 in De Vos et al., 2002). The guide was compiled in accordance to five categories of questions for focus groups as described by Morgan and Kruger (1998). The guide used aimed to allow the maintenance of a flexible conversation by using open-ended questions,

which were well considered and clearly stated. This is crucial for research done by means of focus groups, (Morgan & Krueger, 1998).

The questions focused upon the relationship between patient experience and their support group membership, and the perceived functions and benefits of the group. To achieve this, the researcher followed the principles for formulating questions as suggested by De Vos et al. (2002): Questions were asked in an everyday conversational style, clearly formulated and understandable and limited to a single dimension. The focus group guide is included as *Appendix D*.

2.5.3.2 Letter of consent

In order for the researcher to have obtained written consent from participants for participation in focus groups, a letter of consent (*Appendix E*) was given to each participant before focus group sessions started. The letter described the title, aim and implications of the study to ensure that participants were orientated in terms of what was expected from them during focus group discussions. Participants were assured that information provided would be treated as confidential and will be used solely for research purposes.

2.5.4 Research procedure

2.5.4.1 Pilot study

In the set-up of a focus group, it is difficult to separate the questions asked from the context in which it is asked (Morgan & Krueger, 1998). This complicated the conduction of a pilot study,

as the first group held would have to be considered as the pilot study. However, this was not cost- or time effective and therefore the following alternative procedures were followed:

1. Individuals who adhered to selection criteria, but who could not participate in focus groups, were asked the questions in the focus group guide. They were asked to give feedback in terms of how the questions should be changed. Their comments were taken into account, and relevant changes were made to ensure that the content and concepts were understood (De Vos et al., 2002). The participants of the pilot study for the focus groups were not allowed to partake in the actual focus group discussions.
2. Two experts in the field of focus groups were also approached to evaluate the questions in the focus group guide. Adaptations were made to the questions according to their suggestions.

2.5.4.2 Planning of focus groups

The following points describe the structure, group composition, size and amount of focus groups.

2.5.4.2.1 Structure of focus groups

The aim of less structured focus groups is to stress the perspectives and opinions of the participants (Morgan & Kreuger, 1998). As this phase of the proposed research aimed to describe the actual outcomes of support group meetings as perceived by adult cochlear implant recipients, a less structured group was selected. Thus, the majority of conversation was generated by members; the remainder was used by the researcher to guide the group discussion.

2.5.4.2.2 Group composition of focus groups

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Great consideration needs to be given to the composition of groups, as the interaction between members form the core of a focus group (Van der Spuy, 2006). For the purpose of this study, participants who adhered to certain selection criteria (as explained in 2.5.1) were selected. As unity in this homogenic group could be facilitated, less time was spent on group members having to get to know each other and more time was spent discussing subjects of importance (Morgan & Krueger, 1998b).

This phase of the study was concerned with detail and in-depth analysis of information obtained from a discussion between selected individuals.

Participants of focus groups in the study were part of an established support group which existed before the conduction of the focus groups. This brought upon shared experiences, which in turn lead to spontaneous discussions (Van der Spuy, 2006).

2.5.4.2.3 Size of focus groups

Established guidelines for focus group techniques states that the normal size of focus groups are between six and ten participants (Morgan & Krueger, 1998). For the purpose of this study, smaller groups were selected (four and five members selectively). This was decided based on the argument that fewer participants enable group members to share their views and personal experiences in more detail and depth, which gives the researcher a more comprehensive understanding of the determined discussion topics (Morgan & Krueger, 1998).

2.5.4.2.4 Amount of focus groups

For the purpose of conducting a valid and reliable study, Morgan and Krueger (1998) suggested that two to five focus groups should be held. This is suggested due to the fact that participants

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are diverse and matters in qualitative research can be complex. More than one focus group was held for this study, as the validity of reactions could be increased and depictions could be made on similarities and shared experiences (Van der Spuy, 2006). Participants who were involved in support groups for adult cochlear implant recipients were grouped into different focus groups based on their language of preference (thus an Afrikaans and English focus group was held). This was done in order to ensure an optimal environment for comfortable communication and interaction.

2.5.4.2.5 Recruitment of participants of focus groups

As discussed in 2.5.1, members for each focus group were selected from a group of individuals who attended the support groups for adult cochlear implant recipients. The following three steps were followed to recruit members for focus groups for this phase of the study:

1. Selected members were contacted three to four weeks prior to the meeting of the focus group.
2. Selected members received a letter stating and confirming the time and place of the planned meeting one week prior to the meeting.
3. One day prior to the meeting of focus groups, members were contacted telephonically to confirm attendance at the focus group.

2.5.4.3 The role of the moderator in focus groups

The primary researcher conducted the role of the moderator of each focus group discussion; while an assistant-moderator took notes in order to prevent that valuable verbal, as well as non-verbal information went astray, (Van der Spuy, 2006). The moderator had the responsibility to

facilitate interaction objectively as well as to create an atmosphere where members could, unabashedly, share their opinions and experiences in a group setting (Kritzinger, 1994 in Van der Spuy, 2006).

2.5.4.4 Conduction of focus groups

1. Amount and size of focus groups were decided on. Guidelines as mentioned in Sections 2.5.4.2.3 – 2.5.4.2.4 were followed.

2. Members were contacted to establish place and time of meeting.

3. A focus group guide was compiled (as discussed in 2.5.3.1) and adapted according to suggestions made after the pilot study have been conducted.

4. A letter of consent, (which assured participants that confidentiality and anonymity will be maintained throughout and that participants have the right to withdraw from the study at any time without negative consequence) was signed by each member, before the focus groups commenced. The letter was available both in Afrikaans and English.

5. An assistant moderator was appointed and coached in terms of her role in discussions as well as the dot down on notes.

6. Focus groups were recorded on video and notes were made continuously by the assistant moderator.

7. At the meeting, the researcher introduced herself, described the aims of the research, indicated that the discussion will be video recorded and provided an opportunity for members to ask questions before data collection commenced.

8. Focus group discussion then took place.

9. At the end participants were thanked for their involvement and the researcher briefly provided an interpretation of the discussion and encouraged member comments as an initial check to the accuracy of the interpretation.

10. A summary session was held after the conduction of every focus group. During this session, the content and happenings of focus group discussions were critically discussed. This discussion was recorded and used in addition to data transcription.

2.5.4.5 Recording of data and data analysis

1. Each focus group discussion was recorded and transcribed directly after the discussion for data analysis. This was done to provide an accurate transcription of the interview. This also reduced the likelihood of researcher interpretation and memory bias.

2. The researcher (moderator) and assistant moderator made detailed notes on the interview transcripts regarding content (descriptive category) and theme (interpretation or meaning).

3. The researcher and assistant moderator then met, and through a process of discussion they agreed on a coding frame based on notions of consistency, commonality, and the function and effects of specific themes.

4. Two experts in qualitative research were asked to read the interview independently after transcription, in order to ascertain the major themes emerging, and to develop a coding frame.

5. The complete data set was then coded, line by line, by the researcher, after which a group meeting was held to discuss any new unforeseen themes, and to re-evaluate the inclusion of themes which appeared with low frequency.

6. The interpretation of these themes was conducted by a process of reading and re-reading, as well as reference to relevant literature and consultation with colleagues.

This process followed what Stenner (1993:114) has termed a 'thematic decomposition', a close reading which attempts to separate a given text into coherent themes or narratives which reflect subject positions allocated to or taken up by a person (Davies & Harre, 1990).

2.5.5 Validity and Reliability

Validity was ensured by completing a thorough literature study before the focus group guide was compiled to ensure that relevant and research-based questions were included. A pilot study took place before the focus groups during which the application and accuracy of each question was critically evaluated. The interviews were recorded and transcribed verbally which contributed to the validity of the responses. The transcribed data was cross- checked with the audio recording by another researcher in order to ensure that an accurate representation was transcribed and to reduce any element of bias. The language of questions asked was adapted to eliminate any uncertainty and confusion of concepts. This led to better reliability of the focus group discussions.

Reliability of a measurement instrument refers to the extent to which it yields consistent results when the characteristics being measured haven't changed (Leedy & Ormrod, 2005). Reliability was also ensured by selecting participants that were proficient in Afrikaans of English. As a result, misinterpretation of responses was eliminated by not translating questions and answers in another language.

2.6 Ethical considerations

The implementation of ethics is an integral part of the research design (Babbie & Mouton, 1998). Ethical guidelines must be in place in order to protect the research subjects from any form of harm; an issue which is central to the area of research in the social sciences (Neuman, 2006). Keeping ethical guidelines in research is vital, requiring that researchers weigh the value of advancing knowledge against the value of non- interference in the lives of the research subjects (Neuman, 2006).

Ethical research entails that subjects are informed in writing of the goals, procedures and importance of a specific study, the risks and benefits involved, plans for dissemination of the findings, as well as the measures taken to ensure confidentiality and anonymity (Maxwell & Satake, 2006).

For this reason, ethical clearance was obtained from the Ethical Research Committee of the Department of Communication Pathology prior to conducting this study (see *Appendix F*). Furthermore, the researcher adhered to the guidelines given by the South African Speech-Language Hearing Association (SASHLA) code of ethics for speech-language therapists and audiologists (1997). The pillars of ethics, namely: beneficence and non-maleficence, autonomy, justice, veracity, and fidelity were applied.

- **Beneficence and non-maleficence:** While carrying out this study, the researcher acted with the best interest of the participant in mind to not inflict any harm on the participant. In terms of this study, no physical or emotional harm was inflicted on the participants, and all questionnaires remained anonymous (as stated in *Appendix B* and *Appendix E*). Participants had the right to withdrew from the study at any stage, and were made aware

of this fact by stating this in the cover letter and informed consent (see *Appendix B* and *Appendix E*).

- **Autonomy:** The researcher respected the participant's beliefs and values. In this study, the views and values of the participants were respected while analyzing results. The views and beliefs of the researcher were in no way forced on to the participants.

- **Justice:** In order to maintain distributive justice the cover letter accompanying the informed consent (*Appendix B* and *Appendix E*) clearly stated that the participants would not be given anything by participating in the study, and that the results of the study would have been used for the establishment and motivation of support groups. Justice also involves ensuring that the services provided are available and accessible to all people, and that they are appropriate and relevant to the individual and community needs. All the adult cochlear implant recipients of the UP CIU were approached to join in the study.

- **Veracity:** The researcher was honest at all times, and did not deceive the participant. A carefully constructed cover letter (*Appendix B* and *Appendix E*) was important in this regard.

- **Fidelity:** The researcher retained confidentiality and ensured that all data and information used in the study remained anonymous. To this effect, all questionnaires and participants in focus groups were kept anonymous at all times. Confidentiality also enjoyed high priority and was mentioned in both *Appendix B* and *Appendix E.*

2.7 Summary

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This chapter provides a layout of the planning and implementation of research that describes the need for and perceived outcomes of support group meetings for ACIR.

The aims of the research are formulated and thereafter the motivation for the chosen research design is given. Both phases of research are described (including the description of the selection criteria, participants, research material, data collection and data analysis). The validity and reliability of this study, as well as the relevant ethical considerations for this research were also described. The results obtained are conveyed in the next chapter.

CHAPTER 3: RESULTS

3.1 Introduction

In this section data was organized and analyzed in order to address the respective sub-aims of this study, as stipulated in the methodology. Furthermore, the data was interpreted, evaluated and discussed in depth in order to draw conclusions regarding the set sub-aims and to determine whether there is a need for a support group and to describe the specific needs for and perceived outcomes of the support group for adult cochlear implant users.

The results are presented and discussed according to the two research phases (as explained in Section 2.2.2). In both phase one (Quantitative descriptive phase) and phase two (Qualitative deepening phase), the results are described according to the formulated sub-aims of the study.

In phase 1, results were obtained from the questionnaires and were quantitatively analyzed and discussed according to the following sub-sections: The first sub-section addresses the current support systems of adult cochlear implant users, as well as the need for support groups for adult cochlear implant users. In the second sub-section, the specific needs and requirements of adult cochlear implant users with regard to support groups are addressed. This will be done by looking at logistical arrangements for group meetings, as well as giving a description of the topics indicated to be covered during group meetings.

Data was collected by means of focus group discussions in the second phase of the study. The aims of this phase were to elaborate on the need for and specific requirements with regard to support groups and to establish actual outcomes of support group meetings as perceived by adult cochlear implant users.   Therefore, the results were qualitatively analyzed and discussed

according to the following sub-aims: To determine the need for support groups for adult cochlear implant users; to determine the specific needs and requirements of adult cochlear implant users with regard to support groups; to describe the actual outcomes of support group meetings as perceived by adult cochlear implant users.

3.2 Results

3.2.1 Phase 1: Need for support groups and specific requirements of ACIR with regard to a support group

Current support systems

In order to determine whether ACIR have a need for continued support, participants were asked about their current support systems in Section A of the questionnaire. The results are presented in figure 1.
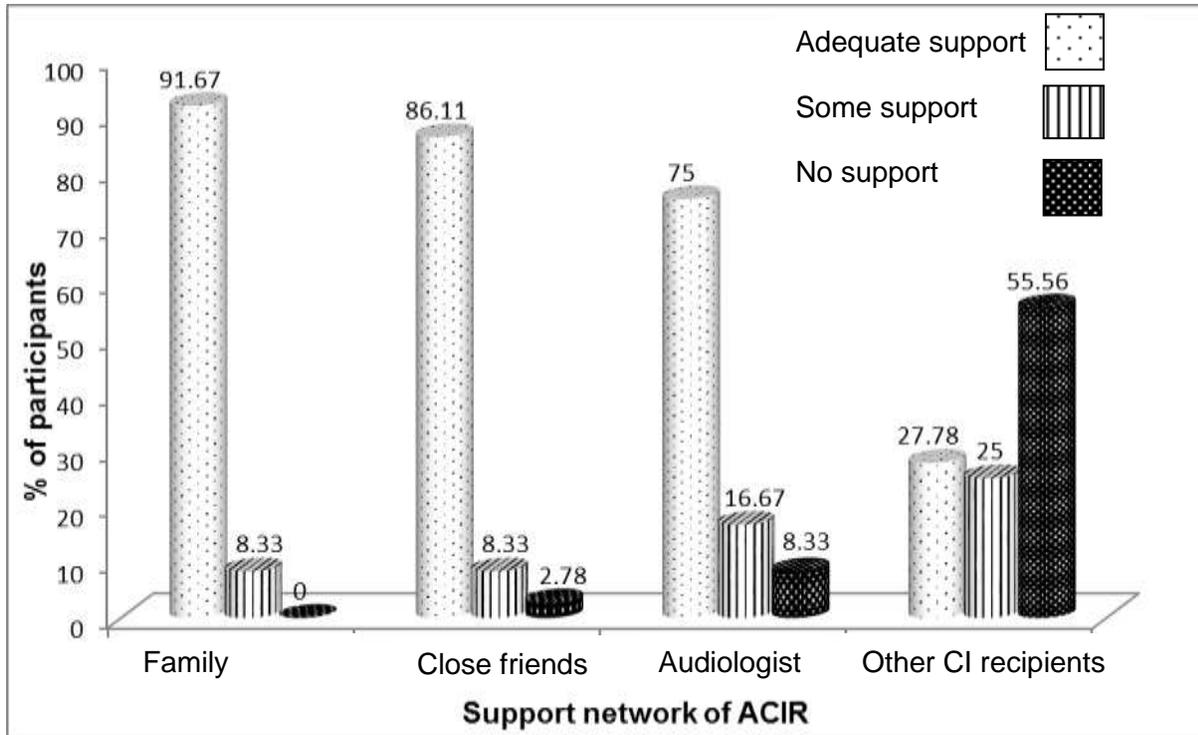
Figure 1. Description of the support network for adult cochlear implant recipients (ACIR) (n=36).

As depicted in figure I, the majority of participants rated that they receive *adequate* support from family members (33/36; 92,67%) and close friends (31/36; 86,11%). Seventy five percent of respondents (29/36) receive *adequate* support from their audiologists, only 16,67% (6/36) received *some* support and 8,33% (3/36) of the respondents indicated that they do not receive support from audiologists. The majority of ACIR receive *adequate* support from family members, friends and audiologists, while the majority ACIR indicate that *no* support is received from other ACIR. Fifty six percent of participating ACIR (20/36) indicated that *no* support is received from other cochlear implant recipients. Only 25% (9/36) of the respondents reported to receive *some support*. It is therefore evident that, prior to the commencement of the support group meetings, there was limited supportive interaction with other cochlear implant recipients.

The vast majority of participants (29/36; 80,56%) indicated the need to be part of a support group for ACIR. The seven participants who indicated that they do not want to be part of a support group all indicated that they receive adequate support from family, close friends and their audiologists. It is interesting to note, though, that participants who indicated the need to belong to a support group also indicated that adequate support was received from family and friends.

Specific needs and requirements for support groups

In order to determine the specific needs and requirements of ACIR with regard to support groups, the preferred logistical arrangements for group meetings as well as topics to be discussed during group meetings were determined. Table 6 represents a summary of the indicated preferred logistics for group meetings for participants:

Table 6: Summary of preferred logistical arrangement for support group meetings

Logistical arrangements for support group meetings	Logistical arrangements as preferred by majority of participants (n=36)
Frequency of support group meetings	Quarterly – every 3 months (56%)
Day of the week	Saturday (64%)
Time of day	Morning (53%)
Venue	In the building where the cochlear implant centre is situated (75%)
Manner to receive correspondence about meetings	Via e-mail (72%)
Attendance of family members or friends	Occasionally (42%)
Opportunity to meet informally and interact socially	Yes (78%)
Who should be responsible for organizing meetings	Professionals associated with local cochlear implant program (94%)

After considering the logistical arrangements for support group meetings as preferred by the majority of respondents, it can be said in summary that support group meetings should take place quarterly on Saturday mornings, in the building where the cochlear implant centre is situated. The professionals associated with the local CI program should be responsible for organising the meetings and the preferred manner of correspondence of information regarding the support group meetings was indicated to be via e-mail. Seventy-eight percent of respondents indicated a need

to meet informally and interact socially as part of the support group meetings. Furthermore, attendance by family or friends should be allowed occasionally.

Participants were asked to indicate which topics should be discussed during support group meetings. A summary of the topics considered to be *essential to discuss* is depicted in figure 2.
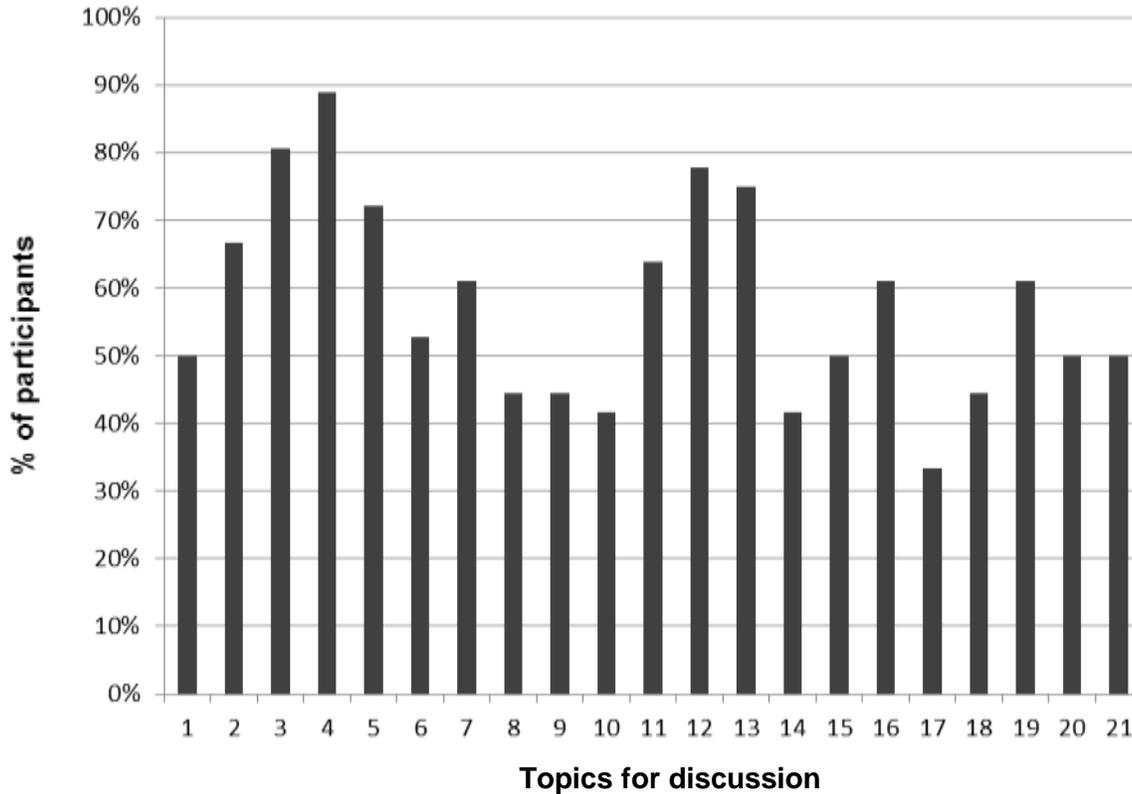
Figure 2. Topics indicated to be essential to discuss during group meetings

	Topic for discussion (n=36)
1	Components and working of cochlear implant
2	Programs available on processor
3	Assistive listening devices eg. telephone, loop systems etc.
4	New technologies
5	Recent research on cochlear implants
6	Information on a bilateral cochlear implant
7	Up-grades and trade-ins of speech processors
8	Taking care of the cochlear implant and speech processor
9	Battery life of the speech processor
10	"Life expectancy" of cochlear implants and speech processor
11	Troubleshooting a cochlear implant and speech processor
12	Medical aspects concerning cochlear implants (e.g. middle-ear infection etc)
13	Information on travelling (by airplane) and recreational issues
14	Rehabilitation options after implantation
15	Tips on improved communication
16	Tips on telephone use
17	How to educate and involve my family and friends in cochlear hearing

18	Opportunities and limitations with regard to career options
19	How to handle issues in my workplace with regards to my cochlear implant
20	My rights in the workplace (legislation/tax/etc.)
21	Training on and tips to improve assertive behavior

The majority (70% or more) of respondents indicated that topics related to *assistive listening devices*, *new technologies*, *recent research, medical aspects of cochlear implantation* and *information on travelling and recreational activities* are essential to discuss during support group meetings. More than 60% (but less than 70%) of the respondents also indicated that the *programsavailable on the speech processor, up-grades and trade-ins of speech processors, troubleshooting the device, tips on telephone use* as well as *tips on how to handle issues in my workplace with regard to CI* are essential to discuss during support group meetings.

3.2.2 Phase 2: Perceived outcomes of and requirements for support group meetings

Summary of themes

In the second phase, which served as a deepening qualitative phase, focus group discussions were conducted after four consecutive support group meetings, in order to establish the perceived outcomes of support group meetings as reported by ACIR. During the focus group discussions, participants also elaborated on the need for and specific requirements with regard to support group meetings.

Three main themes were identified to represent the aims of this study, namely the general need to belong to a support group, the specific needs and requirements of ACIR with regard to support groups and the perceived outcomes of support group meetings as reported by ACIR. A review of

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transcripts led to the identification of further topics and sub-categories under each theme. Table 7

outlines the topics and sub-categories identified, together with illustrative quotes.

Table 7: Themes and topics derived from focus group discussions (Derived from Tjornhoj-Thomsen, 2009)

Topic	Sub-categories	Illustrative quotes
Theme 1: The need for ACIR to attend support group meetings		
Personal experiences with regard to cochlear implantation.	Hearing loss being an "invisible" impairment.	1. FG1-04"When I was hearing so badly; the worst my hearing was, the harder I tried, not only to hear, but to make people aware of my hearing needs…and they are so sorry when you say that, because they don't realize you are deaf, because that is the problem with hearing impairment: it's invisible. Unless you tell them: look I can't hear", then they can't help you." 2. FG2-03 "…because hearing people who don't work with disabled people don't understand, because they can't see you are deaf… a blind person walks with a stick and they say: "ag shame", or someone in a wheelchair, but when you are deaf they don't know it, so there isn't sympathy."
	Limitations and challenges due to hearing loss.	3. FG2-03 ", I felt when I became deaf, I isolated myself, so I retired…I said it is easier for me to go to my own home than to sit in the company…I became anti-social" 4. FG1-04 "…the effort to stay abreast of a conversation situation with hearing aids, I can't describe it to you, you are so tired when you get home in the evening, you just want to sleep." 5. FG2-03 "As he says, he (FG2-02) had to work twice as hard as a normal child to fit in and to do well at school and, the children who could hear were much more advantaged…"

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6. FG1-01 …"you don't have a, a ability to really communicate …and you loose your, a little bit of self-esteem. Because you know who you are, but you are not that anymore…"

7. FG2-04   "I don't know if you also get depressed and then you feel: "oh, why am I now deaf? Why can't it now be someone else?"

Perceived benefit from cochlear implant: personally and in relationships with others.	8. FG1-02 "I did my operation in 2007, it was an amazing experience for me."

8. FG1-02 "I did my operation in 2007, it was an amazing experience for me."

9. FG1-04 "…so I went for that and it was amazing! As (FG1-03) say, it saved my life. It saved me from going absolutely "cookoo"…"

10. FG2-03 "Really gave my life back to me…If they tell me now it's a million rand, I don't know where I will get it, but it is still a bargain to be able to hear."

11. FG1-02 "For the first time in years I could hear myself and I think there is a little bit of improvement in my speech."

12. FG1-02"My work relationships are amazing now I can hear now …"

13. FG1-03 "…you can't help but feeling you're a person again, you are in society, you're not just sitting at home moping around just doing your own thing, you can go out now and see the rest of the world. To me, it's just given me more confidence so you can go meet people."

14. FG1-01 "…I don't have words to describe it…My children and grandchildren; it's amazing to see their reaction and I can only praise the Lord for me having this assistive

device."

| Need to spend time with other adults with cochlear implants by means of a support group. | Credibility of fellow ACIR in terms of understanding and sharing of experience. | 15. FG2-05 "…to share with people who basically through the same problem…be able to discuss our problems and associate with another person who had the same problem. Now we can tackle the problem…so it causes better communication, sometimes also better communication than the people who work with us."
16. FG2-03 "So I enjoy being with people who have the same problem, who understand, because hearing people who don't work with disabled people don't understand…"
17. FG2-02 "and it's interesting to talk to such people and I understand how it is for them".
18. FG2-04 ""Sorry…I've had a cochlear implant, send me a fax." And, and it's such discussions that come out here, not with normal people, because they don't think about it.
19. FG1-04 "Ja, we have a lot to share. And we can sort out some things that the Audiologist will not necessarily pick up, because we are in the same boat."
20. FG1-04 "There is a difference between what a hearing person can help you with and what a fellow implantee can help you with."
21. FG2-05 "So it causes better communication, sometimes also better communication than the people who work with us." |
| | The value of a support group in assisting prospect cochlear implant candidates or newly implanted recipients | 22. FG2-04 "Because we phoned (two previous recipients)…and it inspired me…It helped me a lot. No look, it absolutely motivated me and if there had been any doubt…for me "go |

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for it".”

23. FG1-04 “…what is important to me in a group like this is to help the new people, share our experience and perhaps to empower parents of children who have cochlear implants...So, I think that's the only thing that I would like to see into this group is people coming and trying to help them as well, you know, rather than afterwards…I do think it is important for people who had been newly implanted, to perhaps have a fellow implantee who can accompany them for part of the journey.”

24. FG1-03 “I do think sometimes that I try to help people that try to decide, well, they gonna have the operation done for the first time and they are very concerned. I think we all been through that when we had our first cochlear implants… try to bring people in that say, will have their operation in two to three months' time, to come sit here and talk to us. We can tell them our experience.”

25. FG1-01 “…so difficult for us to admit that I need aid; hearing aid. It's so difficult. So if we invite somebody, who is already suffering, but he or she does not want to admit it perhaps that would be a good thing for them to see how it is.”

26. FG1-04 “And the other thing is, a group like this can't be your only support group. You have to have friends, family…”

27. FG2-04 “…as it is I have a wonderful circle of friends who absolutely carry me through and do anything for me.”

28. FG2-03 “I now fortunately… my husband

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The importance of other support structures, namely family and friends.		supports me so much now…and such a support network is very important to one. I think it must be very lonely if you didn't have that."
		29. FG1-04 "I had a friend with a cochlear implant, she tried to socialize exclusively with hard of hearing people and cochlear implantees and then one day I said to her, "you know, if I meet someone who has got the same problem that I have and I don't have other points of communicating. If we don't share a love for music or a this or a that or the other, it's not going to be a friendship, never mind if we have the same hearing problem…we can share…but we will not necessarily become friends and it…it just has to do with being people."
		30. FG1-02 "I think I agree. You can't only be with hearing loss people, cause we are at that stage where we can communicate with "normal people" like we are, you know."

Theme 2: The specific needs and requirements of adult cochlear implant recipients with regard to support groups.

Group composition.	Inclusion of prospective adult cochlear implant candidates and newly implanted recipients.	31. FG1-04 "For some reason perhaps because we are only a group of adults. The previous support groups that we had, they tried to split into teenagers and small children and adults and it was difficult for them to cater for everybody's needs. This group is specifically for the adults, so uhm, I find that they are speaking to us at our level…"
		32. FG1-03 "I think that's a little bit that's missing at the moment, is to try to bring people in that say, will have their operation in two to three months' time, to come sit here and talk to us…"

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Attendance

33. FG2-04 "One feels so, I would now really also like to see his girlfriend or his wife or so, but you know what, it's as if they don't have the same togetherness as us. Ah, but still it would perhaps once a year want our people, or you husband, wife or children to come too…"

34. FG1-02 "I don't know how we can get more people here, maybe by word of mouth, maybe. But uhm, my experience, a lot of hard of hearing people are difficult to get together; about 99,9% of hard of hearing people will say, sorry, I can't hear well and leave it."

35. FG1-03 "What I think is that we don't know who the other people that has cochlears is…It's up to the people in the office and these people, they are the one's who can do it, not us. Or, they can give us a list of e-mails or telephone numbers and say: "right, go about". But yes, they should, if you can try to pull more of those people in, I think they will benefit out of it."

36. FG1-04 "That's where a Facebook group come in. If each of those people can, are linked up to that Facebook page, then, it's one way of befriending one another and getting to know one another."

Language preference

37. FG2-03 "…when I became deaf I found it difficult to follow English…But I often feel they must switch over (to Afrikaans) a bit and not always just…it is not so easy for everybody to hear in English…Yes one must

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		so, in such a group you can establish how many, uh say 80% is Afrikaans, present in Afrikaans."
		38. FG2-04 "One can't lip-read English."
		39. FG2-02 "because if one speaks English all the time you think you understand the story, then when they say it in Afrikaans, you see they don't mean it like that."
Topics to be covered during group meetings.	Assistive listening devices and new technology	40. FG1-04 "…suddenly there is an explosion of knowledge about assistive devices…Then you vaguely read about it on the internet; the loop systems and so on, but it's not available in South-Africa and now, all of a sudden, we have suppliers saying "I've got this, I've got this, I've got this," and I say: "I want it, I've been wanting it for years." And we now have a pool of knowledge which we can access."
		41. FG1-02 "I think it's good, cause a group like this, we hear about new technology and other stuff that can help improve our lives."
		42. FG2-03 "Because I who sit there far in the plains, it's actually far behind because like the technology that today here, I don't even know about it, so it's, now it forces me to come and it is very valuable to me, I appreciate it a lot."
Establishment of an improved hearing environment during group sessions.	Positioning	43. FG1-04 "…we don't realize how important a hearing environment is for a group like this. It's an absolute must that we must be able to see each other. I don't know how, but, most of us can't hear what the people who are sitting with their backs to us, we can't hear their questions; I can't…the lady can ask: "is there somebody who can't hear the questions and we can change positions…I went and stood in front where the speaker was so that I

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could see what people were saying. Otherwise I might lost the conversation."

44. FG2-03 ". It's just difficult when one sits like this, we must also just be able to see each other. Perhaps sit in a circle." (FG2-01;02;04;05 *Agrees*)

45. FG2-03 "Yes, it sometimes gets difficult to hear people. I always try to sit right in front so that I can hear and can see the person."

| | Assistive listening devices | 46. FG1-04 "There must be assistive…the assistive devices must start here… I think a loop set, a loop for any meeting that we have is a must." |

47. FG2-05 "…this miss now had that system that made it a bit louder, it was very nice. I found the sound very clear…something to think about…to get such a system just to follow better in general."

48. FG2-04 "Yes! Here was such a, I just call it "surround sound"…"

Speaker's speech rate

49. FG2-04 "…this one…who talked so fast. I followed her now, but I felt that she spoke too fast."

50. FG2-05 "Yes, that one went very fast, looked as if she was in a big hurry…"

The use of the internet for ongoing support and information sharing.

Positive attitudes

51. FG1-04 "…our meetings are not so often; we need an interim thing. I think we need an e-mail discussion group where people can post quick questions. Say, I've got like this wrong with my (cochlear implant), I am far from my Audiologist or whatever. You must be able to post questions; not about cookie recipes and stuff like that, but about our hearing issues…another social medium that

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we should use is Facebook… it is an advertising medium for our group…it's a way of spreading awareness about our group…I've gained immensely from being on Facebook with (name) and (name), because we often share hearing issues."

52. FG2-02 "…where I get the most, fastest information is by e-mail."

53. FG2-05 "If you use the internet, you get a lot of information there…useful, because it's things that people that have already experienced the same problem as you, so you get a lot."

Negative attitudes	54. FG1-02 "Why? I don't have time for Facebook!"...(after further explanation by FG1-04) "I've never done that."
	55. FG1-04 "So, Facebook is a more social medium, but the e-mail, uhm group, there are international groups like the "Saywha?" club, but I resigned from them, because they were becoming too big and they were actually swopping out cookie recipes, which I am not interested in. I don't want to know how to bake biscuits, I want to know about hearing issues."
	56. FG2-04 4: "I don't like facebook at all. I am there, but I don't like it at all…it doesn't have nearly the impact that a talk here has for me. Not nearly."
Liaise with an established support group in another region	57. FG1-04 "…a group like this is we, you must not function in isolation, it joins up with what we have been saying now. Uhm, my dream is that we can "lobby". There is a lot of advocacy that needs to be done…if we have a

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united voice…then we have a significant group of people pushing, because we are not deaf. I am not aligned with the deaf people in the deaf community and the signing community. I've got nothing against them, but I am not deaf and it's not my primary language."

Theme 3: The outcomes of support group meetings as perceived by adult cochlear implant recipients.

The occurrence of a positive emotional response when sharing similar situations with fellow ACIR	Mutual understanding and encouragement	58. FG1-01 "I think it's clear from the discussion: it is meaningful for us, because we feel that the other people understand and we encourage one another…"
		59. FG1-04 "I see a group like this as getting for myself but also giving out to the other guys from my experience…"
		60. FG1-02 "I would think because we do, I would recommend it, because we…have the many problems. And I think it's a good place, a safe place to see there are actually people like you…
		61. FG2-04 "And I have often thought, (a hearing aid company) is much nearer to me, but it is as if this cuddling, this love is not at (a hearing aid company)…here I feel like one of a team."
	Improvement of self-image, confidence and assertiveness	62. FG1-02 "At the beginning, there was a bit of shyness…but I think as we carried on, it did get better…as we get to know each other I am finding more freedom to share our own experiences with other people."
		63. FG1-01 "I came the first time not knowing what to expect. But I find it, you know, I find some kindness in the atmosphere…when I came today, all of a sudden spontaneously I

presented myself: "good morning to all" (laugh). I would never do that (laugh)."

64. FG1-02 "…and you can be yourself and you can improve your self image…"

Value and enjoyment

65. FG1-01 "But I must, I mean, I saw some sunshine in your eyes this morning (pointed to number 2). She was very glad to be here."

66. FG2-04 "I really enjoy the meetings a lot…then I just feel very good again…"

67. FG2-03 "So I enjoy being with people who have the same problem…I enjoy it, it is good for me…"

68. FG2-05 "…it was very interesting…I think I quite enjoy it! You know, the people are nice. It's enjoyable, it's a bit, it's actually relaxing…It is actually very pleasant here. I enjoy it very much here."

69. FG1-03 "…benefit out of it…"

70. FG2-05 "…So it's valuable to me…"

71. FG2-04 "I will really take trouble, I will put of a holiday to attend such a meeting. It is really very valuable to me."

72. FG2-03 "The caring and the trouble you take are much appreciated, because we would have been so much poorer if it didn't begin…it is very valuable to me, I appreciate it a lot…Yes, definitely worth it!"

73. FG2-04 "…it is almost a must for me…"

74. FG1-01 "O yes, of course. (By attending the groups, your support network are expanded) to a certain extent, like she said, it's not necessarily friendships, but on this level it's

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	Established network of contacts and services.	wonderful to have a support group."
		75. FG2-02 "…since coming here, I am starting to see how other people who are also hearing disabled are…"
		76. *"...these meetings have broaden you support network?"* FG2-04 "Certainly, yes…"; FG2-03 "Yes…"; FG2-02 "Yes, it did."
Empowerment as a result of information sharing	Informative	77. FG1-01 "… it is meaningful for us, because…we get information…"
		78. FG2-03 "That I would never have known if I hadn't come today…Learn, we learn from each other…"
		79. FG2-05 "…it was very interesting, today was now particularly interesting to me."
		80. FG2-04 "I find it very interesting and educational…"
	Motivational and inspirational	81. FG1-02 "I would think because we do, I would recommend it, because we can learn…and see: but he is doing this, but wow, I can do that too. And that type of thing, so I think it's very good…"
		82. FG2-04 "…and it's such discussions that come out here, not with normal people, because they don't think about it…I would never have asked someone else, so you definitely get fine detail information that doesn't appear on paper, in this group."
		83. FG1-04 "That was something I taught myself; having assertiveness, because I decided either I have somebody around all the time that can hear for me and help me to carry on or I can help find ways to help myself…it's something you have to push

yourself, it's never effortless, it's always effort…Push, push, push…."

Drive for advocacy.	84. FG1-04 "There is a lot of advocacy that needs to be done; there is a need for loop sets all over the place. There is a need for proper accommodation for hard of hearing people at airports…But if we are a group and we can light our voices…eventually we must become advocates…My primary world is a hearing world and in that, the hearing world must make some accommodations for us. If they can make ramps for wheelchairs, then they can make things for us to hear better."
	85. FG2-04 "…I would still like to do educational work. Like in schools and, you know, go to show people: this is what it looks like, it is not as bad as what you think at all… Do you know, two of the eighty women who were there new about cochlear. The others heard it there for the first time…they just don't know…I think (raising awareness) is very necessary."

3.2.2.1 Theme 1: The need for ACIR to attend support group meetings

It was clear from the results obtained in phase one of the study that ACIR experience the need to belong to a support group. The first part of the focus group discussions elaborated on the results obtained in phase one. The introductory question during the focus group discussions requested that the participants share personal experiences regarding cochlear implantation. They were also asked whether they had the need to spend time with other adults with cochlear implants in the form of group meetings. Further subcategories emerged from these two topics:

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Personal experiences with regard to cochlear implantation.

Hearing loss being an "invisible" impairment.

Hearing loss being an invisible condition appeared to be a recurring theme in both focus group discussions and it was clear that the "invisible" impairment of having a permanent hearing loss provoked strong emotions of anger and frustration in participants (table 7, quotes 1-2).

Limitations and challenges due to hearing loss.

Although information regarding the limitations and the challenges experienced as a result of a hearing impairment was not elicited by a question, participants nonetheless commented on their perceived limitations and challenges. Participants especially commented on how their communication efforts often lead to isolation and feelings of depression (table 7, quotes 3-7).

Perceived benefit from cochlear implantation: personally and in relationships with others.

The perceived benefits from cochlear implantation were discussed in terms of "personally" and "in relationships with others". When participants had to describe how they experienced life after implantation, they referred to their experience as being "life-saving" and "priceless" (table 7, quotes 9-10). Improved participation in daily life and improvement in speech production were also described (table 7, quotes 11, 13). It was indicated that relationships with others drastically changed for the better after cochlear implantation (table 7, quotes 12, 14).

Need to spend time with other adults with cochlear implants by means of a support group.

Credibility of fellow ACIR in terms of understanding and sharing experience.

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The participants clearly articulated how "having the same problem" can lead to better understanding when problems are shared amongst each other (table 7, quotes 15-18). Comments about the value of being counselled by a peer rather than being counselled by an audiologist or a person with normal hearing were also made (table 7, quotes 19-21).

The value of a support group in assisting prospective cochlear implant candidates or newly implanted recipients.

Participants from both focus groups indicated that belonging to a support group provides a golden opportunity for assisting and guiding prospective cochlear implant candidates in decision making (table 7, quotes 22 and 24). The group should also be a platform where newly implanted recipients can be assisted, supported, and guided in the process of adapting to the device by an experienced cochlear implant recipient (table 7, quotes 22-25).

The importance of other support structures, namely family and friends.

Despite the fact that a support group consisting of ACIR was reported to be of great value to all participants, group members also mentioned the importance of a support network consisting of people who do not have hearing difficulties. Support provided by both family and friends has been found to be of significant importance to cochlear implant recipients (table 7, quotes 28-30). It is possible for ACIR to communicate effectively with their normal hearing peers and family. Participants reported that this makes them feel included in the normal hearing society and that they value the fact that they are not limited to interacting exclusively with ACIR (table 7, quote 29, 30).

3.2.2.2 Theme 2: The specific needs and requirements of ACIR with regard to support groups.

The participants were invited to provide input with regard to the structure, content, set-up and vision of the current support group. After four consecutive support group meetings, the participants had the opportunity to indicate how the group meetings could be altered.

Group composition

Inclusion of prospective adult cochlear implant candidates and newly implanted recipients

The fact that the current members of the established support group were all ACIR was mentioned to be beneficial, as communication and discussion of topics took place on the participants' level of understanding (table 7, quote 31).A limitation of the group that was identified was the lack of inclusion of candidates and new recipients (table 7, quote 32).

Attendance

Participants reaffirmed the finding in phase one that family and friends should join the meetings occasionally (table 7, quote 33). In the initial phase of the study, respondents were asked to indicate how attendance of group meetings could be ensured. Only the options of a cellphone text message or e-mail were provided as preferred manners of receiving correspondence about the group meetings. During the focus group discussion, the suggestions were added to utilise Facebook (table 7, quote 36) as well as word of mouth and networking amongst each other to ensure better attendance of groups (table 7, quotes 34 and 35).

Language preference

The support group meetings were attended by both Afrikaans and English participants, but were mostly conducted in English. It was observed that most Afrikaans speaking support group participants understood English and that not all English speaking participants understood Afrikaans. In the second phase (focus groups) the participants were divided into an English group and an Afrikaans group. The Afrikaans focus group mentioned language to be an issue during the first phase, as they found it more effortful and more difficult to follow and lip read English (their second language) (table 7, quote 37-39).

Topics to be covered during group meetings.

Assistive listening devices and new technology

It was very clear, from both the research phases, that there was a need to learn more about assistive listening devices and new technology. During the discussion of the specific needs and requirements for ACIR with regard to support group meetings, the subject of assistive devices was indicated to be of great interest to the participants (table 7, quotes 40-42). This indication correlates strongly with the results obtained in phase one of the study where more than 80% of respondents indicated that they regard it as essential to discuss the topic of assistive listening devices.

Establishment of an improved hearing environment during group sessions.

Positioning

In order to ensure an optimal listening environment, participants made practical suggestions on the positioning of group members during the group meetings. It was recommended that all group

members sit in a circle in order to make visual cues available for support in following the conversation (table 7, quote 43-45).

Assistive listening devices

During one of the support group meetings, a hearing aid company demonstrated the working of an FM system by giving the ACIR the opportunity to trial the FM receiver on their speech processors. The participants reported that this contributed significantly to an improved listening environment (table 7, quotes 46-48). One participant suggested that a loop system should be used to assist listening in group meetings (table 7, quote 46).

Speaker's speech rate

The speech rate of the speaker can have an influence on how effectively a message is communicated. A few remarks were made with regard to the fast speech rate of some of the speakers who shared information during the support group meetings (table 7, quotes 49-50). The fast speech rate made it more difficult for the participants to follow what was being said.

The use of the internet for ongoing support and information sharing.

Positive attitudes

The arguments in favour of using the internet for support were the availability of posting hearing related questions and having an interim platform for support and for sharing information (table 7, quotes 51-53). The main motivation for the use of Facebook was to spread awareness of hearing loss and cochlear implants and to share hearing related matters.

Negative attitudes

Most of the negative responses pertaining to interim online support can be ascribed to the participants being unfamiliar and inexperienced with Facebook (table 7, quote 54). It was also mentioned that online support groups do not always discuss hearing related issues (table 7, quote 55) and that meeting other ACIR in person was more effective and valuable than receiving support from other ACIR online (table 7, quote 56).

Liaise with an established support group in another region

During the focus group discussions participants were reminded of the support group meeting where they were introduced via conference call to an established support group in another region. Three participants wrote down the web address of that particular support group and there seemed, therefore, to be some interest in connecting to them.One participant commented on the value of a united voice, especially for the purpose of advocacy (table 7, quote 57).

3.2.2.3 Theme 3: The outcomes of support group meetings as perceived by adult cochlear implant recipients.

A further aim of the study was to describe the perceived outcomes of support group meetings as reported by ACIR. Four topics and related sub-categories that emerged form these topics are described below, in order to discuss and analyse the relationship between patient experience and support group membership.

The occurrence of a positive emotional response when sharing similar situations with fellow ACIR

Mutual understanding and encouragement

According to the participants' responses, there are several positive emotional responses that occur when sharing similar situations. Firstly, the experience of being understood generates a feeling of belonging which can also contribute to encouragement (table 7, quotes 58-61).

Improvement of self-image, confidence and assertiveness

The perceived outcomes of support group attendance include improved self-image, confidence and assertiveness. Socialising with others in a group setting was reported to lead to improvement in the development of social skills and increased confidence (table 7, quotes 62-64).

Value and enjoyment

It was obvious that attending the support group meetings was associated with enjoyment. Statements made by various participants illustrate the pleasure and satisfaction derived from attending the support groups (table 7, quotes 65-67). Various participants of both focus groups stated that the group meetings were of great value to them and that it was much appreciated (table 7, quotes 69-73).

Established network of contacts and services

Participants were asked whether their support network had expanded since they started to attend the group meetings.The consensus seemed to be that group meetings facilitated the expansion of the participants' support network (table 7, quotes 74-76).

Empowerment as a result of information sharing

Informative

Participants gained from discussing relevant topics and from sharing information and experiences with each other. Participants recounted how they learnt from one another and how they gained useful and practical information from the suggestions given by fellow ACIR (table 7, quotes 77-80).

Motivational and inspirational

Participants reported that they were inspired and equipped by interacting with one another. They were inspired by new ideas and suggestions made by other ACIR and motivated by the successes attained by other group members (table 7, quotes 81, 82). The stories of determination and creative problem solving empowered patients with hope to overcome the challenges they face. The sharing of inspirational true life stories and battles fought gave participants practical examples and insight into the benefits of assertiveness (table 7, quote 83).

Drive for advocacy

One participant suggested that the group should become a platform for advocacy for individuals with hearing impairment (table 7, quote 84). Another participant also indicated that ACIR should be trained and encouraged to present educational talks at schools in order to raise awareness of hearing impairment and cochlear implants (table 7, quote 85).

3.3 Summary

Chapter 3 contains the results of both the questionnaire and the two focus group discussions. The results are organised, analysed and described according to the sub-aims of this study. The discussion of the results follows in chapter 4.

CHAPTER 4: DISCUSSION

4.1 Discussion

The implementation of a combined quantitative and qualitative methodology to collect information from ACIR with regard to their need to attend support group meetings provided valuable data which resulted in the establishment of group meetings for ACIR. Furthermore, data concerning the specific needs and requirements of participants with regard to support group meetings were obtained by means of the mixed methodology. This was central to the planning and execution of support group meetings. Feedback from the participants after they had attended the group meetings allowed the researchers to determine the effectiveness of the logistical arrangements and topics discussed, and to make recommendations for improving group meetings in the future. The positive feedback from participants during the qualitative research stage confirmed the prediction that ACIR will benefit from participating in support group meetings.

In order to establish whether ACIR have the need to attend group meetings, personal experiences with regard to cochlear implantation were investigated, together with how participants perceive their current support system. Participants commented on how hearing impairment is often overlooked (Stone, 1993; Mortenson, 2012, Hallberg, Ringdahl, Holmes & Carver, 2005) and how, as a result, they experience limitations and challenges, such as reduced social interaction and restriction in activities, that often lead to depression and reduced confidence (Hetu, 1996; Stone, 1993). On the other hand, participants indicated significant personal and social benefit after receiving their cochlear implants (Hallberg & Ringdahl, 2004; Hogan et al., 2002; Sanches-Cuadrado et al., 2013; Togher, Power, Rietdijk, McDonald & Tate, 2012). Another aspect observed to be contributing to their reported improved quality of life was participants' current support structures (Togher et al., 2012). Participants emphasised the value of the support they

received from their family, friends, and, to a lesser extent, also the audiologists involved. Notwithstanding the support they receive from family and friends, the participants indicated a definite need to belong to a support group and spend time with other ACIR. An important aspect that they stressed when asked to explain why they had the need to attend support group meetings was the credibility of fellow cochlear implant users in terms of understanding each other's limitations and sharing each other's experiences. Participants commented that counselling by a peer can be of more value on certain occasions, especially when providing practical tips on use of the device and communication strategies, than counselling by an audiologist (Ross, 1987). In the quantitative phase of the study, although participants indicated that "no support" was received from other ACIR (at the time of data collection), 81% of participants had the need to attend group meetings for cochlear implant recipients and 78% of the participants indicated a need to socially interact with fellow ACIR before or after group meetings. It was strongly recommended that candidates for CI should be assisted by ACIR in the process of decision making. The group meetings should also be a platform where newly implanted recipients are supported and mentored in the adaptation process by a veteran cochlear implant recipient. The support provided by experienced group members has previously been described as an essential requirement for rehabilitation programs in general (Preminger, 2007; Hawkins, 2005).

When considering the practical suggestions that were made and the valuable input that was contributed by participants after attending the group meetings, it is clear that group members should be given the opportunity to provide feedback about their group meeting experience after several sessions. Taking into account the specific needs and requirements indicated by participants, support group meetings were organised by the audiologist who served as the team coordinator for the specific cochlear implant unit. Meetings took place quarterly on Saturday

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mornings in the same building where the centre is situated. It was indicated that significant others should attend support group meetings only occasionally. Since normal hearing significant others do not share the impairment, participants were of the opinion that some of the content of the group discussions may be irrelevant to them. Since the participants' family and friends are considered to be the parties who assist the ACIR to apply communication strategies and adapt to the communication environment, however, both these individuals and the person with the cochlear implant will benefit from their occasional attendance (Heydebrand et al., 2005; Sanches-Cuadrado et al., 2013). The participants also stressed the importance of inviting and including prospective cochlear implant candidates to join the support group meetings.

The use of Facebook and e-mail to increase the awareness of the group and, in turn, ensure better attendance was also mentioned. As e-mail and internet have become popular methods of communication for peer-to-peer self-help groups (Potts, 2005; Fox & Fallows, 2003), participants suggested that contact should be established on the internet and more specifically Facebook in between consecutive group meetings. Positive and negative responses were received when participants in the focus group made this suggestion. Most of the negative responses to the suggestion of interim online support can be ascribed to the participants being unfamiliar with Facebook or, in some cases, with the internet. After it was explained how a Facebook group could be utilised, the previously reluctant participants considered investigating the possibility of interim online support. Numerous online support groups are available for cochlear implant recipients (and prospective candidates) and these groups are readily accessible, with little effort required to join (Dillenbourg & Schneider, 1995). Participants nevertheless expressed the need to discuss practical issues and topics directly related to hearing impairment, whereas many of the cyber support networks seem to be more focussed on social support.

Furthermore, the value of face to face interaction was extolled since the internet is often perceived to be rather impersonal.

With regard to the logistical arrangements during the support group meetings, participants explained the importance of positioning during information sharing and discussions. The importance of facing one another by sitting in a circle in order to ensure better visual cues was mentioned. The listening environment and the communication partner's communication strategies can make a significant difference to what the individual with a cochlear implant perceives through the sense of hearing (Heydebrand et al., 2005). For an optimal listening environment, participants suggested the use of assistive listening devices such as loop systems or FM systems during group meetings, since these devices ensure an improved auditory signal. The speech rate of the speaker is also an important factor to consider, as participants reported that a speaker with a rapid speech rate is difficult to understand.

The topics that were indicated as essential to discuss during the support group meetings were used as a guideline for planning the content of the meetings. There is an evident need to learn and share experiences about assistive listening devices and new technology. The participants who attended the four group meetings also mentioned the value of discussing the topic of assistive devices during the support group meetings.

All participants who attended the group meetings reported positive outcomes. Several possible factors that may have contributed to these positive outcomes were indicated. The emotional responses to sharing similar situations and experiences with fellow ACIR were clearly positive. The support group meetings were also described as a setting in which ACIR were understood, where experiences were validated and help was offered and received (Togher et al., 2012). It

was evident that the group meetings facilitated increased confidence and self-image, as well as the feeling of belonging (Hetu, 1996; Hogan et al., 2002; Docherty, 2004). Participants expressed feelings of enjoyment and satisfaction in attending support group meetings. The input of other ACIR when sharing their experiences can be of great value to educate, encourage, and establish confidence, emotional balance and competence in fellow ACIR. This, in turn, results in the ability to rise above stigmatisation, restructure one's environment and change the communication style of communication partners (Heydebrand et al., 2005; Binzer, 2002). Thus, support group meetings were perceived to be ideal to facilitate the development of insight and self-confidence. The group meetings are perceived to be not only informative, but also motivational, because group members realise that they are "not alone" and they are inspired and equipped by interacting with one another. During the support group meetings as well as the focus group discussions, shared humour and a sense of understanding was noticeable. The benefits of attending group meetings are therefore recognised, not only on account of the specific content of the lessons, but for the many unspoken factors intrinsic to the group experience (Ross, 1987).

As hearing impairment is an invisible condition and society in general is unaware of the associated challenges and difficulties, a great need for advocacy exists among ACIR specifically. Recipients emphasised the matter of raised awareness to ensure that the hearing impaired population is accommodated in the "hearing world". A participant highlighted the fact that if a group pursues the same ideals, chances are better that those goals will be achieved, because a group will have more impact than an individual. The suggestion was made of presenting educational talks and awareness campaigns planned by and organised by the support group. It

was said that the equivalent of *Deaf Pride* in the Deaf Community can be created when persons with hearing loss belong to support groups (Hogan 2001).

When considering the beneficial outcomes of group meeting attendance reported by the participants, the relationship between group attendance and positive experience is evident. Outcomes such as positive emotional responses, valuable education, increased assertiveness and drive for advocacy indicate the significance of support group attendance by ACIR. The needs analysis which determined the specific needs and requirements of participants regarding logistical arrangements and topics to be discussed was a crucial prerequisite for establishing effective group meetings. Without the use of a qualitative approach entailing focus group discussions, however, the opportunity to confirm and refine the efficacy of the support group meetings for future meetings would have been missed.

4.2 Summary

This chapter is a discussion of the results, as well as the chosen research design through which the results were obtained. In chapter five, conclusions drawn from the results and discussion of the results are depicted. The closing chapter (Chapter 5) ends with a discussion on clinical implications, limitations of the study and recommendations for future research.

CHAPTER 5: CONCLUSIONS, CLINICAL IMPLICATIONS AND RECOMMENDATIONS

5.1 Conclusions

The establishment of much needed support group meetings benefited ACIR to a great extent and ACIR reported positive outcomes as a result of their group meeting attendance.

During support group meetings, members shared relevant information, related personal experiences, offered understanding and empathy and shared solutions to common difficulties with one another. Furthermore, psychosocial and emotional support was provided and acceptance was facilitated through support and understanding. Attendance of the group meetings also positively influenced ACIR quality of life in terms of the reported improvement in self-image, confidence and assertiveness. The major perceived benefits of group meeting in this study were positive emotional responses that occur when sharing similar situations with others; established network of contacts and available services; education received when interacting with others and sharing information; development and improvement of social skills and confidence when socialising with others in a group setting.

Close relationships developed between group members and hope was engendered when members exchanged information and shared their views. It can be confirmed that support group meetings for ACIR are effective in improving assertiveness and confidence, as well as reducing social withdrawal associated with hearing loss, which leads in turn to improvement in self-image and self-perceived quality of life. The opportunity for group members to offer and receive support also led to a greater sense of personal investment among group members and created a sense of empowerment.

In conclusion, there is an evident need for ACIR to attend support group meetings. The outcomes of support group meetings which are perceived to be beneficial and positive, motivate for the implementation of group meetings for ACIR.

5.2 Implications for research and clinical practice

Information regarding the need to attend support group meetings as well as the specific requirements for the logistics and content of the support group meetings were obtained by using a mixed methodology approach. The use of qualitative methodology in the second phase of the study allowed the researchers to evaluate the efficacy of support group meetings and demonstrate the positive outcomes to be derived from group attendance, through the exploration of personal experiences and feelings rather than through quantitative outcome measures (Togher et al., 2012). This was valuable for the purposes of understanding the participants' experiences of the support group meetings (Togher et al., 2012). The qualitative data furthermore identified facets of the support group meetings which participants found to be important and those that could be improved. This valuable information about participants' experiences would have been lost without using a qualitative approach in combination with the quantitative approach in phase one of the research.

The establishment of support group meetings is an integral part of intervention services and contributes to holistic service delivery for ACIR. The benefits of having a support network as part of the rehabilitation process cannot be omitted or neglected and should be considered a necessity in any cochlear implant program's rehabilitation services. It is recommended that a needs analysis be done with regard to specific logistical needs and requirements prior to the establishment of support group meetings. The questionnaire used in phase one of this study could be used to conduct this needs analysis of topics to be covered, as well as logistical

arrangements for future support groups. After attending a number of support group meetings, feedback should be obtained to suggest improvements and to guide modifications for future support group meetings. This procedure will allow clinicians to ensure patient-centred practice.

With regard to support structures, clinicians involved with ACIR should constantly be aware that the involvement of the ACIR's family and friends is crucial. Counselling prior to and post implantation should include the significant others in order to make them aware of their critical contribution to outcomes after cochlear implantation. The clinician should also empower and equip the ACIR' family to provide ongoing support.

Clinicians involved with ACIR should refer all ACIR and prospective cochlear implant candidates to existing support groups. In addition to discussing expectations and the importance of support from significant others with cochlear implant candidates, clinicians must emphasise the importance of support from fellow ACIR. Candidates should be encouraged to join an established support group and if possible a veteran ACIR should be appointed to mentor prospective ACIR. More information on assistive technology should also be included during routine clinical sessions with ACIR pre- and post-implantation.

The establishment of group meetings for parents of children with cochlear implants should also be considered, since this will provide a setting where parents will be understood and where help could be offered and received. A similar research design could be employed to investigate the need and perceived outcomes of a support group for parents of children with cochlear implants. The need for and perceived outcomes of support group meetings for teenagers with cochlear implants should also be investigated.

5.3 Limitations of the study

The data represent information from a relatively small group of participants and therefore the results cannot be generalised to the larger population of ACIR. The data that were collected to determine participants' perceived outcomes of the support group meetings represented participants' experiences. This qualitative data derived from the information that participants provided was likely to have been affected by intrinsic factors such as their ability to recall their experiences from the support group meetings and their mood at the time. The participants were acquainted with the researcher and their possible desire to please the researcher by reporting positive outcomes (Togher et al., 2012) could also have affected the information given. An independent researcher could have conducted the focus group discussions in order to minimise bias and interpret participants' experiences with greater depth.

Another limitation of the research is the lack of focus on and elaboration of the use of the internet to provide on-going support and raise awareness of support group meetings. The effectiveness of the use of the internet, especially Facebook, is relevant and this platform must be explored and investigated in greater depth in future research (Potts, 2005; Fox & Fallows, 2003; Horrigan, 2001; Dillenbourg & Schneider, 1995).

5.4 Recommendations for further research

It can be suggested that a bigger representative sample of participants be included in further research, enabling researchers to investigate the impact of various external factors such as age of implantation, unilateral versus bilateral implantation, private versus public health sector, culture and socio-economic status on the need for and perceived outcomes of group meetings for ACIR.

Limited studies focusing on parents of children with cochlear implants and the children with cochlear implants' need for and perceived outcomes of support group meetings have been conducted.

Further research could investigate the current role and the effectiveness of online support groups for ACIR and parents of children with CI. The accuracy of information given on the internet, as well as the need for and perceived outcomes of online support- and information sharing forums should be investigated.

5.5 Summary

It is clear that an evident need for ACIR to attend support group meetings exists. The establishment of much needed support group meetings benefited ACIR to a great extent and ACIR reported positive outcomes as a result of their group meeting attendance. The outcomes of groups meetings which are perceived to be beneficial and positive, motivate for the implementation of group meetings for ACIR. It is clear that what Ross so wisely stated in 1987, still holds true:

"Support groups are a development that should be encouraged, fostered and cooperated with to the fullest extent possible", (Ross, M., 1987:20).

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Appendix A1: Consent to conduct research: UP CIU.

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Denkleiers • Leading Minds • Dikgopolo tša Dihlalefi

Fakulteit Geesteswetenskappe
Departement Kommunikasiepatologie

Professor J Swart

Hoof: Pretoria Kogleêre Inplantingsprogram

Departement Kommunikasiepatologie

Universiteit van Pretoria

Augustus 2010

Geagte Prof Swart,

VERSOEK VIR DIE GEBRUIK VAN INLIGTING VAN VOLWASSENES MET KOGLEêRE INPLANTINGS VIR NAVORSINGS PROJEK:

"SUPPORT GROUPS FOR ADULT COCHLEAR IMPLANT USERS: NEEDS AND PERCEIVED OUTCOMES."

Ek is tans 'n meestersgraad student by die Departement Kommunikasiepatologie, Universiteit van Pretoria. Ek beoog om 'n navorsingsprojek uit te voer ter voltooiing van my nagraadse studies. My studie gaan uit twee fases bestaan. Die doel van die eerste fase (data-insameling by wyse van 'n vraelys) van my studie is om die spesifieke behoeftes van volwasse kogleêre inplanting gebruikers te bepaal met betrekking tot ondersteuningsgroepe. Gevolglik sal daar dan vanuit hierdie behoeftebepaling riglyne saamgestel word om so 'n groep(e) te begin. Na 'n tydperk van ongeveer 6 maande waar die groep(e) gereel bymekaar gaan kom, sal die tweede fase van die studie uitgevoer word (data-insameling by wyse van fokus-groep besprekings) om dan die waarde en die sukses van die groepe te bepaal.

Die studie sal fokus op volwassenes wat geïmplanteer is by die Pretoria Kogleêre Inplantingsprogram (PKIP), tussen die ouderdom van 18 en 59 jaar. Deelname aan die studie is vrywillig en deelnemers mag ten alle tye onttrek van die studie sonder enige negatiewe gevolge. Alle inligting wat verkry word, sal vertroulik hanteer word.

Inligting wat verkry word met die studie sal waardevol aangewend kan word om riglyne neer te lê vir die koördinering en bestuur van ondersteuningsgroepe vir volwasse kogleêre inplanting gebruikers. Resultate sal beskikbaar gestel word aan die Pretoria Kogleêre Inplantingsprogram (PKIP) wat ook tot gevolg sal hê dat volwassenes in die PKIP aangemoedig word om in te skakel by 'n ondersteuningsgroep om sodoende 'n meer holistiese benadering tot ouditiewe rehabilitasie te bied.

Ten einde hierdie studie uit te voer wil ek graag gebruik maak van die kontakbesonderhede en biografiese inligting van volwassenes in die PKIP. Indien u toestemming gee dat ek die inligting kan gebruik, word u gevra om hierdie toestemmingsbrief te ondertekenteken.

U is welkom om my te kontak vir enige verdere navrae.

Ek hoop dat u my versoek gunstig sal oorweeg.

Vriendelike groete,

_____

Susan Loots

Navorser (074 181 7472)

_____

Me Talita van der Spuy

Studieleier

_____

Dr Maggie Soer

Waarnemende Hoof: DEPT KOMMUNIKASIEPATOLOGIE

TOESTEMMING VIR DIE GEBRUIK VAN INLIGTING VAN DIE

PRETORIA KOGLEêRE INPLANTINGSPROGRAM:

Hiermee gee ek, **Prof. J. Swart** toestemming dat inligting van pasiënte van die Pretoria Kogleêre Inplantingsprogram gebruik kan word vir die navorsingsprojek:

"SUPPORT GROUPS FOR ADULT COCHLEAR IMPLANT USERS: NEEDS AND PERCEIVED OUTCOMES."

Toestemming: _____
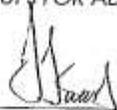
(Prof. J. Swart)

Datum: _____ 15 - 9 - 2010 _____

Appendix A2: Consent to conduct research: Ethical Research Committee of the

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Department Communication Pathology

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Office of the Deputy Dean

1 March 2011

Dear Ms van der Spuy

Project:	**Support groups for adult cochlear implant users: needs and perceptions outcomes**
Researcher:	**S Loots**
Supervisor:	**Ms van der Spuy**
Department:	**Communication Pathology**
Reference number:	**26014981**

I am pleased to be able to tell you that the above application was **approved** by the **Postgraduate Committee** on 15 February 2011 and by the **Research Ethics Committee** on 24 February 2011. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

0Prof John Sharp
Chair: Postgraduate Committee &
Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: john.sharp@up.ac.za

Appendix B: Cover letter and informed consent: Phase one (Questionnaire)

UNIVERSITEIT VAN PRETORIA
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Faculty of Humanities
Department of Communication Pathology

October 2010

Dear participant,

INFORMATION REGARDING RESEARCH PROJECT

I am a Master's degree student enrolled for the degree M.Communication Pathology at the Department of Communication Pathology, at the University of Pretoria. I have to conduct a research project and write a research dissertation on it in fulfilment of my postgraduate degree. The title of my research study is: *Support groups for adult cochlear implant users: needs and perceived outcomes.* Your participation in this study will be greatly appreciated.

Purpose of this study:

The purpose of this study is to determine the need for and perceived outcomes of cochlear implant member meetings for adult cochlear implant users. The study will therefore aim to determine whether there is a need for member meetings and describe the specific needs and requirements of adult cochlear implant users with regard to member meetings. Should the participants indicate a need to attend member meetings, such meetings will be organized and several sessions will be conducted. The structure and content of these meetings will be guided according to the specific requirements as indicated by the participants. After several meetings have been held, the study will aim to describe the actual outcomes of member meetings as perceived by adult cochlear implant users.

Procedure:

Participation in the initial phase of the study only requires that a questionnaire should be completed and returned to the researcher within a week. Informed consent is given by completing and returning the questionnaire and attached informed consent form.

Risks and possible discomforts:

There are no risks involved by participating in this study, although you will have to spend about 20 minutes to complete the questionnaire. This research project entails no financial implications or any other discomforts for you as participant.

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Value of the study:

As there are currently no organized member meetings for adult cochlear implant users of the Pretoria Cochlear Implant Programme, I hope to determine whether adult cochlear implant users have the need to attend such meetings. If a need is indicated, member meetings can be organized which will provide adult cochlear implant users of PCIP with the opportunity to meet other adult cochlear implant users. This will facilitate the exchange of information in a safe environment as well as the empowerment of participants to become advocates and contribute to the community of adult cochlear implant users through social networking and the discussion of relevant topics. Member meetings can further contribute to a joint effort of finding solutions to everyday problems that adult cochlear implant user's experience.

By determining the perceived outcomes of the member meetings, the importance of such meetings can be motivated, which in turn, will ensure a more sustainable program and the provision of crucial peer support and networking.

Participant's rights:

Participation in the study is entirely voluntary and participants maintain the right to withdraw from the study at any stage without negative consequences.

Confidentiality:

All the results obtained from the questionnaires will be treated as strictly confidential. The results may be represented anonymously in a complete discussion of the findings of the research project. The data will be stored for 15 years for archiving and research purposes, where after it will be destroyed.

If you have any queries or concerns, please feel free to contact me (Susan Loots: 0741817472) or my research supervisor (Talita van der Spuy: 012 4202815).

Thank you in advance for your co-operation and time.

Kind regards,

_____

Susan loots

Researcher

_____

Talita van der Spuy

Supervisor

_____

Dr. Maggi Soer

Acting Head of Department: Department Communication Pathology

INFORMED CONSENT

Title of research:

Support groups for adult cochlear implant users: needs and perceived outcomes.

Researcher:

Susan Loots

Study leader:

Me Talita van der Spuy

I understand what this study is all about, how it is going to be conducted as well as what is expected of me. I understand that the information which I supply will be treated as strictly confidential and that I have the right to withdraw at any time during the study, with no negative consequences.

I understand that Prof. Swart as head of Pretoria Cochlear Implant Programme has given his permission to conduct the study. I also understand that the information which I will provide by completing the questionnaire will be used anonymously for research purposes.

Herewith I give consent that the information I'm going to provide can be used for these research purposes.

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_____   _____

Participant   **Date**

_____

Susan Loots

Researcher

_____

Me Talita van der Spuy

Study leader

Appendix C: Questionnaire

INSTRUCTIONS:

Please read through all the questions carefully.

The questionnaire is divided into 3 sections:

Section A – Background Information

Section B – Logistics surrounding support groups

Section C – Topics to be covered during support group meetings

Please answer ALL the questions by marking the appropriate block or supplying a short answer. Please note that by completing and returning the questionnaire, you give consent that the information you are going to provide can be used for research purposes and you agree to understand:

- What this study is all about, how it is going to be conducted as well as what is expected of you.

- That the information which you supply will be treated as strictly confidential.

- That you have the right to withdraw at any time during the study, with no negative consequences.

- That Professor J.G. Swart, Head of Pretoria Cochlear Implant Programme, has given his consent that the research may be conducted.

Section A – Background information

Age:	

Gender:	Male	Female

Language preference:	

Highest level of education:	

Year in which you received your cochlear implant:	

Marital status:	Single	Engaged	Married

Number and ages of children:	

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Please rate the perceived benefit from your cochlear implant on the following scale:

Scale: 1 = a great deal of benefit, to 5 = no benefit

1	2	3	4	5

Do you currently belong to a support group for cochlear implant users?

Yes	No

If yes, please specify the platform, e.g. online support groups, facebook groups, societies, etc:

How do you experience the availability of social support in the following? (Please rate the availability of the support according to the scale provided)

Scale: 1 = no support, to 5 = adequate support

Family member(s)

1	2	3	4	5

Close friend(s)

1	2	3	4	5

Audiologist(s)

1	2	3	4	5

Other cochlear implant users

1	2	3	4	5

Other (please specify)

1	2	3	4	5

Do you have the need to attend a support group for cochlear implant users?

Yes	No

Section B – Logistics surrounding support groups

With regards to support group logistics, please indicate your preference concerning the following:
(Please tick the option you prefer)

Meeting frequency:

Less frequent meetings which are more lengthy	More frequent meetings which are less lengthy

Group size:

Small group, e.g. less than 10 members	Large group, e.g. more than 10 members

Time of week:

Weekdays	Weekends

Time of day:

Morning	Afternoon	Evening

Venue:

Set venue	Alternating venues

Correspondence:

SMS	e-mail

Duration of meeting:

Less than 45 minutes	45 – 90 minutes

Involvement of significant others:

Yes	No

Structure of meetings:

Informal discussions	Formal predetermined topics	Combination

Importance of opportunities to interact socially outside of organized sessions:

Need to meet other cochlear implant users and form new friendships	No need to meet other cochlear implant users and form new friendships

Section C – Topics to be covered during support groups

Please rate, on a scale ranging from 1 to 5, the importance of discussing the following topics during support group meetings: (Scale: 1 = not important, 5 = very important)

How to educate and involve my family and friends in communication	1	2	3	4	5
Tips on and training of communication strategies and/or communication repair strategies	1	2	3	4	5
Training to improve auditory ability	1	2	3	4	5
Training on and tips to improve assertiveness	1	2	3	4	5
Information on telephone use	1	2	3	4	5
Developing skills for advocacy	1	2	3	4	5
Technology of cochlear implants OR Information on what your cochlear implant is made of and exactly how it works	1	2	3	4	5
Discussion and explanation of program options on cochlear implants (adro/whisper/etc.)	1	2	3	4	5
Hearing aid technology with cochlear implants	1	2	3	4	5
Bilateral vs. unilateral cochlear implants	1	2	3	4	5
Compatibility of my implant(s) with mobile phones, iPods, etc.	1	2	3	4	5
Troubleshooting my cochlear implant	1	2	3	4	5
Battery life and associated issues	1	2	3	4	5
How to go about fulfilling my educational needs	1	2	3	4	5
Opportunities and limitations with regard to career options	1	2	3	4	5
Adjustment in the workplace					
My rights in the workplace (legislation/tax/etc.)	1	2	3	4	5
Administrative guidance concerning disability grants, etc.	1	2	3	4	5
Concerns regarding travelling issues e.g. should devices be turned off during air travel/warranty/guarantee/etc.	1	2	3	4	5
Information and practical demonstrations of assistive devices	1	2	3	4	5
Rehabilitation options after implantation	1	2	3	4	5
New developments in cochlear implant technology	1	2	3	4	5
Medical aspects concerning cochlear implants, e.g. infections possibly influencing the function of cochlear implants, etc.	1	2	3	4	5

Discussion of results of studies conducted in the field of cochlear implants	1	2	3	4	5
Disposal of old batteries and other equipment	1	2	3	4	5
Options for used implants in case of upgrade or death	1	2	3	4	5
Time cochlear implant can be expected to be in working order	1	2	3	4	5

Please check that you have answered **ALL** the questions.

Thank you for completing the questionnaire. Your co-operation is appreciated and your responses are valuable to us.

Group meetings for adult cochlear implant users: Needs and perceived outcomes

Dankie vir u deelame aan hierdie studie waaroor ons reeds gesels het. Hier volg die vraelys wat 'n belangrike deel uitmaak van die studie.

Deurdat u die vraelys voltooi en terugstuur, gee u skriftelike toestemming om deel te neem aan die studie.

INSTRUKSIES:

Lees asseblief alle vrae aandagtig voordat u antwoorde verstrek.

Die vraelys bestaan uit 3 dele:

- Afdeling A: Agtergrondinligting

- Afdeling B: Reëlings vir groepbyeenkomste

- Afdeling C: Onderwerpe vir bespreking by groepbyeenkomste

Antwoord asseblief ALLE vrae deur die toepaslike blokkie te merk of 'n kort antwoord te verskaf. Nadat u dit voltooi het, moet dit asb terug gefaks word na: 0123441245.

Let asseblief daarop dat, deur die vraelys te voltooi en terug te stuur, u toestemming gee dat die inligting wat verskaf word vir navorsingsdoeleindes gebruik mag word en dat u die volgende verstaan en bevestig:

- Dat u breedvoerig ingelig is oor die aard en uitvoering van die studie en wat van u verwag word;

- Dat die inligting wat deur u verskaf word as streng vertroulik hanteer sal word;

- Dat u die reg het om, sonder negatiewe gevolge, enige tyd van die studie te onttrek; en

- Dat Professor J.G. Swart, Hoof van Pretoria Kogleêre Inplantingsprogram (PKIP), toestemming gegee het dat die navorsing uitgevoer mag word.

Afdeling A – Agtergrondinligting

A:1 Geboortedatum:

d	d	m	m	j	j

A:2 Geslag:

Manlik	Vroulik

A:3 Beroep:

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A:4 Datum van inplantering(s)

Eerste inplanting	J	J	J	J
Tweede inplanting (indien toepaslik)	J	J	J	J

A:5 Huwelikstatus:

Enkellopend	Verloof	Getroud	Geskei	Weduwee	In 'n verhouding

A:6 In u ervaring, dui aan tot watter mate u kogleêre inplanting vir u voordelig is:

Tot groot voordeel	Sommige voordele	Geen voordele

A:7 Woon u tans groepbyeenkomste vir volwassenes met kogleêre inplantings by?

Ja	Nee

A:8 Indien ja, dui asseblief die tipe groepbyeenkoms aan:

Nie van toepassing	Ondersteuningsgroep	Ondersteuningsgroep op die internet	Facebook

Ander (noem asb):
_____

A:9 Ontvang u ondersteuning van die volgende individue?

Dui asseblief aan of u a) genoegsame ondersteuning, b) min ondersteuning of c) geen ondersteunig, ontvang.

Familielid (lede)	Genoegsame ondersteuning	Min ondersteuning	Geen ondersteuning
Goeie vriend(e)	Genoegsame ondersteuning	Min ondersteuning	Geen ondersteuning
Oudioloog	Genoegsame ondersteuning	Min ondersteuning	Geen ondersteuning
Ander kogleêre inplantingsgebruiker(s)	Genoegsame ondersteuning	Min ondersteuning	Geen ondersteuning
Ander (dui asb aan) ………………………………..	Genoegsame ondersteuning	Min ondersteuning	Geen ondersteuning

A:10 Sal u belangstel om groepbyeenkomste vir volwassenes met kogleêre inplantings by te woon?

Ja	Nee

Afdeling B: Reëlings vir groepbyeenkomste

Antwoord asseblief elke vraag wat sal bydra tot die beplanning van die groepbyeenkomste. By elke vraag, kies asseblief slegs **EEN** opsie.

B:1 Hoe gereeld moet die groep bymekaar kom?

Weekliks	Maandeliks	Kwartaaliks	Halfjaarliks	Jaarliks

B:2 Watter tyd van die week sal u verkies vir groepbyeenkomste:

Maandag	Dinsdag	Woensdag	Donderdag	Vrydag	Saterdag	Sondag	Enige dag

 B:3 Watter tyd van die dag sal u vir groepbyeenkomste verkies:

Oggend	Middag	Aand

B:4 Het u 'n voorkeur vir 'n spesifieke lokaal vir groepbyeenkomste?

Universiteit van Pretoria	Plaaslike Restaurant	Privaat woning.	Lesingssaal (wat nie by Universiteit van Pretoria is nie)

Ander (noem asb):_____

B:5 Op watter wyse sal u inligting, aangaande groepbyeenkomste, wil ontvang:

Per SMS	E-pos

B:6 Sal u verlang dat familie en vriende groepbyeenkomste bywoon?

Ja	Nee	Somtyds

B:7 Sal u voor of na die groepbyeenkoms informeel- en sosiaal met ander groepslede wil verkeer?

Ja	Nee

B:8 Dink u dat Pretoria Kogleêre Inplantingsprogram (PKIP) verantwoordelik moet wees vir die fasilitering van groepbyeenkomste?

Ja	Nee

B:9 Indien **nee**, wie sou volgens u mening verantwoordelik behoort te wees om die groepbyeenkomste te fasiliteer:

_____

Afdeling C – Onderwerpe vir bespreking by groepbyeenkomste

Dui asseblief aan, by elke onderwerp wat gelys is, of u sou verkies dat die onderwerp tydens die groepbyeenkomste bespreek word (belangrik om te bespreek) OF as u nie omgee as dit 'n punt van bespreking is nie (interessant, maar nie belangrik nie) OF as dit glad nie belangrik is om te bespreek nie (nie nodig vir bespreking nie).

	Onderwerp vir bespreking	Belangrik om te bespreek	Interessant, maar nie belangrik nie	Nie nodig vir bespreking nie
C:1	Inligting oor my kogleêre inplanting: waaruit die inplanting bestaan en presies hoe dit werk.			
C:2	Bespreking en verduideliking oor die verskeidenheid programme en opsies wat beskikbaar is op my spraakprosesseerder (Geraasprogram; fokus program; musiek program ens.)			
C:3	Inligting en praktiese demonstrasies van telefone, ipods en ander produkte wat saam met			

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		Belangrik om te bespreek	Interessant, maar nie belangrik nie	Nie nodig vir bespreking nie
	my kogleêre inplanting gebruik kan word.			
C:4	Nuwe ontwikkelinge in die tegnologie van kogleêre inplantings.			
	Onderwerp vir bespreking	**Belangrik om te bespreek**	**Interessant, maar nie belangrik nie**	**Nie nodig vir bespreking nie**
C:5	Bespreking van onlangse navorsing wat gedoen is oor kogleêre inplantings.			
C:6	Inligting oor 'n bilaterale (tweede) kogleêre inplanting.			
C:7	Opgradering en inruiling van spraakprosesseerders.			
C:8	Hoe om vir my kogleêre inplanting en spraakprosesseerder te sorg.			
C:9	Verwagte battery "lewe" van die spraakprosesseerder en verwante probleme.			
C:10	"Lewensverwagting" van kogleêre inplantings en spraakprosesseerders.			
C:11	Hoe om die probleem op te spoor in my kogleêre inplanting en spraakprosesseerder.			
C:12	Mediese aspekte met betrekking tot kogleêre inplantings. (bv. middeloor infeksie ens.)			
C:13	Inligting aangaande moontlike probleme in verband met reis (per vliegtuig) of rekreasie (sport) wat ek as gebruiker mag ondervind.			
C:14	Opsies vir rehabilitasie (ouditiewe opleiding en spraakterapie) na inplantering.			
C:15	Riglyne om kommunikasie te verbeter.			
C:16	Riglyne oor hoe om die telefoon te gebruik.			
C:17	Hoe om my vriende en familie in te lig en betrokke te kry by verbeterde kommunikasie na afloop van die inplantering.			
C:18	Geleenthede en beperkings wat beroepsopsies aanbetref.			
C:19	Hoe om hindernisse, wat te doen het met my kogleêre inplanting, in my werksomgewing te hanteer.			
C:19	My regte in die werksomgewing (wet/belasting/ens.)			
C:20	Opleiding en riglyne om meer selfgeldend te wees.			

Indien u aan enige ander onderwerpe kan dink wat u dink in groepbesprekings aandag behoort tegeniet,lysditasseblief:

_____

_____

_____

U word vriendelik uitgenooi na 'n informele samekoms van volwassenes met kogleêre inplantings van die Pretoria Kogleêre Inplantingsprogram saam met 'n algemene inligtingsessie. Gedurende hierdie byeenkoms sal daar ook terugvoer gegee word oor die vraelyste wat voltooi is. Die byeenkoms vind plaas Saterdag, 11 Junie 2011 van 10h00 tot 12h00 by die Departement Kommunikasiepatologie, by die Universiteit van Pretoria (waar die Pretoria Kogleêre Inplantingsprogram geleë is).

Dui asb aan of u die byeenkoms op 11 Junie 2011 gaan bywoon:

Ek sal dit graag bywoon	Ek sal dit nie kan bywoon nie

Maak asseblief seker dat u **ALLE** vrae beantwoord het.

Dankie dat u die vraelys voltooi het. U samewerking word opreg waardeer en u insette is baie waardevol vir ons.

Appendix D: Focus group guide

Question Type	Goal	Description	Question in focus group guide
Opening question	Participants get to know each other.	Each member will be provided with the opportunity to answer the question. The question will be asked in order to establish a feeling of trust and identification between members.	**What is your name and where are you from?**
Introductory question	Initiate discussion of topic.	Introduction of the general topic. Participants get the opportunity to reflect on personal experiences with regard to the topic.	**Why did you get a cochlear implant?**
Transitional question	Transition from the introductory question to the key questions.	Participants gain insight in terms of other participants' opinions and views of set topic. This question connects the participant to the topic of discussion.	**How do you experience life after your cochlear implant?**
Key question	Gain insight in areas of concern for this specific study.	This category usually consists of two to five questions. Sufficient time should be allowed for the discussion of these questions.	• **Do you have the need to spend time with other people who have cochlear implants?** • **How did you experience the previous group meetings?** • **Did your support network expand after you attended the group meetings?** • **Do you think that it is important for people with**

			cochlear implants to meet and spend time with each other? • **Do you have any suggestions on how the group can be changed?**
Concluding question	Assist the researcher to summarize the discussion and end off session.	Each participant gets the opportunity to reflect on the discussion and identify the most important aspects. This will allow the participants to share their final opinion with regard to the topic of discussion.	**Would you encourage other adults with CIs to attend the group?**

Depicted from Morgan & Kruger (1998) in van der Spuy (2005)

Appendix E: Cover letter and informed consent: Phase two (Focus group)

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

Department of Communication Pathology

Dear Participant,

INFORMATION REGARDING RESEARCH PROJECT

I am a Master's degree student enrolled for the degree M.Communication Pathology at the Department of Communication Pathology, at the University of Pretoria. I have to conduct a research project and write a research dissertation on it in fulfillment of my postgraduate degree. The title of my research study is: *Support groups for adult cochlear implant users: needs and perceived outcomes.* Your participation in this study will be greatly appreciated.

Purpose of this study:

The purpose of this study is to determine the need for and perceived outcomes of cochlear implant member meetings for adult cochlear implant users. The study will therefore aim to determine whether there is a need for member meetings and describe the specific needs and requirements of adult cochlear implant users with regard to member meetings. Should the participants indicate a need to attend member meetings, such meetings will be organized and several sessions will be conducted. The structure and content of these meetings will be guided according to the specific requirements as indicated by the participants. After several meetings have been held, the study will aim to describe the actual outcomes of member meetings as perceived by adult cochlear implant users.

Procedure:

Participation in the second phase of the study only requires that a focus group session should be attended by selected participants who attended the member meetings. The focus group will be held on 28 January 2012 at 12h00. Informed consent is given by completing and returning the form attached at the bottom of this letter.

Risks and possible discomforts:

There are no risks involved by participating in this study, although you will have to spend about 90 minutes to participate in a focus group session. This research project entails no financial implications or any other discomforts for you as participant.

Value of the study:

As a need for member meetings was indicated by adult cochlear implant users of PCIP, such meetings were organized. The member meetings that were conducted provided members with the opportunity to meet other adult cochlear implant users. This hopefully facilitated the empowerment of participants to become advocates and contribute to the community of adult cochlear implant users through social networking and the exchange of information. However, it is imperative to determine the outcomes of these member meetings as perceived by the participants themselves. By determining the perceived outcomes of the member meetings, the importance of such meetings can be motivated, which in turn, will ensure a more sustainable program and the provision of crucial peer support and networking.

Participant's rights:

Participation in the study is entirely voluntary and participants maintain the right to withdraw from the study at any stage without negative consequences.

Confidentiality:

All the results obtained from the focus group discussion will be treated as strictly confidential. The results may be represented anonymously in a complete discussion of the findings of the research project. The data will be stored for 15 years for archiving and research purposes, where after it will be destroyed.

If you have any queries or concerns, please feel free to contact me (Susan Loots: 0741817472) or my research supervisor (Talita van der Spuy: 012 4202815).

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Thank you in advance for your co-operation and time.

Kind regards,

_____

Susan loots

Researcher

_____

Talita van der Spuy

Supervisor

_____

Dr. Maggi Soer

Acting Head of Department: Department Communication Pathology

<u>INFORMED CONSENT</u>

Title of research:

Support groups for adult cochlear implant users: needs and perceived outcomes.

Researcher:

Susan Loots

Study leader:

Me Talita van der Spuy

_____

I understand what this study is all about, how it is going to be conducted as well as what is expected of me. I understand that the information which I supply will be treated as strictly confidential and that I have the right to withdraw at any time during the study, with no negative consequences.

I understand that Prof. Swart as head of Pretoria Cochlear Implant Programme has given his permission to conduct the focus group sessions. I also understand that the information which I will provide by completing the questionnaire will be used anonymously for research purposes.

Herewith I give consent that the information I'm going to provide can be used for these research purposes.

_____   _____

Participant   **Date**

_____

Susan Loots

Researcher

_____

Me Talita van der Spuy

Study leader

Appendix F: Transcription of English focus group

Focus group transcription (Focus Group 1: English speaking participants)

Where are you from?

1: Ek bly op die lekkerste plek in Suid-Afrika, in die bosveld, Leeupoort. Ek hou van die diere en die blou lug, skoon lug, die natuur. Lekker rustig.

2: Ek is van Pretoria, Wilgers.

3: London, England. I came here 30 years ago, I enjoy this country.

4: Ek is ook van Pretoria

Waarom het jy 'n kogleere inplanting gekry?

1: Ons het nou daaroor gepraat. Myne, wel ek was my lewe lank, nou ja, tot ek, tot dit nou gebeur het, was my gehoor uiters goed. My pappie was hardhorend op sy ou dag, maar hy het ook nooit apparate gedra nie. En toe was my man vroeg oorlede, hy was maar 35 en toe het ek vier klein kindertjies en het gewerk, ek het studeer, ek was in die onderwys, 'n musiekdosent. Toe is ek Frankryk toe vir kinderevangelisasie en het daar 'n ander taal aangeleer en my doktorale studies klaargemaak. So, my lewe was baie intensief. Ek dink in daardie jare wat ek meer gegee het as wat ek dalk gehad het, het my gehoor, wat die hardste werk in musiek, ek dink my gehoor se fyn draadjies het net begin deurmekaar raak. Toe ek Frankryk toe gaan, het ek uit eie vrye wil 'n apparaat gekoop, maar dit was te sterk, my gehoor was te sterk en toe het ek dit lank nie gedra nie, eers toe ek begin opleiding gee het ek hom begin dra. Eers van 2008 af het ek in al twee ore gekry. So, my gehoor het baie agteruit gegaan en my indruk was, hoe meer ek my apparaat dra, hoe swakker word my gehoor, dit was my indruk. En toe in 2010 het dit steeds afgegaan, veral hierdie kant (wys na regteroor) en 2010 het ek geimplanteer en die omkeer was geweldig. Intussen het dit so verswak dat as ek dit afhaal, dat ek die televisie op sy hardste sit, dan hoor ek niks. So, ek het nou geleidelik gehad, vinnig af, baie geleidelik en toe vinnig. Maar ek kom baie goed reg. My brein begin nou die musiekklanke aanvaar, ek kry nou meer

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selfvertroue as ek speel, die orrel. So, ek is baie dankbaar. Regtig, ek is, maar ek is nogal effens bekommerd oor die nagte, ek bly alleen.

Nommer 2 en jy?

2: I lost my hearing at the age of four and they detect my hearing loss at the age of six. I spontaneously taught to lipread and nobody else could find anything wrong with me. My speech was not so good at that stage, maar the Speech Therapist couldn't find anything wrong so I just carried on.   At age of six they detected my hearing loss. So, I started schooling at Sonnitus School, school for hard of hearing in Pretoria. I still wore my hearing aids (body worn). And I carried on, matriculated, started studying, Radiography. I did my operation in 2007, it was an amazing experience for me.

Number 3?

Well I, at the age of fifty, 1993, I was flying into Heathrow and my hearing went totally. That was it. I had a shock, ended up in hospital. Nothing could be done. Came back to South-Africa, I was the technical advisor of an international company here and I just couldn't carry on working, so I retired. Like you, I learnt to lip read, as it was the only way of communicating. Then my sister died in 2004 and at the funeral what was the director of Cochlear Europe, just happened to be, I didn't know him, but it was my sister's best friend's husband. And through the whole of the afterball of the funeral, I just pumped him with questions of what was going on with Cochlear. The result was, I was so convinced that as soon as we came back to South-Africa, I found prof. Swart, had the first one done and then through (number 4), who kept on about getting a second one done, I got the second one done. Now to me it, it saved my life. Now I can hear my grandchildren and all things in life.

4: My story is very much the same, uhm, I lost my hearing when I was five. It was a gradual loss, I could still hear enough to mainstream. My mom just said, you stay in a "normal" school. When I was eleven, I got my first hearing aid, ook daardie boksies met die drade, oe, I hated it. And when I was fourteen my first behind-the-ear hearing aid, which already made a big difference. And then when I was in my twenty's, I went to see prof. Carel du Toit in the Cape, the big man himself and I said: can't we do anything? "No, it's a sensory-neural hearing loss, we can't operate. Why don't you wear two hearing aids" and I said nobody has ever told me I can

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wear two hearing aids. It was revolutionary those days. Anyway, that one was already a quantum med and I went on for a very long time. But I found my hearing going down and down and I was in a management position and I was the communication officer of my organization. So, I had to do a lot of phoning, arranging events, everything. I tried all kinds of assistive devices like, uhm, modem and paging services and things like that and every time I saw my Audiologist I said can't we get me a cochlear implant? "Nee (number 4) jy hoor nog te goed." And then at one of our hard of hearing groups we met prof. Swart and Dr. Burden and I went to them afterwards and asked "can't we do something for me" and he said "you will be an excellent candidate, come and see Dr. Burden." That was in 2002. I got my first implant then. And then a while later, a few years later there was a discount offer for someone who wanted a second one, so I went for that and it was amazing! As (number 3) say, it saved my life. It saved me from going absolutely "cookoo", because the effort to stay abreast of a conversation situation with hearing aids, I can't describe it to you, you are so tired when you get home in the evening, you just want to sleep. That's me.

And I think we answered the second question as well. I wanted to ask, how did you experience your life after the cochlear implant? But I think we've covered that.

2: Ja

1: I don't have words to describe it. Psychologically spoken, it's like this (demonstrate a turn over with her hand). As (number 4) said, that, with gradually going down and down and down you don't have a, a ability to really communicate and you loose your, a little bit of self-esteem. Because you know who you are, but you are not that anymore and what is most difficult for me is that sometimes people are very sympathetic towards the blind, but towards those who can't hear anything, they are even negative and make jokes about you and I think that's, ja. But I am so grateful; on the musical side, I found that since last year………………….I had to play the organ from Sunday to Sunday and it's amazing to realize and to feel self confident again and my brain is adapting to the situation and to the sounds. It's not the sounds that…………………, it's my brain.

2: For the first time in years I could hear myself and I think there is a little bit of improvement in my speech. My work relationships are amazing now I can hear now; on the Dr's side in the theatre ………

3: I think exactly what you two have been saying, you can't help but feeling you're a person again, you are in society, you're not just sitting at home moping around just doing your own thing, you can go out now and see the rest of the world. To me, it's just given me more confidence so you can go meet people.

4: Uhm. When I was hearing so badly; the worst my hearing was, the harder I tried, not only to hear, but to make people aware of my hearing needs. I was at a wonderful workplace where they were accommodating; they would give me assistance for the telephone and everything that I needed so I could work. My one colleague even trimmed his moustache so that I could see his lips. That was the kind of environment, empowering environment, I was in. But I was always fighting for more. More for hard of hearing people in general than for myself. But it's very exhausting to get to that point of assertiveness where you say to the clerk: don't talk to the keyboard, talk to me, I can't hear. And they are so sorry when you say that, because they don't realize you are deaf, because that is the problem with hearing impairment: it's invisible. Unless you tell them: look I can't hear", then they can't help you.

1: And your relationships suffer. And after you had that chat you experience that your relationships start improving and everybody around you is more relaxed to talk to you. My children and grandchildren; it's amazing to see their reaction and I can only praise the Lord for me having this assistive device.

Do you have a need to spend time with other people who also have cochlear implants?

3: I think I need to ask questions, we all have questions. Like here, we sit here and listen to somebody and some of us, sort of put their hands up and you can talk, you know, between us, which is nice. To have that sort of communication, it doesn't have to be lots of times, but it's just nice if somebody who has the same problem as you…

1: Who understands, yes!

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3: …can help you out.

2: Uhm, one of the cochlear implantees, (name), is one of my, is my best friend, so, ja. I can interact with other people as well, for example like you. So you come here "ok, I am using this and it makes my life better or this didn't work" or whatever. Ja, I would say I do, ja.

4: I had a friend with a cochlear implant, she tried to socialize exclusively with hard of hearing people and cochlear implantees and then one day I said to her, "you know, if I meet someone who has got the same problem that I have and I don't have other points of communicating. If we don't share a love for music or a this or a that or the other, it's not going to be a friendship, never mind if we have the same hearing problem." We can share and what is important to me in a group like this is to help the new people, share our experience and perhaps to empower parents of children who have cochlear implants. So, I see a group like this as getting for myself but also giving out to the other guys from my experience but I, we will not necessarily become friends and it has nothing to do with our personalities, it just has to do with being people.

2: And I think I agree. You can't only be with hearing loss people, cause we are at that stage where we live very good and we can communicate with "normal people" like we are, you know.

And how did you experience the previous group meetings?

2: At the beginning, there was a bit of shyness, because you are English (points to number 3), they "ah", English, "ah", but I think as we carried on, it did get better.

4: I think the group is good. For some reason perhaps because we are only a group of adults. The previous support groups that we had, they tried to split into teenagers and small children and adults and it was difficult for them to cater for everybody's needs. This group is specifically for the adults, so uhm, I find that they are speaking to us at our level and as we get to know each other I am finding more freedom, vrymoedigheid to share our own experiences with other people.

1: I came the first time not knowing what to expect. But I find it, you know, I find some kindness in the atmosphere and when I came today, all of a sudden spontaneously I presented myself: "good morning to all" (laughs). I would never do that (laughs).

3: I do think sometimes that I try to help people that try to decide, well, they gonna have the operation done for the first time and they are very concerned. I think we all been through that when we had our first cochlear implants. I think that's a little bit that's missing at the moment, is to try to bring people in that say, will have their operation in two to three months' time, to come sit here and talk to us. We can tell them our experience.

2 and 4: (Nods and agrees with statement made by number 3)

3: I mean when I had, before I had mine done, I wouldn't have it done, because I thought what I would hear would be a "robotic sound" as if I am not going to hear your voice, I am just going to hear like a robot, mechanical noise, of course which is totally wrong. I can hear your voices and I can hear the differences in your different tones. So, I think that's the only thing that I would like to see into this group is people coming and trying to help them as well, you know, rather than afterwards.

1: But, it's very important that you say, about the sound that you hear. After the operation everything sounded like Donald Duck voices…

4: Qwack, qwack, qwack

1: But now, I can hear normal voices…

3: Yes

1: …and it's only the brain, it needs time to adapt itself.

4: I would like to add to (number 3)'s suggestion. I do think it is important for people who had been newly implanted, to perhaps have a fellow implantee who can accompany them for part of the journey.

Like a mentorship?

3: Uhm, yes.

4: Ja.

2: (nods) Yes.

1: Uhm

4: Ja, we have a lot to share. And we can sort out some things that the Audiologist will not necessarily pick up, because we are in the same boat.

1, 2, 3: (Agrees)

4: There is a difference between what a hearing person can help you with and what a fellow implantee can help you with.

1: But why is it so difficult for us to admit that I need aid; hearing aid. It's so difficult. So if we invite somebody, who is already suffering, but he or she does not want to admit it, perhaps that would be a good thing for them to see how it is.

4: That was something I taught myself; having assertiveness, because I decided either I have somebody around all the time that can hear for me and help me to carry on or I can help find ways to help myself. Even now, I know when I hear badly, for instance in the supermarket. And the first thing I tell the cashier if I see her looking into the distance, then I say: "you must attract my attention; you must talk to me; you must make sure I am looking at you and then we can have a conversation." And I do that with many people and it's something you have to push yourself, it's never effortless, it's always effort.

Do you think that by attending the groups, did that expand your support network amongst one another?

1: O yes, of course. To a certain extent, like she said, it's not necessarily friendships, but on this level it's wonderful to have a support group.

3: Yeah, yeah!

And the sharing of tips amongst one another, would you say that is valuable?

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2, 3: Yes, yeah!

4: I want to stop you. I wanted to talk and add: what the difference between this group and previous groups is that suddenly there is an explosion of knowledge about assistive devices. It's been one of my biggest fights over the years of dinges. I say: "isn't there a phone that can help me? Isn't there a…."no there is nothing"". I went to the deaf federation and I got a shake awake. I had to go into the deaf world to get that alarm clock and there was nothing else. Then you vaguely read about it on the internet; the loop systems and so on, but it's not available in South-Africa and now, all of a sudden, we have suppliers saying "I've got this, I've got this, I've got this," and I say: "I want it, I've been wanting it for years." And we now have a pool of knowledge which we can access.

1: Yes. Ja. And I think this Department is working hard at it. Working on the development at this level, the research.

We have started on that, but are there any suggestions that you have to improve the group meetings? Ek wild it in Afrikaans ook stel: Is daar enige voorstelle vir hoe die groepbyeenkomste verander moet word?

3: More like today where we had companies come in and say this is their products which they sell.

1,2,4: (Agrees stongly)

3: That is good, you know, there is a lot more from example Telkom themselves. They can tell us themselves, they can tell us what telephonesthey could supply us for free, you know, that sort of thing. Yes, that's the nice thing, get those sort of people in.

1: I have somebody in Pretoria who would already, he is not ready right now to decide, but he would appreciate something. He and his wife.

2: I think it's good, cause a group like this, we hear about new technology and other stuff that can help improve our lives. And the other thing is, a group like this can't be your only support group. You have to have friends, family. But it's good. I don't know how we can get more

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people here, maybe by word of mouth, maybe. But uhm, my experience , a lot of hard of hearing people are difficult to get together; about 99,9% of hard of hearing people will say, sorry, I can't hear well and leave it.

4: You know why, because it's such hard work to hear. It is, and the deaf couple who was sitting there in the corner, they lost the conversation. They were having a signing conversation amongst themselves. They lost track and the speakers could not engage them, somehow. But, uhm, there are a few suggestions that I have: one is, uhm, we don't realize how important a hearing environment is for a group like this. It's an absolute must that we must be able to see each other. I don't know how, but, most of us can't hear what the people who are sitting with their backs to us, we can't hear their questions; I can't. Maybe some of the others can, but I can't…

1, 2, 3: (Agrees)

4: You have to listen very carefully. There must be assistive….this is a group for support, the assistive devices must start here…

1: Yes!

4: …And I think a loop set, a loop for any meeting that we have is a must.

1: But we can ask, the lady can ask: "is there somebody who can't hear the questions and we can change positions.

3: Yes, yes!

2: (Agree)

4: Otherwise who ever is the speaker and who is coordinating the questions, must be aware of this. At the very first meeting we had, I went and stood in front where the speaker was so that I could see what people were saying. Otherwise I might lost the conversation. Secondly I think, uh, our meetings are not so often; we need an interim thing. I think we need an e-mail discussion group where people can post quick questions. Say, I've got like this wrong with my dinges, I am far from my Audiologist or whatever. You must be able to post questions; not about cookie recipes and stuff like that, but about our hearing issues. I am in Durban, where can I find

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something or whatever, you know. And then thirdly, another social medium that we should use is Facebook.

2: (Agrees)

1: Why? I don't have time for Facebook!

1, 2, 3, 4: (Laughs)

4: But you know what, it is an advertising medium for our group and we, it's a way of spreading awareness about our group, it's a way of spreading awareness about the resources that we have available. It's a way of spreading the word about people like us. I've gained immensely from being on facebook with (name) and (name), because we often share hearing issues.

1: I've never done that.

And Hear2day; we had a session on hear2day. Have you linked up with them? Hear2day: they are based in Cape Town, but they've got a website www.hear2day.co.za. That's their website; it's like a blog, a forum, it's a place where people can, on the internet, can connect and ask questions and their vision is to get everyone in South-Africa, to make it a national organization, with satellites.

1, 2, 3: (Wrote down web address)

There was one session that we "skyped" with them, in which they gave us some informationwith regard to what they are and what they stand for. If we can join our forces and link up with them…

1: Ja

2, 4: (Nods in agreement)

…especially in the cyber community on the internet, that's something to look in to.

1: Will you please write…

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Yes, (write down web address). So, would you join them, like you said (point to number 4) for that internet support?

4: (Nods). So ja, Facebook is a more social medium, but the e-mail, uhm group, there are international groups like the "Saywha?" club, but I resigned from them, because they were becoming too big and they were actually swopping out cookie recipes, which I am not interested in. I don't want to know how to bake biscuits, I want to know about hearing issues. The other thing about a group like this is we, you must not function in isolation, it joins up with what we have been saying now. Uhm, my dream is that we can "lobby". There is a lot of advocacy that needs to be done, there is a need for loop sets all over the place. That's what Fanie du Toit"s awareness on is. There is a need for proper accommodation for hard of hearing people at airports. And that, and we, otherwise you are just a poepie in a donderstorm. But if we are a group and we can light our voices. For instance I started enjoying subtitles on my TV, on my mnet, and then we got PVR that record it and guess what: it hasn't got the subtitles facility. Push, push, push.

And do you think the group has a place in gathering people to advocate?

4: Ja. So eventually we must become advocates, but we must, if we have a united voice we can at least add to what the hear2day group; if we can also add our voice to theirs, then we have a…

1, 2: (Nods)

4: …significant group of people pushing, because we are not deaf. I am not aligned with the deaf people in the deaf community and the signing community. I've got nothing against them, but I am not deaf and it's not my primary language. My primary world is a hearing world and in that, the hearing world must make some accommodations for us. If they can make ramps for wheelchairs, then they can make things for us to hear better.

And in closing, I just want to know: would you advise other adults with cochlear implants to attend group meetings like this, and why?

1: Well, I think it's clear from the discussion: it is meaningful for us, because we feel that the other people understand and we encourage one another and we get information, but what I also think is would it be impossible to have a national day of hearing problems…

We have Deaf Awareness Week in South-Africa.

1: …but I am sure I have read somewhere about a day for…

4: It's usually September, there is a national Deaf Week. Yes, yes. For some issues, accessibility issues, we can definitely align ourselves with the deaf community. Can you hear me (number 3)?

3: Ja.

4: You're deaf aren't you?

1, 2, 3, 4: (Laughs)

Ok. (Number 2), what would you say, would you recommend…?

2: Ja ja. I would think because we do, I would recommend it, because we can learn and have the many problems. And I think it's a good place, a safe place to see there is actually people like you, and you can be yourself and you can improve your self image and see: but he is doing this, but wow, I can do that too. And that type of thing, so I think it's very good. Fun. Good.

1: But I must, I mean, I saw some sunshine in your eyes this morning (pointed to number 2). She was very glad to be here.

1, 2, 3, 4: (Laughs)

Yes, (number 3)?

3: What I think is that we don't know who the other people that has cochlears is, for instance, when we go into the office where they are mapping, there's all this photographs of, there's hundreds of them, but when you look there, ok the majority of them are children, but then there's quite a lot of adults there, now we don't know who they are. It's up to the people in the office and these people, they are the one's who can do it, not us. Or, they can give us a list of e-mails

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or telephone numbers and say: "right, go about".   But yes, they should, if you can try to pull more of those people in, I think they will benefit out of it.

4: That's where a Facebook group come in. If each of those people can, are linked up to that Facebook page, then, it's one way of befriending one another and getting to know one another.

And inform them about group meetings?

4: Ja.

Thank you so much! Is there any closing comments?

1: Thank you and may God bless your research and success.

Appendix G: Transcription of Afrikaans focus group (Afrikaans and English)

Translated Focus group transcription (Focus Group2: Afrikaans speaking participants)

Where are you from?

1. I am from Pretoria.

2. I live in Boksburg, but I am originally from Klerksdorp.

3. I live in Frankfort, Free State.

4. I live in Cullinan.

5. I live in Pretoria

Wow, there are three of you who travel far to be here. OK, then I quickly want to hear from you why did you get your cochlear implant?

5: Can I start? It doesn't matter who starts first. Must I start with the history from the beginning, or shall I just short and sweet?

Just short and sweet.

5: Basically mine was as a result of nerve deafness that they could not really establish why, but they accepted that it was because of infection from seawater from which I became very ill when I was much younger. Now with the cochlear implant: I knew my hearing was getting poorer over the years, but I had a normal life, had normal schooling and everything. Then after school then they noticed then they said no, my ears have become much weaker, they don't know how I got through school. OK, in any case. Then I wore a hearing aid, I worked, I was in the air force for a few years and then a few, about six years ago, seven years ago my hearing began to be much weaker and then I got one.

4: I think I was actually born deaf, because I remember at one stage as a child, my mother always told us why she hit us, then she said: she is not hitting me because I broke the bottle, but because she told me four times that I was going to break the bottle. Now that I am grown up I realized that I did not hear then, but they first noticed it when I was in standard four. So from ten years I have been wearing a hearing aid. Normal life, took part in athletics, Victrix Laudorum of the school (we were only 84 in the school). Yes, I lived normally. Had my children normally. I

could hear a bit to a certain extent and, uhm. I had as a child, they mad eardrums for me that disintegrated. The right side came to lie against my balance, which was removed in 1991 and this left one about five years ago. It takes 30 years to grow, damaged my whole left side. To such an extent up to against my brain that I had brain surgery. At first they only did a bone implant. Just the bone implant and it worked, but after the cholesteatoma was removed for the second time, it didn't work. And then I cried my eyes out and then prof. said: well, if they do the brain surgery, he will do the cochlear. And, but then I was totally deaf, like now, but now I hear well.

1 ,2, 3, 4, 5: (Laugh)

(Number 3)

Yes, 14 years ago … we had a traumatic business. Our only son committed suicide and uhm, afterwards I started noticing that I wasn't hearing. I don't hear over the telephone, I uh. I was still managing, then we went for aids and uh, I could hear fairly well for six years and then I went for new aids and then I could hear wonderfully when I got new aids, in May, in 2004. In May 2005 I woke up one morning and I was totally and completely deaf. So I was totally and completely deaf for 18 months and then I came for an evaluation. I told (number 4) just now, uhm, the evaluation: when I was with the psychologist I told my husband they would never approve me for a cochlear, because I am pathetic, because I cried all the time, because she dug up all those things again. And then they did approve it and then in 2006 I got a cochlear. Really gave my life back to me. What I told the rest now, perhaps I am satisfied with little, I don't want to hear everything on the television, I just want to be able to talk on the telephone. It is important to me you know, can communicate. I can't just phone other children, perhaps I am lazy, I don't know. But that's, that's just my story.

Thank you. (Number 2)?

2: Yes I was, I was born deaf. My sister was also born deaf, both of us just had hearing problems and then I still always had the, I went to school normally, and had the Super Phonak.

1: The old aids.

2: …aids, yes. I wore the aids for a long time. Then I still finished school, after school I did, then I heard my sister is now wearing the cochlear. Then she said this one is much better, she can start the paper, the crinkle of papers, she says she hears it make such a noise. So I just started to listen and my mother and them said I should just start thinking and planning to get the cochlear, because I mostly struggle a lot with the telephone. We don't like telephones much. When people phone, when it rings I just sit (pretends he doesn't hear), dad says: "answer the phone", "ah, ok", then I do try, but just pass it to my dad again. I can't talk well on the phone anyway. So, just later, the more I went to work, I noticed I was getting better on the phone. So, it takes a while to get used to the phone. So yes, that is where I had a cochlear. At the moment this ear is my weakest (points to right ear; not implanted).

1: OK, I was born like this, we were in Pretoria then. I grew up here. Then the usual aids.

3: I just want to say: I walked around from one doctor to the other without finding out and Prof. Harmse, who was prof before Prof. Swart, then he said I had, well did tests, I have Meniere's disease. It is caused by the herpes virus (I never knew). So, I never even get a cold sore. Then he said but it can lie inactive in your system for 40 years and any trauma, whether serious illness or something like that, can activate it and then it attacks your body.

So, in short, I think many have touched on it now, but in short: how are you experiencing your life after the cochlear implant?

5: Well, I must tell you, in general, perhaps because I had a normal life in the beginning. OK, my hearing suddenly became bad and well and now I am about, I associate with exactly the same people. OK, I sometimes have noise and things, but otherwise I associate exactly the same as other people.

4: Well, I also told you now that I led a purely normal life and so, if I could really have a choice at this stage, which now isn't the case, I would prefer before the cochlear, what with the hearing of my two Phonak aids. But one must adjust in your life, with me it was now also due to the choleastomas that grew. Actually Dr. Burden said I had 3 months left to live and the Dear Father decided differently, it's now 6 years later already and it's not ideal, but as I told someone the other day when I had it serviced and it costs some money, but it's still a bargain. If they tell me now it's a million rand, I don't know where I will get it, but it is still a bargain to be able to hear.

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5, 2: (Agree)

4: If you heard and there, I was like in 12 to 13 months totally and completely deaf. Do you know I stop breathing because I don't hear myself breathing? That my, in the night my husband has to tell me: breathe, breathe. Because, I always wore the hearing aid here and heard myself breathing. And when I didn't hear myself, I knew it was broken. So it is a huge adjustment to me. But as someone said once in one of these groups: before the cochlear she was deaf and after the cochlear she is hearing disabled. And for me that is really how it is. I talk on the telephones. If you were to phone me now I won't know you. If you say: "number 4) it's Susan Loots of the cochlear team, can you hear me?" you understand, then I memorise you, because I have this bit of brain damage now. Do you know, when you phone next time I will remember you? Because my brain will absolutely know and I think someone who has never heard in his life has a bigger learning process than me who could always hear. I lived normally everything, I gave birth normally, everything. I even went to do skyway trail after my cochlear. I have decided that if I have to die in three years' time, I am doing everything I want to now. And it's just wonderful, but I think a lot depends on one's own attitude. As I told (name) this morning, he has had it for a year now. I told him, you know, I have had it for six years, it's an adjustment every month or after every mapping, but I would do it again if I could.

3: I must say, it is still an adjustment. Yes, these aids were a constant irritate to me and that's wonderful of the cochlea, you don't have to rub your ears all day and that irritation.

(Number 2)?

2: You have now already asked the question, but I didn't hear well.

How do you experience your life after the cochlear implant?

2: There is quite a big difference between the analog, the analog can only, let's say, the low sounds, now this one can the high sounds. Now this is quite a huge adjustment, an interesting adjustment when you sit in the room and you can hear the crickets. A cricket is quite bloody irritating, then I thought, well my mom said there is a cricket in my room, but before it worked I was like this (shrugs).

1, 2, 3, 4, 5: (Laugh)

2: You know those little sounds, those high little sounds that I hear now, makes it quite a lot better than to…

4: But it's interesting that he says he hears the crickets, I just never did. I never heard a car passing in the street and now, after my brain surgery (actually before that the prof said I must walk a lot, but I love walking, but I must walk more), you know it is lovely to walk, because I hear the cars coming. In the past I always slogged in the grass, because I don't hear a car. And I invigilate at Unisa examination students: I just hear the writing of pens, but I'm not even certain that's what I'm hearing, now I write to my chief supervisor: (Name), is it the pen's scratching that I'm hearing? Then she says: "yes". Listen here, the moment the turn a page then I hear it then I go and look if it isn't "crip notes".

(Everybody laughs)

One didn't realize that it is actually necessary for a quality life.

2: Except the speech. If you now had the analog, this old aid, you could only hear the high sounds, the person's voices. Now you start to talk like the /s/ and the /r/ then the person notices that I roll my r's. (Laughs). It borders so, your speech also starts to improve.

And tell me, now we come back a bit to, do you have a need to spend time with people who have also had cochlear implants?

5: I think, I think actually. Wait, I can answer it in two. I will say: yes, to a certain extent, OK, there are some people who probably have a greater need than others. I will say that the people who may have had a greater loss, perhaps have a greater need than people who were perhaps used to talking normally. So I think yes, I will say yes, yes.

4: I enjoy these meetings of ours terribly, but as it is I have a wonderful circle of friends who absolutely carry me through and do anything for me. I don't really have the need for that type of communication, but I would still like to do educational work. Like in schools and, you know, go to show people: this is what it looks like, it is not as bad as what you think at all. Because we phoned (name) and (name); my twin sister, when I was deaf, and it inspired me. Because now I am, I now laugh so at that (name), we are sitting there, now she takes it out and shows it to us.

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After a while she says: "but I don't hear you", puts it back again. Then she had one in, then I realized, but…

And that contact helped you?

4: It helped me a lot. No look, it absolutely motivated me and if there had been any doubt, the visit around (name) and (name) just for me "go for it".

5: Yes, look, physically you know, to share with people who basically through the same problem…look, I don't think in general if we didn't know each other, then we wouldn't be able to discuss our problems and associate with another person who had the same problem. Now we can tackle the problem and say: "Listen, so we all have the same problems. So it causes better communication, sometimes also better communication than the people who work with us.

The "talk together" then?

5: That's right.

3: You know, I also think so, because we all have the same problem, so to, it is, yes, I felt when I became deaf, I isolated myself, so I retired…

4: Yes.

3: When I in a company…I always got scolded by my son-in-law, because then he says: "Ma, you always run away." And then I said it is easier for me to go to my own home than to sit in the company and say: "what are you saying, what are you saying?" So I enjoy… and I became anti-social… so I enjoy coming in again. Especially today, because Pa is not here and I "ride on his back". He talks for me, a lot, and he does a lot for me, so now it did me good today… when I say to (number 4) "I came late and I was tense, I parked there far, I take a little while to really hear again." So I first here, I heard nothing about Phonak, I didn't hear that first woman at all. It almost seems to me as if I , excuse the word, have become "stupid." One has to come in again. So I enjoy being with people who have the same problem, who understand, because hearing people who don't work with disabled people don't understand, because they can't see you are deaf…

5, 2: Yes.

3: … a blind person walks with a stick and they say: "ag shame", or someone in a wheelchair, but when you are deaf they don't know it, so there isn't sympathy. I enjoy it, it is good for me to…

2: Yes, it was for me too, yes. Because I was actually in an ordinary school I just always got along with hearing people all the years. Now, since coming here, I am starting to see how other people who are also hearing disabled are… I had become so used, so adjusted around normal. Now I see, "o, but this person talks so and so" and it's interesting to talk to such people and I understand how it is for them.

And do you to a certain extent have a need to have contact with them now and again?

2: Yes, yes.

So it is just people who understand, there is more… in a previous group they mentioned that it is more credible, of greater value if it comes from someone…

2, 3, 5: Yes (nod)

Then I just want to hear from you, what was your experience of the previous group meetings?

5: Well I must actually tell you, it was very interesting, today was now particularly interesting to me. I think I quite enjoy it! You know, the people are nice. It's enjoyable, it's a bit, it's actually relaxing. Just the other day I said to someone again: "you know, I think these working conditions I am in, are much more stressful working conditions than the general, even now when I was helping prof Johan… you know it has been terribly relaxing to work with the people here. I think the university itself, as a whole, has a stigma of just a relaxing feeling. I don't know, I don't think you know what stress is. (Laughs). It is actually very pleasant here. I enjoy it very much here. And one also learns many things you did not know, like today now for instance. Many of us didn't know about the equipment, what is available. I have already worked with it to an extent, but many of the people don't know about it at all. So it's valuable to me, to a person, certainly.

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4: Well I also enjoy it, I really enjoy the meetings a lot and some days, I don't know if you also get depressed and then you feel: "oh, why am I now deaf? Why can't it now be someone else?" But when I come here and I see others that get along with more difficulty than me, then I just feel very good again and I find it very interesting and educational. And I have often thought, (hearing aid company) is much nearer to me, but it is as if this cuddling, this love is not at (hearing aid company)… at (hearing aid company) I feel like an instrument that is being handed in…

5: I agree.

4: …here I feel like one of a team. I will really take trouble, I will put of a holiday to attend such a meeting. It is really very valuable to me. And especially the chats afterwards…

Yes, I wanted to ask about the social…

4: …yes, because I now also realize (number3), then I was sitting and thinking just now: you must get fax machines for you children that can't hear you (points at number 3). I have an aunt in Lydenburg who is deaf, she does't hear me. I can hear her, but she doesn't hear me at all. Then one year my twin sister and I bought her a fax machine and you know, now she suddenly doesn't hear at all, everybody sends on the fax machine. And when I answer my phone, then I say… it's a firm, sometimes you can hear Telkom or SARS, then I say: "Sorry I am deaf, I've had a cochlear implant, send me a fax." And, and it's such discussions that come out here, not with normal people, because they don't think about it.

2, 5: (Agree)

4: And you look normal. All of us, so then they think we are normal, and actually we aren't, we are special (laughs).

3: The caring and the trouble you take are much appreciated, because we would have been so much poorer if it didn't begin. Because I who sit there far in the plains, it's actually far behind because like the technology that today here, I don't even know about it, so it's, now it forces me to come and it is very valuable to me, I appreciate it a lot.

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2: Yes, I often just didn't arrive, but then I just begin to see again it is now perhaps interesting again. Like for instance today. Then I just jump into my sister's car again and I enjoy it. And it's a few new little things that I don't know about. And as she (points at number 3) also says, it's quite interesting… here is a thing that vibrates that you put under your pillow, (laughs), but yes.

I also saw that you and (number 5) also had a nice chat, it's almost just those "tips"…

2: Yes, and here is the thing. Often if one is now sleeping and when you wake up and you say (looks at watch) I can sleep some more, oh man, it's still an hour", then you must make a plan.

4: Yes, poor sleep that last while.

2: If you now wake up by yourself, now you must put the aid on this side and turn your head, you can't sleep on this side now.

5: Get yourself a cheap cellphone and get yourself a shirt with a pocket with a zip. Then you put it on and then you sleep. Just a R200 cellphone, it works very well.

4: (Laughs)

(Number 1, how do you experience the meetings?)

1: Very interesting.

4: Yes, this little one from Phonak who talked so fast. I followed her now, but I felt that she spoke too fast.

5: Yes, that one went very fast, looked as if she was in a big hurry… shame.

2: As they say, that uncle at the business… when I go to him, " what does he want me to do?", the guy says, as you say (closes his mouth with his hand) and mutters.

5: Yes I said to him, that lecturer was so annoyed, it's a project that I had to do. He asks me a question, but you know it's like (hand in front of his mouth). I became so angry, you know, I finally told him: "listen here, so in the first place, just take your hand away from your mouth so that I can hear what you are saying, please."

Do you think these meetings have broaden you support network a bit?

4: Certainly, yes. I think so. Do you know what is sometimes the thing. One feels so, I would now really also like to see his girlfriend or his wife or so, but you know what, it's as if they don't have the same togetherness as us. Ah, but still it would perhaps once a year want our people, or you husband, wife or children to come too, but now the intention actually of the end of year function, isn't it? But I would not want it more than once every two months, because I don't want to miss it, but I would also not be able to fit it in every month.

(Number 3?)

3: Yes, I now fortunately… my husband supports me so much now, I ride on his back: he is my secretary. He has to do all the phoning and he has to arrange people and such a support network is very important to one. I think it must be very lonely if you didn't have that. Because one isolates yourself. As he says, he had to work twice as hard as a normal child to fit in and to do well at school and, the children who could hear were much more advantaged… it is an adjustment. It is very good to have a support network.

2: Sorry, quickly ask the question again.

I'm asking, did attending the meetings broaden your support network?

2: Yes, it did.

Then I just want to ask in general, do you think it necessary that people with cochlear implants should spend time together?

5: Yes. I think so. Yes.

4: Yes.

3: Yes!

2: Yes! It's very interesting to hear what every person has to say, about fax machines and here's a fax machine there. (Laughs)

3: I think it's necessary. Yes. It's just difficult when one sits like this, we must also just be able to see each other. Perhaps sit in a circle.

1, 2, 4, 5: (Agree)

My next question is precisely: Do you have any suggestions on how the group meetings could change? For example, like you've just said, number 3, that we must sit in a circle.

3: Well, I was sitting right in front of (name) so I could hear what (name) was saying, but I could also not hear what (name) was saying there, for example, or hear the man talking.

4: Yes, (name) speaks very softly, I just lip-read her, I almost don't hear her at all.

2: Uhm.

3: Yes, it sometimes gets difficult to hear people. I always try to sit right in front so that I can hear and can see the person. I also try to sit with my right side to the person as my hearing aid is on the right. And just now also, when he (points at number 2) sits at the side I can't hear him so well.

4. I feel perhaps, although as we say one gets fond of each other, rotate. Say for instance invite me, for the sake of argument, to the Bloemfontein group and then another time say, our little group goes to the Welkom group for support. You understand just just to go and learn from others too.

OK, then more in terms of the group, is there something specific that you can think of how we can change it?

5: Yes, I now want to, if I now think of something I will, when we started here now this miss now had that system that made it a bit louder, it was very nice. I found the sound very clear, I don't know if you also heard it. But that's also something we must think about, to get such a system just to follow better in general. I don't know how you experienced it?

3: The first one.

4: Yes! Here was such a, I just call it "surround sound", I don't know what else, yes…

3: But I was so late that time…

4: Yes, you didn't hear that part.

3: I think it is quite good, I think, yes, yes, yes. I went to school in English, but when I became deaf I found it difficult to follow English…

5: I agree.

3: I learnt in an English school and spoke a lot of English, but it was difficult for me. It was actually a bit bad when everything is in English, I don't begrudge the English people. But I often feel they must switch over a bit and not always just… it is not so easy for everybody to hear in English. I don't have a problem with English but we Afrikaners must always stand back for the English.

4. Yes, but for interest sake, Prof Swart told me, I was at a black school, an English school, he told me about it. One can't lip-read English.

3: No, it's difficult.

4: Because my first realization of it was, sometimes you just hear a little word, then you make your deductions, when I now heard less well. Now and then, I hear the little word "here". Then I don't know does the chap say "do you hear me" or does he say year, because it was in December: "Happy New Year". And you know there are hundreds of such words in English and I see, but I am very good at lip-reading especially as I was now in a black school, they now speak another language that I say to them why do you now speak your own language so loudly and English so softly! Then they say: "Yes, but English is a modulated language". Then I now laughed about it, but it is interesting because now I'm thinking again when I lip-read, but at least I can hear now.

2: I like lip-reading because say (shows far away) I can listen to what he is saying.

5: The same over a cellphone to me, if the person speaks Afrikaans to me the chat is much better, as than it is in English. In English it is difficult for me to understand, I can sometimes not make out.

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Yes and now if the majority of the group is Afrikaans it actually makes…

5: Yes, yes.

3: Yes one must so, in such a group you can establish how many, uh say 80% is Afrikaans, present in Afrikaans and that as they are now again presenting to us in Afrikaans, as the English do for us.

2: Yes, because when we speak in English, he can also again speak a bit in Afrikaans, because if one speaks English all the time you think you understand the story, then when they say it in Afrikaans, you see they don't mean it like that.

5: I actually find it rather funny, because we are so many Afrikaans people. (Laughs)

1, 2, 3, 4 (Laugh)

OK, then I want to hear from you quickly: would you recommend to other adults with cochlear implants to attend the groups and why.

5: Well, I personally think, yes. Why I say that, anything they get here will be to their advantage, so I can't see why not.

4: I also really think, it is almost a must for me for instance I have this little microphone I just call it the "extension". If there are many people in the car and I am driving, I attach it here to my blouse, because I find if I give it to the guy in front of me here, they always sit and play with the things and I, now I am wondering if the fault is with me. And I was talking to one of the cochlear patients just now. With (name). He also wears it like that, so I asked, doesn't he find it annoying, then he said yes, but I will notice he stands still. I am too busy. It doesn't work for me in the normal day, but in the car it works excellently. But I don't have the guts to ask the audiologist, because as she says some think we are senile, we are actually only deaf. But uhm, I have, one is rather careful to ask such stupid questions with experts, but actually it is important to us. Because now I feel better because he says he can also not a lot, he says, he fastens his to the seat belt, but I move and change the gears, so mine is fine just here on my sleeve, so I would never have asked someone else, so you definitely get fine detail information that doesn't appear on paper, in this group.

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3: Yes, one learns from the others, so you actually have, if you don't come… I have learnt a lot now. Of all sorts of gadgets that you don't know about. All that is important to me is the telephone. From (name) I, she has the thing around her neck, I have been threatening for how long that I, because apparently you can keep that thing here with you and attach your landline to it, so you can also attach your landline so that your cellphone rings through it. That I would never have known if I hadn't come today. Learn, we learn from each other. Yes, definitely worth it!

2: At the moment I am still using nothing any gadgets, but at the moment I have now seen how she the telecoil, what do call it, the telecoil be on the phone. I will just start to try some of the things and work more on the phone. So yes. I tried one of the things today, didn't work for me today. Sometimes I think it is difficult at first, because then you hear it on your ear, then it isn't noisy. When you put it on the phone, the sound starts changing. Then you don't understand that sound so well.

And it is probably better for you to hear if from someone who has already experienced it.

4: Personal experience. I mean to say it doesn't mean that what works for me will work for someone else. But, uh, if you don't try it and know about it, then you will not be able to do it or know it.

1, 2: Oh yes.

3: It's now like that one that (name) wears, that you can now borrow for one or two weeks and you can just use it. But when I said: "Yes, but I don't live here." Then she said, uhm, it's not a problem, I can post it. They give you another… I can post it, post it back. Now you buy it, R2000, whatever, and it doesn't really work. Yes, but and then, even that little lapel thing, I can also borrow to see, how does it work. Look, stupid that I am, I never even knew you had to clean it on this ear corner. I don't know, and when I now heard from (name), I would never have known it. Mine is pitch black and I have never done it, because I didn't know. I just mean, it's things that one learns.

2: Yes, yes, yes, yes.

3: I wouldn't even have known where to look to clean it.

And for the younger people, how would you, say you had to tell someone of your age that you suggest they come to the group. Why would you tell them they must come?

2: Well, I would tell them it is interesting to see how people are that have hearing aids. If I now have to tell people of my age.

4: He said he only comes for the biscuits (laughs).

1, 2. 3, 5: (Laugh)

5: Oh yes, it's true.

4: No, but you know, sometimes one thinks of the outsiders… I now have a twin sister and her husband is an electrical engineer and previously he also went to do these sounds on the computer, so that she could also hear how I was going to hear. But he went to present at the sisters' society, at the NHVF, (what do you call them again, here in Pierneef Street). Do you know, two of the eighty women who were there new about cochlear. The others heard it there for the first time. And, and, uh, I said to him: "why don't you invite me?" I would have gone and stood there, because they know me (in my deafness and went and workded for them at the show, they had too few staff). But the minister only said: "you must look at (number 4) and speak slowly." He didn't say I was deaf. And that is the most wonderful people, it's just that they don't realize… they just don't know. The guy with the stick is blind and the guy in the wheelchair can't walk, but the guy that can't hear doesn't have a place.

2: Yes, a lot, I'm going out a lot now. Many of the people don't notice that I'm deaf when I'm visiting with them. Then only a bit later they notice I'm deaf, they only see my hearing aid: "Oh, OK, I didn't know."

But this came out in the previous group: the role of raising awareness. To make more hearing people aware of the deafness.

4: I think it's very necessary.

Do you think the group can act as a pace from which raising awareness can take place?

3: Yes.

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4: Yes.

5: I think many people are generally very unaware, don't have a clue what a cochlear is. You know what was most interesting to me, mine is on the right, so when I'm driving then an old aunty comes next to you, they are walking here next to you… they look at you so and then she "chat, chat chats" with the uncle and then the uncle also turns and then I think no, this uncle and auntie have now discussed what is this now for a long time, (laughs). They don't know what it is, you know. And also at work. You know, I have been working there for eleven years already and then the other day he asked me: "listen here, is this thing now screwed to your head?"

1, 2, 3, 4: (Laugh)

5: People really have… even in a shopping centre… then people are standing here behind you and sometimes, you can actually feel it (you know someone is here behind you, you just get that feeling) and when you turn around that person has looked straight in your direction, then they don't know what to do. People wonder, but people are funny, people will sometimes wonder about something, but not ask you. You know, it is always rather really funny.

4; What I was also saying to (number 3) just now, actually if a child asks you, at first I was still like that, but then I was much younger. And they ask: "What is that?", then I just say: "Nothing."

But now I tell them: "I wear glasses because I can't see, and these are my ears," and then they say: "aunty, can I see?" and then I say: "But remember, if I take it off I hear nothing." Then I take it off, then they can also listen, then I put it on them, then he says no but he doesn't hear anything. Some do say they hear, but you know how it is. Then I say: "put it back for auntie, it fastens there." And some of my adult friends say: "Oh (name), it's a personal question, but I would really like to know." Then I say: "Come and sit here." I take it out so that they can feel the part under my skin and I put it back. Funnily enough, those people never ask you again. And if they are in the company and somebody asks, they just take the words out of your mouth and they tell the story.

1, 2, 3, 4, 5 (Laugh)

2: It has already happened to me too! And sometimes I already get so technical and then they just look at me so weirdly. They know about the little hairs that make the sound, because it is after all the sound that stimulates the little hairs… he says: "Yes, yes." Now if your hairs are long, you get it better, but what happens now if the little hair is grown a bit short, then you are not able to so much sound that you can hear anymore. That is why one is now deaf. "Gee, that interesting hear!"

1, 2, 3, 4, 5 (Laugh)

Tell me quickly. Did you after our session with Hear2day, did you go and look on the internet at support groups or forums for people with hearing loss?

4: Oh, yes, I actually tried long ago and I don't like facebook at all. I am there, But I don't like it at all. And a chap reads the other articles, but it doesn't have nearly the impact that a talk here has for me. Not nearly.

5: I will say, you know, I won't, I have already gone through it a bit. So the information they give there is very good. Yes. If you use the internet, you get a lot of information there. There is a girl who has written about all these things, but many people write about cellphones, Bluetooth and those things. The blackberry… everyone wants to know because it's also something that we… but in any case. People don't know about it, people tell you something and then nothing further about it. So, the internet and those things are useful, because it's things that people that have already experienced the same problem as you, so you get a lot.

2: I don't know if you read many e-mails perhaps?

4: Uhm. Oh you know , yes, I do, but if I don't have to I don't.

2: Don't feel like it?

4: Actually, the nice thing is, I talk with my sister on internet. I see I have about three, but also not skype. Just e-mail. And all this junk mail that one gets: I just take out the little photos, the pictures, print it out for church leaflets and things, but otherwise no.

2: But you see, where I get the most, fastest information is by e-mail. If someone says to me listen here… it comes directly onto my phone if someone mails me. Oh yes, I must go to read it

on my computer quickly. Facebook also, you know, people start fan mail and things that people don't want to read.

Focus group transcription (Focus Group 2: Afrikaans speaking participants)

Van waar af kom jy?

1: Ek kom van Pretoria af.

2: Ek bly in Boksburg, maar ek kom eintlik van Klerksdorp af.

3: Ek bly in Frankfort, Vrystaat.

4: Ek bly in Cullinan.

5: Ek bly in Pretoria.

Sjoe, daar is drie van julle wat ver ry om hier te wees. Ok, dan wil ek gou by julle hoor: waarom het jy jou kogleere inplanting gekry?

5: Kan ek maar begin? Dit maak nie saak wie eerste begin nie. Moet ek begin by die geskiedenis van voor af, of sal ek net short and sweet?

Sommer short and sweet.

5: Basies was myne as gevolg van senuwee doofheid, wat hulle nie regtig kan vasstel hoekom nie, maar hulle het aanvaar dit was as gevolg van infeksie van seewater waarvan ek baie siek geraak het toe ek baie jonger was. Nou met die kogleere inplanting; het ek geweet my gehoor raak swakker oor die jare, maar ek het 'n normale lewe gehad, normal skool gehad en als. Toe na skool toe kom hulle agter toe se hulle nee wat my ore het nou baie verswak, hulle weet nie hoe het ek deur skool gekom het nie. Ok, in elk geval. Toe het ek 'n gehoorstuk gedra, ek het gewerk, ek was in die lugmag gewees vir 'n paar jaar en toe het hulle so 'n paar, so ses jaar terug, of sewe jaar terug toe het my gehoor nog baie begin verswak en toe het ek een gekry.

4: Ek is eintlik dink ek doof gebore, want ek onthou op 'n stadium as kind, my ma het altyd gese hoekom slaan sy ons, toe se sy: sy slaan my nie oordat ek 'n bottle gebreek het nie, maar omdat sy vier keer vir my gese het die bottle gaan breek. En nou dat ek groot is besef ek date k toe nie gehoor het nie, maar hulle het dit eers agtergekom toe ek in standard vier is. So van tien jaar af

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dra ek 'n gehoortoestel. Normale lewe, atletiek gedoen, Victrix Laudorum van die skool (ons was net 84 in die skool). Ja, ek het net normal gelewe. My kinders gehad normaal. Ek kon tot in 'n mate bietjie hoor en, uhm. Ek het as kind, het hulle vir my oordromme gemaak wat gedisintegreer het. Die regterkant het teen my balans gaan le, wat in 1991 verwyder is en hierdie linkerkantse een het so vyf jaar terug. Hy vat 30 jaar om te groei, my hele linkerkant beskadig. Soveel so tot teen my brein dat ek breinsjirurgie gekry het. Aanvanklik het hulle net 'n beeninplanting gedoen. Net die beengeleiding inplanting en dit het gewerk, maar na die cholesteatoom die tweede keer verwyder is, werk dit nie. En toe huil ek my oe uit en toe se prof: goed, as hulle die breinsjirurgie doen, sal hy die kogleer doen. En, maar toe is ek total en al doof, soos nou, maar nou hoor ek lekker.

1, 2, 3, 4, 5: (Lag)

(Nommer 3)…

3: Ja, ek het 14 jaar terug… het ons 'n traumatiese besigheid gehad. Ons enigste seun het selfmoord gepleeg en uhm, net daarna het ek begin agterkom ek hoor nie. Ek hoor nie oor die telefoon nie, ek uh. Ek het nog oor die weg gekom, ons het toe gegaan vir apparate en uh, ek kon vir ses jaar redelik goed gehoor het en toe gaan ek vir nuwe apparate en toe kon ek wonderlik hoor toe ek nuwe apparate gekry het, in Mei, in 2004. In Mei 2005 het ek een oggend wakker geword en was totaal en al doof. So ek was 18 maande totaal en al doof gewees en toe het ek gekom vir 'n evaluasie. Ek se nou nou vir (nommer 4), uhm, die evaluasie: toe ek by daardie sielkundige was het ek vir my man gese hulle sal my nooit in my lewe keur vir 'n kogleer nie, want ek is 'n pateet, want ek het die hele tyd gehuil, want sy het weer al daai goed uitgekrap. En toe het hulle dit gekeur en toe in 2006 het ek 'n kogleer gekry. Werklik weer my lewe vir my teruggegee. Wat ek nou nou vir die res gese het, ek is dalk tevrede met min, ek wil nie alles op die televisie hoor nie, ek wil net op die telefoon kan praat. Dis vir my belangrik jy weet, kan kommunikeer. Ek kan nie maar ander kinders bel nie, miskien is ek net lui, ek weet nie. Maar dis, dis maar my storie.

Dankie. (Nommer 2)?

2: Ja ek is, ek is doof gebore. My suster is ook doof gebore, ons het al twee maar gehoorprobleme gehad en toe het ek nog altyd die, ek het gewoonweg skool gegaan, en het die Super Phonak…

1: Die ou apparate.

2: …apparate ja. Ek het lank apparate aangehad. Toe het ek nog skool klaargemaak, na skool het ek, toe hoor ek my suster dra nou die kogleer. Toe se sy hierdie een is baie beter, sy kan begin al die papier, die "crinkcle" van papiere, sy se sy hoor dit raas so. En toe begin ek maar hoor en my ma-hulle se ek moet maar begin dink en beplan om die kogleer te kry, want ek sukkel meestal baie met die telefoon. Ons like nie baie van telefone nie. As mense bel, as hy lui sit ek maar (maak of hy nie hoor nie), pa se: "antwoord die foon", "ag, ok", dan probeer ek maar, maar gee maar weer vir my pa aan. Ek kan in elk geval nie lekker op die foon praat nie. So, net later, hoe meer ek werk toe gegaan het, kom ek agter ek raak beter op die foon. So, dit vat so tydjie om gewoond te raak aan die foon. So ja, dis maar waar ek 'n kogleer gehad het. Op die oomblik is hierdie oor my swakste (wys na regteroor; nie geimplanteer nie).

1: Ok, ek was so gebore, toe was ons in Pretoria. Ek het hier groot geword. Toe die gewone apparate.

3: Ek wil net se: Ek het rondgeloop van een dokter na 'n ander sonder om vas te stel en prof. Harmse, wat prof was voor prof. Swart, en toe het hy gese ek het, wel toetse gedoen, ek het Meniere se siekte. Dit word veroorsaak deur die Herpes virus (ek het nooit geweet nie). So, ek kry nooit eers 'n koorsblaar nie. Toe se hy maar hy kan 40 jaar sluimerend in jou sisteem le en enige trauma, hetsy ernstige siekte of so iets, kan hom aktiveer en dan val hy jou liggaam aan.

So, in kort, ek dink baie het nou daaraan geraak, maar in kort: hoe ervaar jy jou lewe na die kogleere inplanting?

5: Wel, ek moet vir jou se ne, oor die algemeen, miskien omdat ek 'n normale lewe gehad het aan die begin. Ok, my gehoor het skielik swak begin word en goed en nou is ek omtrent, ek assosieer my met presies dieselfde persone. Ok, ek het partymaal geraas en goed, maar verder assosieer ek my presies dieselfde as ander persone.

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4: Wel, ek het net nou ook vir hulle vertel ek het 'n splinter normale lewe gelei en so, as ek regtig op hierdie stadium 'n keuse kan he, wat nou nie so is nie, sou ek verkies voor die kogleer, wat met die gehoor van my twee Phonak apparate. Maar 'n ou moet aanpassings in jou lewe doen want, by my was dit ook nou as gevolg van die cholesteatome wat gegroei het. Eintlik het Dr. Burden gese ek het 3 maande oor om te lewe en die Liewe Vader het anders besluit, dis nou al 6 jaar later en dis nie ideaal nie, maar soos ek nou die dag vir iemand se toe ek hom laat diens en dit kos bietjie geld, maar dis nogsteeds 'n bargain. As hulle nou vir my se hys 'n miljoen rand, ek weet nie waar ek dit gaan kry nie, maar dis nogsteeds 'n bargain om te kan hoor.

5, 2: (Stem saam)

4: As jy gehoor het en daar, ek was soos in 12 tot 13 maande totaal en al doof. Weet julle dat ek ophou asemhaal omdat ek myself nie hoor asemhaal nie. Dat my, in die nag moet my man vir my se: haal asem, haal asem. Want, ek het altyd die gehoorstuk hier gedra en myself hoor asemhaal. En as ek myself nie gehoor het nie, het ek geweet hy is stukkend. So dis vir my 'n geweldige aanpassing. Maar iemand het dit in een van hierdie groepe eenkeer gese: voor die kogleer was sy doof en na die kogleer is sy gehoorgestremd. En dit is vir my regtig hoe dit is. Ek praat op die telefone. As jy my nou bel gaan ek jou nie ken nie. As jy se: "(nommer 4) dis Susan Loots van die kogleere span, hoor jy my?", verstaan jy, dan memoriseer ek jou, want ek het mos nou hierdie bietjie breinskade. Weet jy as jy volgende keer weer bel gaan ek jou onthou? Want my brein sal absoluut weet en ek dink iemand wat nooit in sy lewe gehoor het nie, het 'n groter leerproses as wat ek het wat altyd kon hoor. Ek het normal gelewe alles, ek het normal geboorte gegee, alles. Ek het selfs na my kogleer gaan skyway trail doen. Ek het besluit as ek oor drie jaar moet doodgaan, doen ek nou alles wat ek wil. En dis net wonderlik, maar ek dink dit hang baie af van 'n ou se gesindheid. Soos ek vanoggend vir (name) gese het, hy't dit nou 'n jaar. Ek se vir hom, weet jy, ek het hom ses jaar, dis elke maand of na elke mapping weer 'n aanpassing, maar ek sal dit weer doen as ek kan.

3: Ek moet se, dis maar 'n aanpassing. Ja, hierdie apparate was vir my konstant 'n irriteer en dis wonderlik van die koglea, jy het nie nodig om die heeldag jou ore te vryf en daai irritasie.

(Nommer 2)?

2: Jy het nou klaar die vraag gevra, maar ek het nie mooi gehoor nie.

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Hoe ervaar jy jou lewe na die kogleere inplanting?

2: Daar is nogal 'n groot verskil tussen die analoog, die analoog kan mos net, kom ons se, die lae klanke, nou die een kan die hoe klanke. Nou is dit nogal 'n moviese aanpassing, 'n interessante aanpassing as jy in die kamer sit en jy begin die krieke hoor. 'n Kriek is nogal bleddie irriterend, dan dog ek, sjoe my ma het gese daar is 'n kriek in my kamer, maar voor hy gewerk het was ek so (trek skouers op).

1, 2, 3, 4, 5: (Lag)

2: Jy weet nou daardie klankies, daardie hoe klankies wat ek nou hoor, maak dit nogal baie beter as om…

1: 14h45-15h50

4: Maar dis interessant dat hy se hy hoor die krieke, ek het net nooit. Ek het nooit in my lewe 'n kar in die straat hoor verby gaan nie en nou, na my breinsjirurgie (eintlik voor dit het die prof gese ek moet baie stap, maar ek is lief vir stap, maar ek moet meer stap), weet jy dis heerlik om te stap, want ek hoor die karre kom. In die verlede het ek altyd in die gras geploeter, want ek hoor nie 'n kar nie. En ek hou toesig by Unisa eksamen studente; hoor ek maar net die geskryf van penne, maar nou is ek nie eers seker dis dit wat ek hoor nie, nou skryf ek vir my hoof opsiener: Coriena, is dit die penne se gegriffel wat ek hoor? Dan se sy: "ja". Hoor hier, oombliklik as hulle omblaai dan hoor ek dit dan gaan kyk ek of dit nie"crip notes" is nie.

(Almal lag)

Mens het nie besef dis eintlik nodig vir 'n kwaliteit lewe nie.

2: Behalwe die spraak. As jy nou die analoog mos gehad het, hierdie ou apparaat, kon jy net die hoe klanke mos, die mens se stemme hoor. Nou begin jy soos die /s/ en die /r/ praat dan kom die persoon agter ek bry. (Lag). Dit grens so, jou spraak begin ook beter raak.

En sê vir my, nou kom ons bietjie terug na, het julle 'n behoefte om tyd te spandeer saam met mense wat ook kogleêre inplantings het?

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5: Ek dink, ek dink eintlik. Wag, ek gaan dit in twee antwoord. Ek sal sê: ja, in 'n sekeremate, ok, daar is sekere mense wat dalk 'n groter behoefte het as ander. Ek sal se die mense wat dalk 'n groter verlies het, het dalk groter behoeftes as die mense wat miskien gewoond was om normaal te gepraat het. So ek dink ja, ek sal sê ja, ja.

4: Ek geniet hierdie byeenkomste van ons verskriklik baie, maar soos dit is het ek 'n wonderlike vriendekring wat my absoluut deurdra en op die hande dra. Ek het nie regtig behoefte aan daardie tipe van kommunikasie nie, maar ek sou tog wou opvoedingstake doen. Soos in skole en, jy weet, vir mense gaan wys: kyk so lyk dit, dis glad nie so erg as wat jy dink nie. Want ons het vir (name) en vir (name) gebel; my tweeling sus, toe ek nou doof was, en dit het my geïnspireer. Want nou is ek, ek lag so vir die (name) nou, sit ons daar, nou haal sy hom uit en wys vir ons. Na so ruk sê sy: "maar ek hoor julle nie", sit sy hom weer terug. Toe het sy net een in, toe besef ek, maar…

En daardie kontak het jou gehelp?

4: Dit het baie gehelp. Nee kyk, dit het my absoluut gemotiveer as daar enige twyfel was, was die besoek om (name) en (name) vir my net "go for it".

5: Ja, kyk, fisies weet jy, om met mense te deel wat deur basies dieselfde probleem …kyk, ek dink nie oor die algemeen as ons mekaar nie geken het nie, dan sou ons nie probleme kon bespreek het nie en geassosieer het met 'n ander person wat dieselfde probleem gehad het nie. Nou kan ons die probleme aanvat en sê: hoor hier, so ons het almal dieselfde probleme. So dit veroorsaak beter kommunikasie, partykeer ook beter kommunikasie as die mense wat met ons werk ook.

Die "saam praat" dan?

5: Dis reg.

3: Weet jy ek dink ook so, want ons het almal dieselfde probleem, so om, dit is, ja, ek het gevoel toe ek doof geword het, het ek myself geïsoleer, so ek het teruggetrek…

4: Yes

3: As ek 'n gesels…ek het altyd by my skoonseun raas gekry, want dan sê hy: "Ma, jy loop altyd weg." En toe sê ek, dis vir my makliker om na my eie huis toe te gaan en boeke te lees as om in die geselskap te sit en te sê: "wat sê jy, wat sê jy?" So dis vir my lekker om…en ek het anti-sosiaal geword…so dis vir my lekker om weer in te kom. Vandag in besonder, want Pa is nie hier nie en ek "ry op sy rug". Hy praat vir my, baie, en hy doen vir my baie, so dit het nou vandag my goed gedoen om…as ek vir (nommer 4) sê: "ek het laat gekom en gespanne gewees, ek het doer parkeer, ek vat 'n tydjie om weer rerig te hoor." So ek het eers hier, ek het van Phonak niks gehoor nie, daardie eerste vrou het ek niks gehoor nie. Dit is vir my al of ek, askuus vir die woord, "dom" geword het. Mens moet weer inkom. So dis vir my lekker om saam mense te wees wat dieselfde probleem het, wat verstaan, want horende mense wat nie met gestremdes werk nie, verstaan nie, want hulle kan nie sien jy is doof nie…

5, 2: Ja

3: …'n blinde man loop met 'n kierie en hulle sê: "ag shame", of iemand met 'n rolstoel, maar as jy doof is, weet hulle dit nie, so daar is nie simpatie nie. Dis vir my lekker, dis vir my goed om.

2: Ja, vir my was dit ook, ja. Omdat ek eintlik in 'n gewone skool was het ek net altyd met horende mense oor die weg gekom al die jare. Nou, van ek hiernatoe gekom het, begin ek half sien hoe is ander mense wat ook gehoorgestremd…ek het al so gewoond, so aangepas om normale. Nou sien ek, "o, maar hierdie ou praat so en so" en dis vir interessant om met sulke mense te kuier en ek verstaan hoe dit is vir hulle.

En het jy tot 'n mate 'n behoefte om nou en dan kontak te he met hulle?

2: Ja, ja.

So dis maar mense wat verstaan, daar is meer…hulle het in die vorige groep genoem dat dit meer "credible", van groter waarde is as dit kom van iemand…

2, 3, 5: Ja, (skud koppe)**.**

Dan wil ek sommer by julle hoor, wat was julle ervaring van die afgelope groepbyeenkomste?

5: Wel ek moet eintlik vir jou sê, dit was baie interessant, vandag was nou vir my besonders interessant gewees. Ek dink ek geniet dit nogal! Jy weet, die mense is nice. Dis lekker, dis bietjie, dis eintlik ontspannend. Ek het nou die dag weer vir iemand gesê: "weet jy, ek dink hierdie werksomstandighede waarin ek is, is baie stresvoller werksomstandighede as die algemeen, so dus, selfs nou toe ek vir prof Johan gehelp het…weet julle dis verskriklik ontspannend gewees om saam met die mense hier te werk. Ek dink die universiteit self, as geheel, het 'n stigma van net 'n ontspannende gevoel. Ek weet nie, ek dink nie julle weet wat is baie stress nie. (Lag). Dit is baie lekker eintlik hierso. Ek geniet dit baie hierso. En mens leer ook baie dinge wat 'n mens nie geweet het nie, soos vandag nou byvoorbeeld. Baie van ons het nie van die toerusting geweet nie, wat beskikbaar is nie. Ek het al redelik daarmee gewerk, maar baie van die mense weet glad nie daarvan nie. So dis waardevol vir my, vir 'n mens, verseker.

4: Wel ek geniet ook, ek geniet regtig baie die byeenkomste en dis party dae, ek weet nie of hulle ook depressief raak nie en dan voel 'n ou: "ag vir wat is ek nou doof? Hoekom kan dit nou nie iemand anders wees nie?" Maar as ek hier kom en ek sien ander wat slegter oor die pad kom as ek, dan voel ek sommer weer baie goed en dis vir my baie interessant en vir my leersaam. En ek het al baie gedink, Phonak is vir my baie nader, maar dis asof hierdie "cuddling", hierdie liefde, nie by Phonak…by Phonak voel ek soos 'n instrument wat ingegee word…

5: Ek stem saam

4: …hier voel ek een van 'n span. Ek sal wraggies moeite doen, ek sal vakansie afstel om so 'n byeenkoms by te woon. Dis regtig vir my baie waardevol. En veral die kuiertjies na die tyd…

Ja, ek wou vra oor die sosiale…

4: …ja, want ek besef nou ook (nommer 3), toe sit ek nou nou en dink: jy moet faksmasjiene kry vir jou kinders wat jou nie kan hoor nie (wys na nommer 3). Ek het 'n tannie in Lydenburg wat doof is, sy hoor my nie. Ek kan haar hoor, maar sy hoor my glad nie. Toe een jaar koop en ek en my tweeling sus vir haar 'n faksmasjien en weet jy, nou hoor sy skielik glad nie, almal stuur op die faksmasjien. En as ek my foon antwoord, dan sê ek…dis 'n firma, partymaal kan jy hoor

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Telkom of SARS, dan sê ek: "Jammer ek is doof, ek het 'n kogleêre inplanting gehad, stuur vir my 'n faks". En, en dis sulke praatjies wat hier uitkom, nie by normale mense nie, want hulle dink nie daaraan nie.

2, 5: (Stem saam)

4: En jy lyk normaal. Almal van ons, so dan dink hulle ons is normaal, en eintlik is ons nie, ons is spesiaal (lag).

3: Die omgee en die moeite wat julle doen, word baie waardeer, want ons sou soveel armer gewees het as dit nie ontstaan het nie. Want ek wat doer in die vlaktes sit, dis eintlik ver agter, want soos die tegnologie wat vandag hier, ek weet nie eers daarvan nie, so dit is, nou dwing dit my om te kom en dis vir my waardevol, ek waardeer dit baie.

2: Ja, ek is baie keer maar nie opgedaag nie, maar dan begin ek maar weer sien dis dalk nou weer interessant. Soos byvoorbeeld vandag. Dan spring ek maar weer in my sussie se kar en dis vir my lekker. En dis 'n paar nuwe goedjies wat ek nie van weet nie. En soos sy (wys na nommer 3) ook sê, dis nogal interessant…hier is 'n ding wat vibreer wat jy sit onder jou kussing, (lag), maar ja.

Ek het ook gesien jy en (nommer 5) het ook lekker gesels, dis amper maar daardie "tips"….

2: Ja en hier is die ding. Baie keer as mens nou so slaap dan as jy so wakker word en jy sê: "Ag (kyk op horlosie) ek kan nog slaap, ag man, dis nog 'n uur," dan moet jy nou 'n plan maak.

4: Ja, swak slaap daardie laaste ruk.

2: As jy nou self wakker word, moet jy nou die apparaat die kant aan sit en jou kop draai, jy kan nou nie die kant slaap nie.

5: Kry vir jou 'n goedkoop selfoon en kry vir jou 'n hemp met 'n sakkie aan wat 'n zip het. Dan sit jy hom in en dan slaap jy. Sommer 'n R200 selfoon, dit werk baie goed.

4: (Lag)

(Nommer 1, hoe ervaar jy die byeenkomste?)

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1: Baie interessant.

4: Ja, hierdie enetjie van Phonak wat so vinnig gepraat het. Ek het haar nou gevolg, maar ek het gevoel sy praat te vinnig.

5: Ja, die een het baie vinnig gegaan, gelyk of sy baie haastig was…shame.

2: Soos hulle sê, daardie oom by die besigheid…as ek na hom toe gaan, "wat wil hy hê moet ek doen?", praat die ou, soos jy sê, (maak sy mond toe met sy hand) en mompel.

5: Ja ek sê vir hom, daardie dosent was so vies gewees, dis 'n projek wat ek moes doen. Vra hy vir my 'n vraag, maar weet jy dis soos (hand voor sy mond). Ek het so kwaad geraak, weet jy né, ek het naderhand vir hom gesê: "hoor hier, so in die eerste plek, vat net jou hand van jou mond weg dat ek kan hoor wat jy sê, asseblief.

Dink julle, het hierdie byeenkomste julle ondersteuningsnetwerk bietjie verbreed?

4: Vir seker, ja. Ek dink so. Weet jy wat is partymaal die ding. Mens voel so, ek sou nou vreeslik graag ook sy vriendin of sy vrou of so wil sien, maar weet jy wat, dis of hulle nie dieselfde samehorigheid het as ons nie. Ah, maar tog sal dit miskien eenkeer 'n jaar wil hê ons mense, of jou man, vrou of kinders moet saamkom, maar die nou die bedoeling eintlik van die jaareindfunksie né? Maar ek sal nie meer as eenkeer elke twee maande wil hê nie, want ek wil dit nie mis nie, maar ek sal dit ook nie elke maand ingepas kry nie.

(Nommer 3)?

3: Ja, ek het nou gelukkig… ondersteun my man my nou baie, so ek ry op sy rug: hy is my sekretaresse.   Hy moet al die bel werk doen en hy moet mense reël en so 'n ondersteuningsnetwerk is baie belangrik vir 'n mens. Ek dink dit moet baie eensaam wees as jy dit nie gehad het nie.   Omdat 'n mens jouself isoleer. Soos hy sê, hy moes dubbel so hard gewerk het as 'n normale kind om in te pas en goed te doen in skool en, die kinders wat kon hoor, is baie meer bevoorreg gewees…dit is 'n aanpassing.   Dit is baie goed om 'n ondersteunings netwerk te hê.

2: Askuus, vra gou weer die vraag.

Ek vra, het die bywoning van byeenkomste jou ondersteuningsnetwerk verbreed?

2: Ja, dit het.

Dan wil ek sommer oor die algemeen vra, dink julle dat dit nodig is dat mense met kogleêre inplantings tyd saam spandeer?

5: Ja. Ek dink so. Ja.

4: Ja.

3. Ja!

2: Ja! Dis nogals baie interessant om te hoor wat elke persoon te sê het, oor faks masjiene en hiers 'n faks masjien daar. (Lag)

3: Ek dink dis nodig. Ja. Dit is net moeilik as mens so sit, ons moet mekaar ook net kan sien. Dalk in 'n kring sit.

1, 2, 4, 5: (Stem saam)

My volgende vraag is juis: Het julle enige voorstelle van hoe die groepbyeenkomste kan verander? Byvoorbeeld soos jy noy gesê het, nommer 3, dat ons in 'n kring moet sit.

3: Wel, ek het reg voor (name) gesit so ek kon hoor wat (name) gesê het, maar ek kon ook nie byvoorbeeld hoor wat (name) daar gepraat het nie, of die man hoor gepraat het nie.

4: Ja, (name) praat baie sag, ek liplees haar maar net, ek hoor haar omtrent glad nie.

2: Uhm.

3: Ja, dit raak moeilik partykeer om mense te hoor. Ek probeer altyd heel voor sit dat ek die persoon kan hoor en kan sien. Ek probeer ook met my regterkant na aan die persoon sit, aangesien my gehoorstuk aan die regterkant is. En nou nou ook, as hy (wys na mommer 2) aan die kant sit kan ek hom nie so goed hoor nie.

4: Ek voel miskien, alhoewel soos ons sê mens raak lief vir mekaar, roteer. Sê byvoorbeeld my eendag nooi, argumentsonthalwe, na die Bloemfontein groep toe en dan 'n ander keer sê, ons ou groupie gaan vir ondersteuning na die Welom groep toe. Jy verstaan net net om by ander te gaan leer ook.

Ok, dan in meer terme van die groep, is daar iets spesifiek waaraan julle kan dink hoe ons dit kan verander?

5: Ja, ek wil nou, as ek nou dink aan iets sal ek; toe ons nou begin het hierso nê, hierdie juffrou het nou mos daai stelsel gehad wat dit bietjie harder gemaak het, dit was nogal baie nice gewees. Die klank was vir my baie duidelik gewees, ek weet nie of julle dit gehoor het nie. Maar dis ook iets waaraan ons moet dink, om so stelsel te kry en net om beter te volg oor die algemeen. Ek weet nie hoe het julle dit ondervind het nie?

3: Die eerste een.

4: Ja! Hier was so, ek noem dit sommer "surround sound", ek weet nie wat anders, ja.

3: Maar ek was daai tyd so laat…

4: Ja, jy het nie daardie gedeelte gehoor nie.

3: Ek dink dit is nogal goed, ek dink, ja, ja, ja. Ek het Engels skool gegaan, maar dit was vir my toe ek doof geword het moeilik om Engels te volg…

5: Ek stem saam.

3: …ek het in 'n Engelse skool geleer en baie Engels gepraat, maar dit was vir my moeilik, dit was eintlik half sleg as alles in Engels is, maar ek gun dit vir die Engelse mense. Maar ek voel baie keer hulle moet 'n bietjie oorskakel en nie net altyd…dis nie so maklik om vir almal om in Engels te hoor nie. Ek het nie 'n probleem met Engels nie maar ons Arikaners moet mos altyd terugtree vir die Engelse.

4: Ja nee, maar vir interessantheid. Prof Swart het vir my gesê, ek was by 'n swart skool, 'n Engelse skool, hy het my gesê daarvan. Mens kan nie Engels liplees nie.

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3: Nee, dis moeilik...

4: Want my eerste besef daarvan was, partymaal hoor jy maar net 'n woordjie, dan maak jy jou iei afleidings, toe ek nou nog minder goed gehoor het. Nou en dan, hoor ek die woordjie "here". Dan, weet ek nie sê die ou "hoor jy my nie" of sê hy jaar nie, want dit was in Desember: "Happy New Year". En jy weet daar is honderde sulke woorde in Engels en ek sien, maar ek is baie goed in liplees veral omdat ek ook nou in 'n swart skool was, hulle praat mos nou 'n ander taal wat ek sê vir hulle hoekom praat julle nou julle taal so hard en Engels sp sag! Dan sê hulle: "Ja, maar Engels is 'n gemoduleerde taal'. Toe het ek nou daaroor gelag, maar dit is interessant want nou dink ek weer as ek liplees, maar ek kan nou darem hoor.

2: Ek hou daarvan om lip te lees want sê nou maar (wys vêr) ek kan luister wat hy sê.

5: Vir my dieselfe oor 'n selfoon, as die person Afrikaans met my praat is baie beter die gesprek, as wat hy in Engels is. En Engels is dit vir my moeilik om te verstaan, ek kan partykeer nie uitmaak nie.

Ja en nou as die meerderheid van die groep Afrikaans is maak dit eintik…

5: Ja ja.

3: Ja, ,mens moet so, in so groep kan jy vasstel hoeveel, uh sê 80% Afrikaans is, in Afrikaans aanbied en dat in soos hulle nou weer vir ons in Afrikaans aanbied, soos was die Engelse vir ons doen.

2: Ja, want toe ons in Engels praat, kan hy ook bietjie weer in Afrikaans praat, want as 'n mens die heeltyd Engels praat dink jy jy verstaan die storie, dan as hulle dit in Afrikaans sê, dan sien jy hulle bedoel dit nie so nie.

5: Dis eintlik nogal vir my snaaks, want ons is so baie Afrikaanse mense. (Lag)

1, 2, 3, 4: (Lag)

Ok, dan wil ek gou by julle hoor: sal julle ander volwassenes met koglieêre inplantings aanbeveel om die groepe by te woon en hoekom.

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5: Well, ek dink persoonlik, ja. Hoekom ek so sê is, enige iets wat hulle hier gaan kry, gaan tot hulle voordeel wees, so, ek kan nie sien, hoekom jy dan nie.

4: Ek dink ook regtig, dis amper vir my 'n moet ek het byvoorbeeld hierdie mikrofoontjie ek noem dit sommer die "extension". As mens baie mense in die kar is en ek bestuur, knyp ek hom hier aan my bloes vas, want ek vind as ek dit vir die ou hier voor my gee, hulle sit altyd met die goed en speel en ek, nou wonder ek of die fout by my lê. En ek het met een van die kogleêre pasiente nou net gepraat. Met (name). Hy dra hom ok so, toe vra ek, is dit nie steurend vir hom nie, toe sê hy ja, maar ek sal agterkom hy staan stil. Ek is te besig. Dit werk nie in die normale dag vir my nie, maar in die kar werk dit puik. Maar ek het nie die guts om dit vir 'n oudioloog te vra nie, want soos sy sê party dink ons is senile, ons is eintlik net doof. Maar uhm, ek het, 'n mens is maar versigting om met kenners sulke onnosille vrae te vra, maar eintlik is dit vir ons belangrik. Want ek voel nou beter want hy sê ook hy kan nie baie, hy sê, hy sit syne aan die seatbelt in die kar vas, maar ek beweeg en it die ratte oor, so myne is vir my fine net hier aan my mou, so ek sou nou nooit dit vir iemand anders gevra het nie, so mens kry defnitief fyn detail inligting wat nie op papier voorkom nie, in hierdie groep.

3: Ja, 'n mens leer by di ander, so jyt eintlik, as jy nie kom nie…ek het nou baie geleer. Van allerande "gadgets' waarvan jy nie weet nie. Al wat vir my belangrik is, is die telefoon. Ek het by (name), sy het die ding om haar nek, ek dreig nou al hoe lank vir die dag wat ek, want jy kan daai ding blykbaar hierby jou hou en jou landlyn met him Koppel, so jy kan jou landlyn ook Koppel dat hy deur jou selfoon lui. Dit sal ek nou nooit geweet het as ek nie vandag gekom het nie. Leer, ons leer by mekaar. Ja, defnitief is dit die moeite werd.

2: Op die oomlik gebruik ek nog niks enige "gadgets' nie, maar op die oomlik het ek nou gesien soos sy die telecoil, wat wat noem jy dit, die telecoil op die foon wees nie. Ek gaan maar begin van die goed maar probeer en uittoets en tog maar meer op die foon werk. So ja. Ek het, een van die goed vandag getoets, het vandag nie vir my gewerk nie. Partykeer klink dit eers moeilik, want dan dit jy hom op jou oor, dan raas hy nie. As jy hom in die telefoon sit, begin die klank verskil. Dan verstaan jy nie daardie klank nog so lekker nie.

En dit is seker vir julle beter om dit van iemand te hoor wat dit al ervaar het.

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4: Persoonlike ondervinding. Ek meen dis nie te sê dit wat vir my werk, gaan vir iemand anders werk nie. Maar, uh, as jy dit nie probeer en daarvan weet nie, dan gaan jy dit nie kan doen of weet nie.

1, 2: O ja.

3: Dis nou soos daardie een wat (name) dra, wat jy nou kan leen vir een of twee weke en jy kan hom maar gebruik. Maar toe sê ek: "ja, maar ek bly nie hier nie". Toe sê sy ja maar, uhm, dis nie 'n probleem nie, ek kan hom mos pos. Hulle gee vir jou 'n ander…ek kan hom pos, terug pos. Nou koop jy hom, R2000, watokal, en hy werk nie regtig nie. Ja, maar en dan, en selfs daardie lapel dingetjie, kan e kook leen om te kyk, hoe werk dit. Kyk, stupid wat ek is, ek het nooit eers geweet jy moet hom hierdie aan die oorhoek skoonmaak nie. Ek weet nie, en toe ek nou by Elize hoor, ek sou dit nooit geweet het nie. Myne is pikswart en ek het hom nog nooit gedoen nie, want ek het nie geweet nie. Ek bedoel maar, dis goed wat 'n mens leer.

2: Ja, ja, ja, ja.

3: Ek sou nie eers geweet het waar om te kyk om dit skoon te maak nie.

En vir die jonger mense, hoe sal jy, sê nou maar jy moet vir iemand van jou ouderdom sê dat jy stel voor hulle kom na die groep toe. Hoekom sal jy vir hulle sê hulle moet kom?

2: Well, ek sal sê dit is vir hulle interessant om te sien hoe is die mense wat gehoorapparate het. As ek nou vir normale mense my ouderdom moet sê.

4: Hy het gesê hy kom net vir die koekies (lag).

1, 2, 3, 5: (Lag)

5: O ja, dis waar.

4: Nee, maar weet jy, maar somtyds, as mens dink aan die buite mense…ek het mos nou 'n tweeling sussie en haar man is 'n elektriese ingenieur en hy het voor die tyd ook hierdie klanke gaan doen op die rekenaar, sodat sy ook kon hoor hoe ek gaan hoor. Maar hy het by die susterskring, by die NHVF, (hoe noem mens hulle nou weer, hier in pierneef straat) gaan toespreek. Weet jy, dat twee uit die tagtig vroue wat daar was het geweet van kogleêr. Die

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ander het dit daar vir die eerste keer daar gehoor. En, en, uh, ek sê vir hom: "hoekom nooi jy my nie?" Ek sou daar gaan staan het, want hulle ken my (ek het in my doofheid het ek op die skou vir hulle gaan werk, hulle het te min staff gehad). Maar die dominee het net gesê: "luister, julle moet net vir (nommer 4) kyk en stadig praat." Hy het nie gesê ek is doof nie. En dit is die wonderlikste mense, dis net dat hulle nie besef…hulle ken net nie. Die ou met die kierie is blind en die ou in die rolstoel kan nie loop nie, maar die ou wat nie kan hoor nie, het nie 'n plekkie nie.

2: Ja, baie, ek gaan mos nou baie uit. Baie van die mense kom nie agter ek is doof nie as ek saam met hulle kuier. Dan eers bietjie later kom hulle agter ek is doof, hulle sien net my gehoorapparaat. "O, ok, ek het nie geweet nie".

Maar dit het in die vorige groep nogal uitgekom; die rol van bewusmaking. Om meer horendes bewus te maak van die doofheid.

4: Ek dink dis baie nodig.

En dink julle die groep kan dien as 'n plek van waaruit bewusmaking kan plaasvind?

3: Ja.

4: Ja.

5: Ek dink baie mense oor die algemeen is baie onbewus, het nie 'n clue wat 'n kogleêr is nie. Weet jy wat vir my die interessantse was, myne is mos aan die regterkant, so as ek bestuur dan kom hier 'n ou tannie langs jou, hulle stap hier langs jou…hulle kyk vir jou so en dan "chat, chat, chat" sy met die oom en dan draai die oom ook sommer en dan dink ek, nee wag, hierdie oom en tannie het nou baie lank bespreek wat is hierdie nou, (lag). Hulle weet nie wat dit is nie, jy weet. En by die werk ook. Weet jy, ek werk nou al vir elf jaar daar en toe nou die dag, toe vra hy vir my: "hoor hier so, is hierdie ding nou vasgeskroef aan jou kop?

1, 2, 3, 4: (Lag).

5: Mense het regtig…selfs in 'n winkelsentrum…dan staan mense hier agter jou en partykeer, jy kan dit eintlik aanvoel (jy weet iemand is hier agter jou, jy kry net daardie gevoel) en as jy so omdraai het daardie person reg in jou rigting gekyk, dan weet hulle nie wat se kant toe nie.

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Mense wonder, maar mense is snaaks, mense sal partykeer wonder oor 'n ding, maar jou nie vra nie. Weet jy, dis nogal altyd baie snaaks.

4: Wat ek net nou ook vir (nommer 3) sê, eintlik as 'n kind mens vra, aan die begin was ek nog so, maar toe was ek baie jonger. En hulle vra: "Wat is daardie?", dan sê ek sommer: "Niks." Maar, nou sê ek vir hulle: "Ek dra brille omdat ek nie kan sien nie, en hierdie is my ore, " en dan sê hulle: "tannie, kan ek sien?" en dan sê ek: "Maar onthou, as ek hom afhaal hoor ek niks." Dan haal ek hom af, dank an hulle ook hoor, dan sit ek hom aan hulle, dan sê hy nee maar hy hoor niks. Party sê nogal hulle hoor, maar jy weet mos maar. Dan sê ek: "sit hom vir tannie terug, hy plak daar vas." En van my volwasse vriende sê: "Ag Kitty, dis 'n persoonlike vraag, maar ek wil so graag weet." Dan sê ek: "Kom sit hier." Ek haal hom af dat hulle die deel onder my vel voel en ek sit hom terug. Snaaks genoeg, daardie persone vra jou nooit weer nie. En as hulle in die geselskap is en iemand vra, dan vat hulle sommer die woorde uit jou mond uit en hulle vertel.

1, 2, 3, 4, 5: (Lag)

2: Dit het met my ook al gebeur! En partykeer begin ek al so tegnies raak en dan kyk hulle my net so weird aan. Hulle ken mos nou al die haartjies wat die klank maak, want dis die klank wat mos die haartjies stimuleer…hy sê: "ja, ja". As jou hare mos nou lank is, kry jy dit beter, maar wat gebeur nou as die haartjie bietjie kort gegroei is, dan kan jy mos nou nie meer so baie klank wat jy kan hoor nie. Dit is hoekom mens nou doof is. "Jis, dis interssant hoor!"

1, 2, 3, 4, 5: (Lag)

Sê gou vir my. Het julle na ons sessie met Hear2day, het julle al bietjie gaan kyk op die internet na ondersteuningsgroepe of forums vir mense met gehoorverlies?

4: Ag ja, ek het eintlik lank terug probeer en ek hou niks van facebook nie. Ek is daar, maar ek hou niks daarvan nie. En die ander artikels lees 'n ou, maar dit het nie naastenby die impak wat 'n praatjie hier vir my het nie. Nie naby nie.

5: Ek sal sê, weet jy, ek sal nou nie, ek het al bietjie daar deurgegaan. So die inligting wat hulle daar gee is goed. Ja. As jy die internet gebruik, kry jy baie inligting daar. Daar is 'n "girl" wat

oor al hierdie goed geskryf het, maar baie mense skryf oor selfone, Bluetooth en daardie goed. Die blackberry…almal wil weet, want dis ook iets wat ons…maar in elk geval. Mense weet nie daarvan nie, mense sê iets vir jou en dan niks verder daarvan nie. So, die internet en daardie goed is handig, want dis dinge wat mense wat dieselfde probleem as jy het al ervaar het, so jy kry baie.

2: Ek weet nie of julle baie e-mails lees miskien nie?

4: Uhm. Ag weet jy, ja, ek doen, maar as ek nie hoef nie dan doen ek nie.

2: Nie lus nie?

4: Eintlik, die lekker ding is, ek praat met my sussie op die internet. Ek sien ek het so drie, maar ook nou nie skype nie. Sommer net e-mail. En al hierdie rommelpos wat mens kry: ek haal net die fototjies, die prentjies uit, druk dit vir die kerkblaadjies en goed uit, maar verder, nee.

2: Maar jy sien, waar ek die meeste, vinnigste, inligting kry is per e-pos. As iemand vir my sê, hoor hier…dit kom direk op my foon as iemand my mail. Oja, ek moet dit gou op my computer gaan lees. Facebook ook, jy weet, mense begin fanmail en goed wat mense nie wil lees nie.