

THE CHALLENGES AND COPING STRATEGIES OF COMMUNICATION PARTNERS OF OLDER ADULTS WITH DISABLING HEARING LOSS USING ASSISTIVE HEARING TECHNOLOGY. A SOUTH AFRICAN STUDY



The Challenges and Coping Strategies of Communication Partners of Older Adults with Disabling Hearing Loss using Assistive Hearing Technology. A South African Study.

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MSTSAF001

Submitted to the University of Cape Town

In (dissertation) fulfilment of the requirements of the degree

MSc in Audiology

Faculty of Health Sciences

University of Cape Town

Date of Submission: 24th December, 2021

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Acknowledgments

Throughout this research project I have received tremendous support and assistance.

I would like to thank my research supervisors Mrs. Lucretia Petersen and Ms. Vera Hlayisi for their invaluable guidance and dedication throughout this research project.

I would also like to acknowledge the cochlear implant unit at Tygerberg hospital and the private audiology practices in Cape Town that provided me with access to the participants for this study.

I am truly grateful to the Health and Welfare Sector, Education and Training Authority for making it possible to complete this study.

My deepest gratitude and affection go to my husband and parents who have continuously supported and encouraged me throughout these years of research.

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Abstract

The effects of disabling hearing loss can create communication barriers that do not only affect the person with hearing loss (PHL), but also the communication partner's (CP) quality of life. Literature has previously been centred around the individual with hearing loss, thus leaving an information gap in South Africa that focuses on providing family centred care that includes the CP in the audiological rehabilitation process. It is important for hearing health professionals to consider the CP's wellbeing when managing older adults with hearing loss, as they have been found to play a significant role in the audiological rehabilitation process. Therefore, exploring the Goal Sharing for Partners Strategy (GPS) tool in a South African context will contribute to the knowledge in the field of audiological rehabilitation. Furthermore, gaining insight into the challenges and coping strategies that CPs experience will improve on the approach to the service provided in audiological rehabilitation.

A qualitative research design was employed with a sample of 10 couples who completed the GPS tool and semi-structured interviews. The data was analysed using thematic analysis. The results revealed four overarching themes that presented the effects of disabling hearing loss on the CP. The impact of disabling hearing loss resulted in daily life communication challenges for the CP. These challenges affected CPs emotionally as well as transformed the way they communicated in their relationships, however, the values, beliefs and personality of the CPs allowed them to cope and develop resilience to the burden of third-party disability. Additionally, the usability questionnaire demonstrated that the GPS tool was an appropriate tool to use in South Africa when adopting a family centred approach to audiological rehabilitation and was most beneficial when implemented as an interview guide administered by an audiologist. The information from this study can be used to provide

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support to other CPs as well as enhance the success of audiological rehabilitation for PHLs
through a family centred approach.

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Abbreviations

Abbreviation	Meaning
CP	Communication partner
PHL	Person with hearing loss
GPS	Goal Sharing for Partner Strategy Tool

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Introduction

This introductory chapter provides an overview of the research topic. It also highlights the relevance of the study, the aims, and objectives as well as the current gap in literature.

Hearing is a fundamental aspect of communication to many, and serves as a means to connect with each other throughout our lives (Marrone et al., 2019). Communication barriers can influence our social connections negatively which can lead to an isolated life from loved ones. The effects of disabling hearing loss can create communication barriers that do not only affect the person with hearing loss (PHL), but also the communication partner's (CP) quality of life and negatively impacts them emotionally, psychologically, and socially. This negative effect on CPs is considered to be third-party disability. CPs are individuals that PHL frequently communicate with, and can refer to significant others such as spouses, children, siblings, relatives, friends, carers and colleagues (Manchaiah et al., 2013). Disabling hearing loss is the most prevalent sensory deficit in the elderly (Dawson & Bowl, 2018), irrespective of the age it develops in the individual's life course, it has a profound impact on one's psycho-social wellbeing, interpersonal communication and quality of life (Olusanya et al., 2014). PHL may experience various barriers to participate and engage in areas of life due to communication difficulties (Granberg, 2015). Aspects of communication such as, listening to sounds, comprehending speech, listening in the presence of background noise, poor visibility of lip reading and facial expression are some difficulties experienced by PHLs (Granberg, 2015). Therefore, the negative consequences can be mirrored by those in their communication circle (Meyer et al., 2015).

The treatment of the hearing loss may include the uptake of assistive hearing devices such as hearing aids, cochlear implants, middle ear implants, auditory brainstem implants,

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bone-anchored devices and audiological rehabilitation (Rutherford & Petersen, 2019).

However, managing disabling hearing loss is not limited to the uptake of an assistive hearing device, but includes counselling for all stakeholders, in the approach (Rutherford & Petersen, 2019)

Providing treatment for the family as a unit, rather than the individual alone is integral to the approach of family centred care (Ekberg et al., 2020). Family centred care in audiological rehabilitation provides a holistic approach to include addressing third-party disability in CPs and also includes CPs to assist the PHL in the process (Hickson et al., 2016). Therefore, each individual, including the CP's wellbeing needs to be considered to allow the family system to function successfully. Traditionally, audiological rehabilitation focused on the individual with the hearing loss, however, studies internationally over the past two decades have been shedding light on their significant other (Nandurkar & Shende, 2020). Studies of audiological rehabilitation in South Africa have shown to be more techno-centric, lacking the involvement of counselling or environmental modifications (Rutherford & Petersen, 2019). Audiological rehabilitation is still a developing area in South Africa due to limited knowledge and implementation of beneficial approaches applicable to the South African context (Makhoba & Joseph, 2016). Therefore, the effects of disabling hearing loss on CPs are not addressed due to the lack of inclusion in providing management strategies in the audiological rehabilitation process in South Africa.

The Ida Institute, a non-profit organisation in Denmark, developed a tool called *Goal Sharing for Partners Strategy Tool* (GPS) as one of many with the goal to foster a better understanding of the human dynamics of hearing loss (Manchaiah et al., 2013). The tool focuses on the communication between the PHL and the CP. Exploring the (GPS) tool in a South African context and gaining insight into the challenges and coping strategies that CPs

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experience, will contribute to the knowledge and improve on the approach to the service provided in audiological rehabilitation.

The current study explored third-party disability with regard to the challenges that CPs experience due to disabling hearing loss of their significant other. By identifying these challenges and the various contexts, the study provides insight into third-party disability and the importance of a family-centred approach involving both the PHL and CP in the management process. This research project aimed to describe the challenges that impacted on the CP's experience when dealing with disabling hearing loss and explored the GPS tool, in terms of its usability to help CPs describe their challenges and to describe the strategies adopted by CPs to overcome their challenges. The focus of this study was on the CPs of older adults with disabling hearing loss.

The following chapters will expound on the current research in the area of third-party disability related to South African CPs of older adults with disabling hearing loss. It will also provide an insight into why conducting research in this field is important and beneficial approaches to be explored in audiological rehabilitation to implement a more inclusive service in South Africa. The methodology will provide insight into the process of obtaining the data. The chapters thereafter will present the results and discuss them into further detail.

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Literature Review

The study explores the challenges and coping strategies that CPs experience living with older adults with disabling hearing loss. The challenges are described with regard to the various aspects of the CPs life such as their everyday activities, environment and personal factors. The coping strategies are described based on the challenges experienced. The main interest areas that underpin this study include disabling hearing loss, CPs, third-party disability, audiological rehabilitation, family centred care.

Disabling Hearing Loss and its Effects

Disabling hearing loss affects 1.5 billion people globally (WHO, 2021) and is defined as hearing thresholds over 40dBHL in adults (Davis et al., 2016). According to the World Report on Hearing (WHO, 2021) 65% of adults over the age of 65 years suffer from disabling hearing loss, with a significant prevalence in developing countries in Sub-Saharan Africa, Asia Pacific and South Asia. South Africa is included in the Sub-Saharan region which makes up 10.6% of the distribution of disabling hearing loss in the world (WHO, 2018). The prevalence of disabling hearing loss in a population sample of 2494 participants in the Cape Town Metropolitan area was 4.57% amongst individuals older than four years old (Ramma & Sebothoma, 2016). The primary consequence of disabling hearing loss is impaired communication (Ropper et al., 2017) which may in turn affects the individual's cognitive, physical, emotional, behavioural and social wellbeing (Trychin, 2012).

Social Impact of Disabling Hearing Loss

The relationship disabling hearing loss has with cognitive decline and fatigue have shown impact on the PHL's communication in multiple ways. Trychin (2012) explains that communication breakdowns can have a severe rupture on a relationship impacting the PHL to the extent that it causes social pain. Social pain refers to the feeling that the PHL experiences

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as a result of the loss of social attachment, that arises from rejection or being passively ostracized due to the communication breakdowns (Trychin, 2012). These communication breakdowns could create major social barriers such as staying connected to those in the individual's direct communication sphere as well as those that are fewer intimate communicators.

Communication Partners and Disabling Hearing Loss

The consequences of hearing loss can have significant effects on the CP. Barker et al. (2017) mentions that CPs could be affected by every phase in the hearing loss diagnosis up to the rehabilitation process. The effects of hearing loss such as social pain, emotional distress, fatigue, reduced attention due to fatigue and cognitive decline may all have an impact on the communication the PHL has with their CPs. It has also been found that the CP's perspective of the PHL changes due to the changes in the PHL's sense of self (Barker et al., 2017). The studies by Manchaiah et al. (2013) and Manchaiah et al. (2012) revealed that family dynamics change as the PHL assumed more dependency on those around them.

CPs may demonstrate emotions such as frustration, guilt and anger due to factors such as social isolation, dependency and communication breakdowns. It was discussed in a few studies that the communication breakdowns had detrimental consequences, affecting the relationships between the PHL and CP (Barker et al., 2017). Factors such as the health of the relationship and personality of the CP may also contribute to the success of the relationship despite the effects of the hearing loss. Preminger et al. (2015) revealed that a hearing loss could either make a good relationship better or a bad relationship worse. Another study by Manchaiah et al. (2013) added to this finding by mentioning that CPs with a more positive attitude were affected less by the psychosocial issues regarding the effects of the hearing loss.

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In South Africa, the family composition differs to other upper middle-income countries (Makiwane et al., 2017). Therefore, the CPs may differ to the CPs used in studies internationally. The family composition in South Africa comprises of various structures including, young adults being the heads of smaller families, elderly parents assuming responsibility for large multigenerational families and other support such as neighbours and friends (Makiwane et al., 2017).

It is important to also understand the role the CP plays in the life of the PHL as the dynamic between the PHL and CP may differ, impacting the way they deal with hearing loss and the way that hearing loss affects the CP. Preminger et al. (2015) also mentions that understanding the obligation and expectation embedded in family relationships may assist the audiologist to manage their clients holistically. There are cultural norms and expectations that exist between various CPs and as a result the support between the CP and PHL may also differ.

In South Africa there are many cultural norms and expectations from the diverse cultural population, therefore it is important to consider the context of the population and how it may differ to the participants used in international studies. In a study where the spouses were the CPs the effects of the hearing loss reported were communication difficulties, emotional problems such as irritation, frustration, anxiety and lifestyle changes such as social restrictions (Scarinci et al., 2012). Similarly, adult-children also experienced psychosocial effects such as irritation, frustration and loss of intimacy in their relationship, however, they did not experience the same social restrictions and difficulties in everyday activities as spouses did (Preminger et al., 2015). This was explained as possibly due to the fact the adult-children did not live with their parents with hearing loss. Despite the differences both CPs experienced third-party disability as a result of the hearing loss.

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The positive impact of disabling hearing loss on CPs were demonstrated in the interpersonal relationship between spouses and the PHL. In a South African study by Govender et al. (2014) it was found that despite the frustration and anger caused by the hearing loss, there appeared to be a natural closeness that developed in the marriage. In another study by Manchaiah et al. (2013) spouses with a more positive attitude adapted to the impact of the hearing loss by finding new ways to communicate with the PHL. This also suggests that the attitude of the CP may determine how their partner's hearing loss impacts them.

Third-party Disability

The World Health Organization (WHO, 2001) has developed a framework within the International Classification of Functioning Disability and Health (ICF) which considers this shared experience of disability as third-party disability. Third-party disability (TPD) is defined as the disability and functioning of family members relating to the health condition of their significant others (WHO, 2001). An Australian qualitative study by Scarinci et al. (2009) further explains how the effects of hearing loss on the CP is mapped into the domains of the International Classification of Functioning, Disability and Health (ICF-DH) framework. This suggests that the effect of the disabling hearing loss expands into many areas of the CP's life, including everyday activities, their environment and personal factors. The study was developed to demonstrate problems in communication; quality and quantity of communication, CP's communication strategies and emotional problems due to communication changes. Scarinci et al. (2009) have demonstrated the presence of TPD among CPs of persons with hearing loss. This finding is supported by another study conducted by Scarinci et al. (2012) which found that 98% of spouses experience some degree of third-party disability. Preminger et al. (2015) also revealed the third-party disability experienced by

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adult-children due to the impact of the hearing loss on the family relationship, communication and their parent's personality. Coping strategies and feelings are modulated as contextual factors that could lead to participation restrictions and activity limitations (Preminger et al., 2015). This suggests that the effect of hearing loss on the CP and the way they manage it could determine the impact it has on their daily life. Therefore, positive coping strategies and a healthy emotional response can decrease the burden that CPs can experience from the effects of hearing loss (Roberts & Delich, 2020).

Literature in the field of third-party disability and hearing loss is limited to international studies such as Scarinci et al. (2009) and Grawburg et al. (2013). Coutts and Solomon (2020) revealed the challenges that South African caregivers experience when administering diet modifications at home. The challenges may not be specific to hearing loss, however they are challenges that are a reflection of the impact of illness in a South African context. The challenges of South African caregivers included financial burden, conflicting beliefs and ideology of the management of the health condition and an increased dependency on the caregiver (Coutts & Soloman, 2020). These challenges differ to the challenges experienced by Australian caregivers due to the cultural, linguistic and socio-economic circumstances of the South African population (Coovadia et al., 2009)

Audiological Rehabilitation and the Involvement of CPs

Audiological rehabilitation may assist to reduce participation restrictions and facilitate better personal and environmental strategies to reduce the disabling effects of hearing loss (WHO, 2001). Traditionally, audiological rehabilitation had a 'one size fits all' approach. This approach focused on the site-of-lesion and emphasized the technology as the primary treatment method rather than it being a component of audiological rehabilitation (Singh et al., 2017). There have been limitations in the traditional approach to solve the problems of

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hearing loss and therefore there is a movement to provide a tailored treatment approach which is more holistic. A comprehensive approach includes helping the person with the hearing loss, their families and communication partners in their unique contexts and to live well with their hearing loss (Rutherford & Petersen, 2019).

Audiological rehabilitation is a developing service in South Africa and the approach to providing the service is not widespread (Makhoba & Joseph, 2016). Makhoba and Joseph (2016) also mentions that audiological rehabilitation is still a limited service provided by audiologists in South Africa due to limited training, time, lack of culturally appropriate resources, and financial constraints. There is also a lack of research conducted in the practices of audiological rehabilitation in the South African context (Rutherford & Petersen, 2019). Therefore, it is important to explore the content of existing tools to determine the cultural appropriacy in the South African audiological rehabilitation setting and the best implementation method of the tool in a resource-stricken country.

Currently the audiological rehabilitation service in South Africa is limited to hearing aid fittings, communication strategy training and information counselling (Makhoba & Joseph, 2016). Despite the increasing evidence of the benefits of including CPs in audiological rehabilitation, research internationally indicated that there is still a lack of inclusion in clinical practice (Ekberg et al., 2020). CPs have been shown to be involved in the rehabilitation process, with regard to the support they provide to the PHL (Hickson et al., 2014). The role of the CP is shown to have an influence at all stages of the audiological rehabilitation process, including prior to assessment and intervention. The first stage of the process where the role of the CP influences the PHL is encouraging them to seek help for their hearing loss (Manchaiah et al., 2012). However, in a study by Ekberg et al. (2015) it was revealed that CPs played a minor role in the appointment session as they were not typically

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invited to join in on the conversation. Similarly, Grenness et al. (2015) found that despite the presence of the CP in the session, the communicative exchange was controlled predominantly by the audiologist with minimal inclusion of the companion. These results imply that the CP is involved in the audiological rehabilitation process by providing support to the PHL, however there is a lack of involvement of the CP directly in the session. The reasoning behind the lack of inclusion of the CP may be due to the audiologists uncertainty around how to implement family centred care practices and the lack of confidence to manage conflict between the CP and PHL (Ekberg et al., 2020).

CPs are also involved by providing emotional support, assist in the decision making, linguistically interpret on behalf of the PHL and facilitate good hearing aid management for the PHL (Meyer et al., 2015). Hickson et al. (2014) also demonstrated that the most significant factor to successful hearing aid uptake was the positive support from the CP. A study by Meyer et al. (2015) supports this finding, as the audiologists in the study also expressed the great benefit that the CP's involvement has on the PHL in the audiological rehabilitation process. The studies all demonstrate that currently the role of the CP is more of a supportive figure to the PHL, and the effects of the hearing loss on them are not managed. Therefore, the CPs are constantly living with the effects of hearing loss but have not been offered the service of intervention to deal with it.

In South Africa the CPs may experience third-party disability and not seek professional assistance independently. A study has shown that when dealing with emotional issues a large majority of South Africans seek help from family or friends before contacting a health professional (Andersson et al., 2013). The lack of seeking help from professionals precludes to the importance of health workers providing intervention for the CP as they are often the person whom the PHL may depend on for emotional support. These are all factors

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that emphasize the need for a family centred approach to be adopted in audiological rehabilitation that provides care to both the PHL and the CP.

Inclusive Audiological Rehabilitation

Internationally studies have observed the involvement of CPs in the audiological rehabilitation setting. According to Manchaiah et al. (2012) several approaches have been implemented to involve the CP in the audiological rehabilitation process such as group audiological rehabilitation programmes, home based education programmes and Conversation Therapy (Lind, 2010). These approaches, however, are structured towards management of the PHL and little benefit was provided to the CP. A study by Preminger and Meeks (2010) focused on evaluating group audiological rehabilitation for spouses. It was found that there was a clear benefit for the PHL in areas of communication and overall quality of life, however there was limited improvement for the spouses. The possible explanation for the negative results outcome were the varying group demographics that the groups were composed of and the comparison individuals made to each other to evaluate their own condition (Preminger & Meeks, 2010). Furthermore, the lack of significant findings were due to the separation of the CP and PHL in the session. The explanations suggest that the demographic composition of the session, the content used in the groups and the inclusion of the CP in the same session as the PHL impacted on how beneficial the audiological rehabilitation group session was for the CP. Therefore, this indicates that even in audiological rehabilitation sessions where the CPs were involved, the focus was still predominantly on the PHL who reaped the benefits.

Family Centred Care

Family centred care is an implementation of health care that provides a service to the individual and considers the significant others/family as partners in the process of planning,

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executing and monitoring treatment (Singh et al., 2017). The use of the family centred approach in the current study does not only apply to individuals in the family unit such as those related to the PHL by blood but, extends to all individuals that are frequent communicators with the PHL. The purpose of family centred care has been described as “seeing the family as part of the individual’s environment or as part of a system; and care should thus be aimed towards the needs of the family as a whole” (Mikkelsen & Frederiksen, 2011). In a family system each individual affects the other. The demonstrated impact of third-party disability on CPs highlights the importance of including family members in the audiological rehabilitation process. Therefore, providing care for the CP experiencing third-party disability will also benefit the PHL. Scarinci et al. (2013) explains that involving family members in the treatment will promote the adjustment to the impairment and benefit the PHL regardless of whether it is a family or individual issue. It also provides a better picture of the family dynamics and prepares the family for beneficial involvement in the management process.

Hearing loss is a condition that affects communication and as research has shown it often affects communication with those who frequently communicate with the PHL. This finding emphasizes the need for a family centred approach to be adopted in audiological rehabilitation as the approach accepts the family as the client rather than the PHL, encourages trust and open communication and establishes a collaborative partnership with the audiologist (Scarinci et al., 2013). The application of this approach will provide the holistic intervention much needed for managing older adults with disabling hearing loss and their CPs in South Africa. Literature has shown that the implementation of the family centred care approach is still lacking in clinical audiology practice (Ekberg et al., 2020). South Africa’s family structure is one that includes several individuals, all of whom may experience some aspect of

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third-party disability; therefore, the audiological rehabilitation structure would benefit both CP and PHL with the inclusion of a family centred approach.

The negative impact of disabling hearing loss on spouses has been apparent in many studies internationally and according to Govender et al. (2014) in South Africa as well. However, third-party disability is not limited to spouses but all CPs in the family. Therefore, in South Africa the concept of family can be described as two individuals that are related through biological, legal or emotional relationships (Scarinci et al., 2013). Audiological rehabilitation in South Africa is still a developing service and therefore provides limited intervention. Previous research in South Africa has focused on providing a family centred approach to early hearing detection and intervention Maluleke et al. (2021), however there appears to be limited information with regard to family centred care in adult audiological rehabilitation. Exploring supportive resources such as the GPS tool will provide more information on expanding our practice of communication rehabilitation and the inclusion of CPs in a South African context, which will ultimately provide better service delivery in audiology. Therefore, to contribute to the field of audiological rehabilitation, this research project will focus on the communication challenges and management strategies South African CPs of older adults with disabling hearing loss experience, and furthermore how usable the GPS tool is in the South African context?

Methodology

The following chapter will include details of the aims and design of the study, the participants, recruitment methods, data collection tools and procedure.

Aims

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1. To describe the communication challenges and management strategies in South African CPs to older adults with disabling hearing loss.
2. To determine the usability of the GPS tool in a South African context in terms of the tool's ease of use, understanding of content, efficiency and success on reaching the intended outcome of the tool.

Research Design

The study adopted a qualitative descriptive design using semi-structured interviews. Descriptive studies intend to describe or explain relationships among phenomena. Using a qualitative research design, the current study was able to obtain an understanding, interpretation and meaning of the CP's experiences interacting and communicating with a PHL (Lichtman, 2014). Semi-structured interviews were included as a component of the design, as it allowed the researcher to ask open-ended questions to gain insight and probe into the thoughts of the individuals in the group (Adams, 2015). The videocall or telephonic interview was for an average duration of 60 mins.

Participants

Inclusion and Exclusion Criteria

To be eligible for the study, the participant's criteria requirements for the PHL were over the age of 60, have a diagnosis of disabling hearing loss and be able to read and write in English or Afrikaans. The inclusion criteria for the CP were over the age of 18 and be able to read and write in English or Afrikaans. The participation of both CP and PHL enabled inclusion into the study, one could not participate without the other. Participants who disqualified from participating in the study were any individual with evidence of a different sensory impairment other than hearing loss (e.g., blindness) or neurological deficit, to confirm that the communication challenges experienced were a result of the disabling hearing

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loss and not due to a different sensory impairment or neurological deficit. There were no exclusions except for a couple who had to change their choice of a CP as their initial choice did not fit the criteria. The participants who refused to participate, were thanked and allowed to leave the study.

Recruitment and Sampling

PHL were recruited through Tygerberg hospital's audiology department and private audiology practices around Cape Town. CPs were recruited through the PHL. The audiologists in the above-mentioned sites assisted with identifying participants who met the criteria for the study, requested their consent then presented them on a list and shared their contact details with the researcher. Purposeful sampling was used as it allowed the researcher to select individuals who meet the criteria and are 'information rich' to contribute to the research purpose (Holloway & Wheeler, 2010). The researcher chose the participants from the list and assured the participants that their participation in the study will not impact on any of the services offered by the institution. Thereafter the researcher contacted the chosen participants, telephonically, via email or text message. When contacted telephonically the researcher established which mode of communication the PHL preferred. Some participants did not answer the phone and sent a text message to inform the researcher of their preferred mode of communication. Once the preferred mode of communication was established, the researcher provided the PHL with an overview of the study.

Sample Size

The sample size for the study was 10 couples (ten CP's and their PHL) which reached data saturation. According to Merriam and Tisdell (2016) small sample sizes with information rich participants are suitable for qualitative designs. The purpose of the study was not to generalize findings across a population but, to explore and describe the

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experiences of the phenomenon of those involved. Qualitative studies previously conducted by Manchaiah et al. (2013) and Scarinci (2008), similar to the current study also utilised a small sample size e.g. nine participants. All the PHL had assistive devices, either cochlear implants or hearing aids.

Data Collection

Collection Equipment and Materials

1. The Ida tool Goal Sharing for Partners Strategy (GPS) tool (Appendix G) was used as an instrument to obtain information regarding the communication challenges and management strategies of PHL and CPs. The GPS discussion tool has been created by the Ida Institute to involve family members as an additional insight into the client's experience with hearing loss and make the CP an integral part of the audiological rehabilitation process. The tool is structured to encourage conversation between the PHL and their CP, to set goals and plan how to achieve them. The objective is to provide a more holistic approach to audiological rehabilitation focusing on patient-centred care.

- The tool is currently available in English only and was translated into Afrikaans to accommodate the participants in a South African context. Permission to modify the questions and translate the questions to Afrikaans was obtained from Dr C. Rutherford. A pilot study was conducted to test the translated content of the tool, and adapt it for the main study.
- The pilot study provided the researcher an opportunity to experience the mechanics of the research process which included testing the GPS tool, interview schedule and questionnaire (Basit, 2010). The content and language of the GPS tool was assessed and adapted for better ease of understanding. There were two participants in the pilot study, an older adult with a diagnosed disabling hearing loss and his communication

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partner. The participants were both over the age of 60 years and were not participants in the main study. The same ethical procedures were applied to the pilot study as the main study. Modifications to the research material were performed based on the feedback provided from the participants and their ease of understanding the instructions.

- There was one question modified on the GPS tool which was question 3 directed at the person with hearing loss. The question “How does the hearing loss affect your partner?” was modified to “How does your hearing loss affect your partner?”. This provided more clarity for the participant. The participants completed the tool independently, however, they required additional instructions regarding the completion of the questions. They were instructed to complete questions one to three independently and questions four to six required discussion between the participants. The participants also required examples to be provided pertaining to question one, “where do you find communication most easy”? They required clarification as they had understood that the question referred to the situation where communication is most easy and not including the environment.
- The readability of the tool has a reading level of 3.8 according to the Flesch-Kincaid analysis.
- The usability of the GPS tool in a South African context questionnaire ([Appendix F](#)) was utilized. The questionnaire was also self-developed to address the aim of the study. The questions are aimed at determining the ease of use of the tool, understanding of the language content, and the functioning of the tool to reach the intended outcome. The questionnaire was reviewed by both the primary and co-supervisor.

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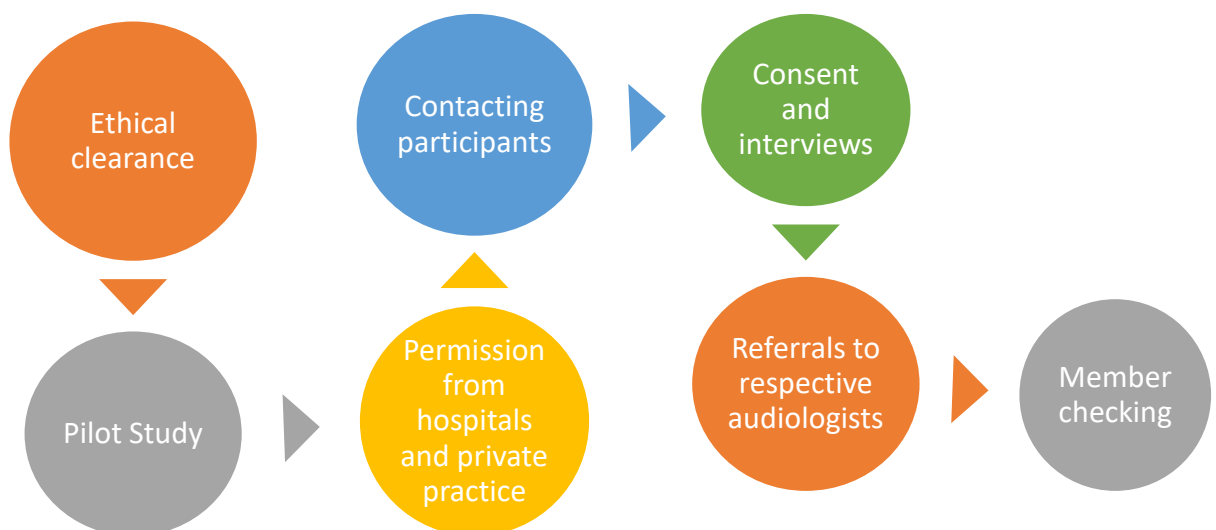
2. A topic guide (Appendix E) was used to structure a discussion with the participants on their responses on the GPS tool. The topic guide was self-developed to address the questions on the GPS tool and obtain information regarding the communication challenges and coping strategies of the CP by asking open-ended questions. Open-ended questions used in qualitative research allows the researcher to obtain data rich information and probe into personal experiences, providing the researcher with quotes from the participants to support the results (Allen, 2017).

Collection Procedure

The procedure of data collection is depicted and described in detail in the points below.

Figure 1

Collection Procedure



1. Following ethical clearance, a pilot study was conducted to ensure that the material used in the data collection procedure, such as the GPS tool was suitable for the study. The content and language of the GPS tool was assessed in a pilot study and was

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slightly adapted. The participants in the pilot study were not included as participants in the main study.

2. Permission from the relevant public hospitals, Western Cape Department of Health and heads of the Audiology departments in public and audiologists in private practice were obtained (Appendix D). A briefing meeting was held telephonically with the audiologists regarding the study goals, their role in the recruitment process and the possibility of a follow-up session with the client if a problem may arise. The audiologists obtained permission from the clients to share contact details with the researcher. Furthermore, Tygerberg hospital is an academic hospital that obtains permission from their clients upon their initial visit to partake in research. The researcher also signed a confidential agreement not to divulge any information obtained from the clients. Clients (PHLs) from Tygerberg audiology department and private audiology practices situated Green Haven and Milnerton were identified. The audiologists presented a list of clients that fit the inclusion criteria for the study based on their own professional discretion. The client's contact details were shared with the researcher to contact and invite the clients to participate in the study. The researcher contacted all the clients on the list. There were eleven clients that were contacted successfully and were provided with further detail on the study and ten clients who displayed willingness to participate in the study.
3. The researcher assured the participants that their participation in the study will not impact on any of the services offered by the institution. Thereafter the researcher contacted the participants, telephonically, via email or text message. When contacted telephonically the researcher established which mode of communication the PHL preferred. Some participants did not answer the phone and sent a text message to inform the researcher of their preferred mode of communication. Some participants

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preferred to communicate via email. The participants choice of communication indicated that all participants were confident to use email, seven participants preferred to video call, four preferred telephonic calls over WhatsApp, and three PHL preferred to communicate via email due to difficulty hearing over the phone. Once the preferred mode of communication was established, the researcher provided the PHL with an overview of the study. All participants requested that further detail of the study be sent via email. The researcher emailed the PHLs and the CPs the information sheet (Appendix A), consent form and overview of the questionnaires that they would be required to be filled in at a later stage. The PHL and CP were provided with a few days to consider the invitation. The researcher contacted the potential participants a second time via their preferred mode of communication to ask questions and confirm their participation, at this point verbal consent was obtained. There was one participant who was an Afrikaans speaker who could read and write in English.

4. Video call, telephone and email were used to conduct the interviews, depending on the participants' preference. Some participants preferred to be interviewed together on video call and some preferred to be contacted individually. If the participants chose to complete the GPS tool independently, they were provided with a detailed written instruction in their preferred language which was emailed to them.
5. The participants completed the GPS tool and emailed the copies to the researcher. Once they were received, the researcher arranged an appointment to video call or telephone the participants. Participants who preferred email were emailed back with questions to elaborate on their answers using the topic guide as a reference to obtain further information. Participants who preferred video call, were interviewed via WhatsApp video call, Skype, Zoom or Microsoft teams. The topic guide was used to allow the researcher to probe and obtain more information from the participants. Once

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- the interview was complete, the researcher administered the GPS tool usability questionnaire. The participants who preferred contact via email, emailed their answers for the usability questionnaire to the researcher.
6. Any challenges that were identified with regard to audiological rehabilitation, were referred to the participants' respective audiologist to provide the necessary management. There was one couple that was referred to their audiologist.
 7. The responses from the interview were discussed with the participants on the day of the interview and after the data analysis was complete to ensure the responses were correctly interpreted.
 8. At the end of the study the participants who were interested received information on the research findings. The participants who were interested were required to fill out their details on the consent form (Appendix B). Any identifying information such as email addresses or signatures were kept separate to the data collected. Only the researcher has access to any contact information. At the end of the study, all contact information will be deleted.
 9. Any individuals affected by the study were advised to contact the UCT Faculty of Health Sciences Human Research Ethics Committee, if necessary. They were allowed to ask questions during any stage of the research process. None of the participants appeared to be affected by the study or required intervention from the Health Sciences Human Research Ethics Committee.

Data Management

The data will be stored in a safe place online for up to 5 years (SAMRC, 2018). Once the data was transcribed it was entered into a table format using Excel. All the raw data is anonymized and kept in an online, password protected space by the supervisor. The list with

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the participants' names and contact details are also stored online in a password protected

location for member checking and will be used to contact the participants in future to share the research findings once the study is complete. Once the research findings are shared with the participants, their details will be deleted. The research findings will be disseminated to the wider community through the submission of an article to a peer-reviewed journal.

Data Analysis

The analysis of this study was conducted qualitatively using thematic analysis.

Thematic analysis focuses on identifying and describing the themes within the data which are the implicit and explicit ideas (Guest et al., 2012). Braun & Clark's (2006) six phase framework cited in (Maguire & Delahunt, 2017) were adopted to conduct the data analysis. This included the researcher familiarizing herself with the data obtained from the GPS tool and the questionnaire on the usability of the tool. The next steps consisted of the researcher transcribing the data, generating meaning from the information in the form of codes, identifying themes, modifying and developing the themes, defining the themes and reporting the findings (Maguire & Delahunt, 2017). The interviews were transcribed by the researcher, who checked the transcripts against the original voice and video recordings for accuracy. The transcribed data revealed 14 codes which were organized into themes ([Appendix J](#)). The similarities and expressions of each participants utterances were the base of the units which the themes were generated from, therefore the meaning of each utterance determined the theme it would be most applicable in.

Audit trails in the form of interview notes ([Appendix I](#)), interview transcripts, and the answers from the GPS discussion tool ([Appendix H](#)) allowed the researcher to gain further insight into the information provided by cross-referencing between documents. These documents also allowed the researcher to analyse specific characteristics of the data that

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generate the codes in the data analysis process (Nowell et al., 2017). The information from the usability questionnaire was analysed using counts as well as content analysis.

Reliability and Credibility

The study ensured that measures were undertaken to obtain reliable and valid information. Reliability in qualitative research is rooted in the consistency of information produced by participants across the study (Spiers et al., 2018). Reliability refers to the trustworthiness of information obtained from the participants. Trustworthiness was established through each phase of thematic data analysis. Methods of ensuring trustworthiness included, documenting reflective and theoretical thoughts keeping records of all field notes ([Appendix I](#)), audit trails of code generation, diagramming theme connections, documenting team meeting regarding themes and providing substantial detail of the coding and analysis process in the report (Nowell et al., 2017). Trustworthiness can be enhanced in a study through credibility, authenticity and confirmability (Cope, 2014).

Credibility refers to the accurate interpretation and representation of the experiences shared by participants with the researcher. The credibility of the research was enhanced through the maintenance of audit trails. The audit trails in this study comprised of the interview transcripts, documents such as the GPS discussion tool, notes from the discussion of the GPS tool, data analysis and drafts of the final report. The audit trail allows another individual to review it and draw the same study conclusion (Cope, 2014). Another strategy that was employed to ensure credibility was member checking. Member checking comprised of the researcher providing feedback to the participants regarding the themes that have emerged from the data analysis. The researcher discussed the responses with the participants after the interview on the day to confirm that the responses are interpreted correctly. The researcher also called the participants after the analysis was completed to discuss and confirm

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the themes. All the participants confirmed the information was interpreted correctly.

However, one CP mentioned since the time of the interview, the communication has improved between partners, there are fewer challenges experienced and there is no longer frustration.

Qualitative research may also present with limitations regarding researcher bias. According to Guest et al. (2012) reliability is a concern when analysing qualitative data, as more interpretation by the researcher goes into defining the data items. However, the study ensured that authenticity is maintained by truthfully documenting the feelings and emotions of the participants in the study. Confirmability was demonstrated by exemplifying that the findings derive from the data in the form of rich quotes from the participants. The participants responses to the discussion were quoted in the data findings to demonstrate the emerging themes.

Ethical Considerations

Ethical clearance from the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee was obtained (HREC REF: 638/2019). Permission was sought from the institutions' management and informed consent from the participants was obtained.

Autonomy: Informed consent was obtained voluntarily from the participant, ensuring that the participants understood the research process which was provided in the information sheet (Connelly, 2014) . The participants were allowed to decline or withdraw from participating in the research process at any time, without any negative consequences. The participants' rights to safeguard their integrity were respected and every precaution was taken to protect their privacy according to the Declaration of Helsinki (World Medical Association, 2013). The information obtained from the participants remained confidential and the

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participants remained anonymous. The participants are referred to as numbers instead of names in the final report.

Non-maleficence: The study minimized any risk through maintaining confidentiality, anonymity and avoiding any deceptive practice. The risk of distress arising from communication difficulties that were not addressed previously were managed with information counselling provided by the researcher and the participant was referred to their respective audiologist for further management. The researcher was committed to complete the data collection process with each participant within one hour. Furthermore, the financial burden for the participants to communicate using data on their phones was taken care of through compensation. Each participant received a compensation of R100.00 for any data costs incurred. This was personally funded by the researcher.

Beneficence: The study did not directly benefit the participants.

Justice: All participants were selected fairly, based on the inclusion and exclusion criteria.. All participants were provided with equal amount of time and the same information. All potential participants and participants were treated in a fair, just and impartial manner.

Results

The following chapter will provide information regarding the challenges that the 10 CPs of older adults with disabling hearing loss experienced and reports their coping strategies. The participants' answers to the questions on the GPS tool can be viewed in the Appendix H. The information extracted from the answers on the tool and the interviews generated four themes: daily life challenges from the CPs perspective and the management strategies, the emotional effect of communication breakdowns, communication changes in the

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relationship and coping strategies. Detail of the themes codes and units are displayed in

Appendix J. This chapter will also provide findings from participants' experience with the GPS tool and its usability.

Participants' Description

Participants	Length of relationship	PHLs type of assistive hearing device	Completion of tool	Medium of data collection
Couple 1 Husband and wife	50 years	Hearing aid	Completed the tool together with researcher in an interview	Video call interview
Couple 2 Husband and wife	unknown	Cochlear Implant	Completed the tool together with researcher in an interview	Video call interview
Couple 3 Cohabitation partners	4 years	Cochlear implant	Completed the tool together with researcher in an interview	Video call interview
Couple 4 Husband and wife	unknown	Cochlear implant	Completed the tool independently and interviewed separately by the researcher	Emailed answers and Interview telephonically
Couple 5 Parent and adult-child	34 years	Cochlear implant	PHL: emailed answers CP: completed tool with researcher in an interview (Note: GPS tool goals were not complete)	PHL: email CP: video interview
Couple 6 Husband and wife	45 years	Hearing aid	Completed tool together and was interviewed by the researcher together	Emailed answers and interviewed over telephone

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Couple 7 Husband and wife	50+ years	Cochlear implant	Completed tool separately and interviewed together by the researcher	Email and video call interview
Couple 8 Parent and adult-child	42 years	Hearing aid	Completed the tool independently.	Emailed answers
Couple 9 Husband and wife	Unknown	Cochlear implant	Completed the tool together.	Emailed answers
Couple 10 Husband and wife	unknown	Cochlear implant	Completed the tool together	Emailed answers

The sample consisted of 10 couples where each pair was a PHL and a CP. All PHLs were over the age of 60. The CP's age ranged from the age of 30 to 80 years. PHLs consisted of five males and five females. CPs consisted of 5 males and 5 females.

Table 1

Participants' Description

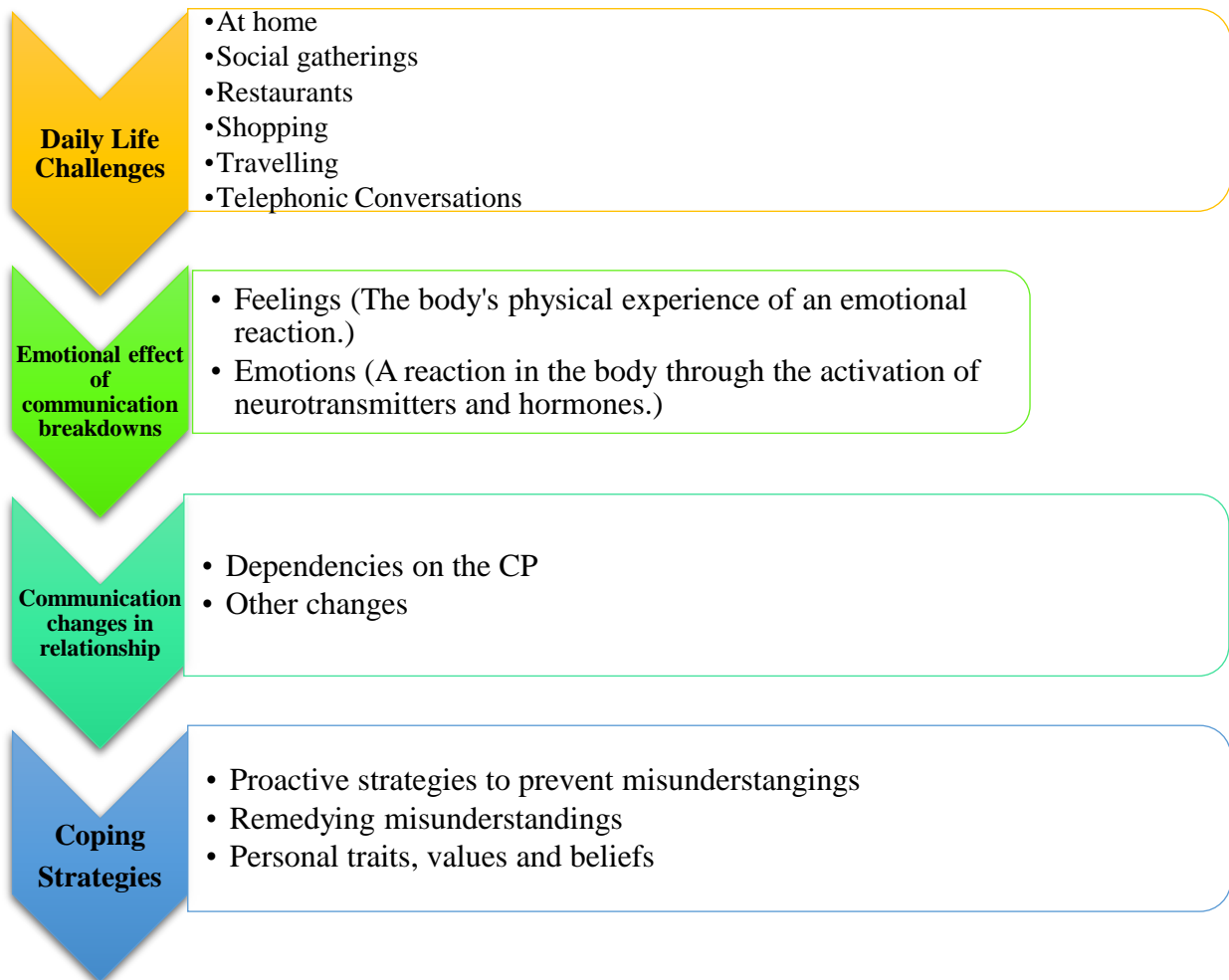
GPS Tool Answers

The participant's answers to the questions on the GPS tool have been summarized into one table ([Appendix H](#)). The four themes that emerged from the data analysis are presented in figure 2, (1) daily life challenges from the CPs perspective and management strategies, (2) the emotional effect of communication breakdowns, (3) communication changes in the relationship and (4) general strategies to assist communication breakdowns.

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Figure 2

Themes and Codes Overview



Themes

Daily Life Challenges from the CPs Perspective and Management Strategies

“Many changes in our lives that we have to cope with”- CP 4

Communication challenges were experienced by both the CP and the PHL. CPs spoke about the various situations in their daily life that were challenging to communicate in and how they managed to overcome the challenges. Some CPs found communicating from a different room of the house with the PHL would result in misunderstandings. Management

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strategies included using a cell phone to contact each other. In some cases where the CP and PHL were within hearing range they would call each other to the same room before initiating the conversation. Most couples mentioned that they have to be in close proximity to each other when conversing to improve communication.

CP 1 commented that communication is the easiest: ‘When (PHL) can read my lips. (PHL) would stand in front of me and I would stand in front of (PHL) and I would speak to (PHL), her many times (PHL) would be in the same room and even if I spoke, (PHL) wouldn’t hear.’ A challenge that required using strategies to remedy the misunderstanding was when the PHL is not wearing their assistive hearing device. CP 1 described what happens when the PHL does not wear the assistive hearing device.

“I will not know if she’s wearing the hearing aid because she’s not wearing it all the time...So I have to treat her like she’s got a hearing loss problem. Make sure she’s looking at my lips. I will ask her “did you hear me” and if she responds I will speak normally. If she keeps quiet, I know she didn’t hear me then I have to speak to her in front of her.”

Not all challenges were managed well. CP 7 complained about participating in a conversation without realising that both parties are communicating about different topics.

Activities that occur in areas with background noise, appeared to cause many communication challenges. However, most couples found ways to manage them. Group conversations are an area that required various coping strategies often due to the overbearing background noise in the different environments. Some couples managed this challenge by requesting to turn down the background noise, if possible. In cases where it was not possible, the couple would move to a quieter area to have a conversation such as the outskirts of the crowd. At dinner parties, the seating would be arranged to ensure the CP sits next to the PHL to assist them in conversation. One couple mentioned that they would limit the number of

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guests they invited to be able to control the conversation and noise. Two couples felt that cocktail parties were too difficult to communicate in and would avoid attending them.

Couples also found challenges communicating in restaurants. One couple mentioned that the CP had to raise their voice to be heard and the rest of the patrons hear the conversation. This resulted in conversation avoidance. CP 1 revealed the social challenge when going out, "When we go to a restaurant, I would speak very little if I had to scream. I would rather just sit quietly." However, other couples managed the background noise in restaurants by arranging their seating prior to arrival in a quiet area of the restaurant. Another difficulty experienced in the restaurant setting was the communication with the waiter and the PHL due to the waiter speaking too fast or too softly. This resulted in the CP assisting to communicate on behalf of the PHL or some would inform the waiter of the PHLs hearing loss.

Shopping was also mentioned as an area that communication challenges occur when it is busy and there is background noise. This was managed by moving to an aisle that was quiet to communicate important information. When travelling the background noise of the vehicle would also make it difficult to converse.

Leisure activities such as watching movies together would become unbearable for the CP due to the volume being too loud to accommodate the PHL. Couples found a way to manage this challenge by enabling subtitles for the PHL. Being able to communicate in a theatre during an ongoing production was also a reported problem as the PHL could not hear the CP whisper. Therefore, resulting in limited communication without any management. CP 2 mentioned how the hearing loss impacted her social life. "I used to join clubs independently, but it was lonely. We adapted. We became more solitary over the years."

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Telephonic conversations are an aspect of daily living that one CP had significant difficulty with due to the interruptions of the phone with the hearing device. Unfortunately, this could not be managed and also limited conversation. CP 5 shared the emotional challenge of not being able to communicate over the phone.

“...you know there’s a few times when you know you not feeling well and you want to talk to your (PHL) then it feels like I can’t because she’s not going to hear me on the phone. I had a disappointment earlier this year where you’re kind of in tears and you want to call your (PHL) and then it is difficult to hear someone when they’re crying...”

Despite the difficulties experienced in daily life, the CPs all felt that the challenges were mild and did not prevent them from attending social gatherings or going out. CP 4 supports this by stating, “...we make do and we do everything. We go together and enjoy ourselves; we don’t let that [hearing loss] affect us.”

The Emotional Effect of Communication Breakdowns

“Feeling of going crazy” - CP 1

CPs described the emotions they felt when there was a communication breakdown. Having to bridge the communication gap in group conversations, especially when having to explain a joke caused some CPs to feel irritated and frustrated.

CP 5 expressed her emotion by stating:

“What’s also irritating is if we are in a social gathering and if (PHL) can’t hear and then (PHL) will ask what are they saying...So, (PHL) wants to know what everyone’s saying. And then it’s not important and then I don’t feel like repeating everything. And I get irritated with that. Or when people are laughing, then (PHL) wants to know what’s going on, then you need to tell (PHL). Especially when it’s something not important to the conversation or that

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it's something that (PHL) doesn't need to know. CP 5 further conveyed how she felt when her PHL would pretend to hear:

“Sometimes your talk to (PHL) and it looks like (PHL) is getting this vacant expression and you'll be like “Can you hear me?” Yes, you just zoning out because (PHL) can't hear what I'm saying but I want (PHL) to hear me because I, I wanted to know what I'm saying. Another irritation that comes up is if you can't hear me tell me, because I want you to hear what I'm saying.”

CP 7 divulged her embarrassment when the PHL 7 doesn't follow rules of group conversation:

‘You are talking as a group. Even with people, then (PHL) comes in and almost starts a new thing or he isn't quite sure what we are talking about. That for me is not so good...But see that actually stops the flow of the conversation you having. And it's actually quite frustrating.’

PHL 7 provided an example of when he was not concentrating on the conversation and caused CP 7 to become irritable,

“I am thinking of an engineering problem I am trying to solve and (CP) is trying to get some wool, some sufficient stuffing for the teddy bears she is getting together to donate to Red Cross hospital and then we talk about something in between and then we lost. Then I say “what are you talking about?” Then CP says “teddy bears! I told you teddy bears!”

CP 7 further expressed her frustration when she was not aware of her partner's attentiveness:

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“Sometimes when I talk to (PHL), the way (PHL) looks at the like (PHLs) heard me. I think, maybe, and then (PHL) says in a couple of minutes “I don’t know you’ve never spoken to me about that.” And I genuinely thought (PHL) had heard me.”

CP 1 describes the feeling of doubt as “going crazy” when he has provided the PHL with an instruction and assumed that the PHL heard it, however it was not heard. CP 6 describes how it feels when she has to communicate with her partner in the presence of background noise. “I actually just go near to him and shout at him. Can’t you hear me when I speak to you. That’s not good but I also get crazy sometimes I get mad. You can only take so much.”

The CPs also expressed concern for the wellbeing of the PHLs. CP 9 mentioned, “What is of concern to me is in an emergency situation that [PHL] doesn't hear what I say like " get out if the way the car is going to hit you". CP 6 was concerned about the PHL not being aware if there are intruders at night when he doesn’t have his hearing aid in.

“Sometimes late at night there’s an outside noise. Then I tell him oh that’s when I really get scared for him. That’s when I have to wake him up and tell him there seems to be a problem on the road. I will wake him up because he’s an aware of it he can’t hear those noises... In case of emergencies that’s when you fear for them most.”

It must be noted that not all participants experienced these emotions, furthermore those that did experience them, felt varying degrees of emotion.

Communication Changes in the Relationship

“I learnt to listen to two conversations”- CP 2

The third overarching theme portrayed the changes in communication that were made in the relationships. CP 2 expresses how her PHL was dependent on her in group

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conversations, “I learnt to listen to two conversations, my conversation and the one my husband was having. In case he missed out on something, I could fill in for him”. CP 5 describes how communicating on behalf of the PHL has become a natural response when ordering a meal at a restaurant.

“When the waiter is there and his asking [PHL] what she wants and then I’ll repeat it to her. Sometimes the waiter will be English and I’ll say it in Afrikaans. I’ll get what she wants then I’ll tell the waiter. This is what she wants. So that kind of happens automatically. And then sometimes I’ll say she struggles to hear, or she’s deaf.”

CP 4 mentioned how she attends doctors’ appointments with her PHL to provide supportive listening.

“When he goes for appointments, I attend and he just might not hear the proper story of the problem, I would just throw an ear, and rectify it and so on. When we go to the doctor, we make sure we get the correct information.”

CP 6 revealed various situations that her PHL is dependent on her for supportive listening.

“... when they driving also if somebody’s hooting. I help him along with hearing. I hear for him most of the time especially at night when he hasn’t got his hearing aids in. In the morning when the fajr azaan [morning call to prayer] is going on, I will tell him OK, hold on the azaan is going on then we will start with our prayers... You know sometimes I’m upstairs and then that somebody by the door then I have to shout there is somebody by the door and then he doesn’t hear then I have to run downstairs.”

Communicative interactions such as whispers were aspects that also changed the way the PHL and CP communicated. CPs mentioned that they had to accept that they cannot

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whisper to their partner anymore. Therefore, jokes and communicating in a quiet space was an interaction that they could not partake in.

Speaking on the phone was an aspect of communication that changed according to CP 5. It was also reported that due to the interference of the hearing device while speaking on the telephone, conversations were disrupted and prevented the CP from conveying intimate messages to their partner. The loss of being able to communicate personal moments was described as an “awful” feeling by the CP 5. The CP also felt empathy for the PHL as the loss of communication was felt by both.

Despite the challenges, all the participants who were either married or cohabitation partners, all felt the hearing loss did not affect their relationship. CP 7 stated, “in fact its better”. The CPs, who were children, differed to the way they viewed their relationship with their parents having a hearing loss. One CP (child) disclosed that the relationship is not often verbal and the other CP (child) could not discuss the impact of the hearing loss with the parent as they (CP) were afraid it may have negative effects on their relationship.

Coping Strategies

“...we just have to adjust and learn to communicate in a different way”- CP 1

CPs described the strategies that they used to prevent misunderstandings from occurring. CP 3 mentioned how “sitting on the right of (PHL)” improves communication. CP 8 stated, “ensuring good lighting for visibility of lip reading and facial expression is important.” CP 1 illustrated how he used to ensure his partner heard him,

“I make sure she’s looking at my lips. I will ask her “did you hear me” and if she responds I will speak normally. If she keeps quiet, I know she didn’t hear me then I have to speak in front of her.”

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The above communication strategy was learnt over time as the CP became more familiar with the PHL.

CPs also explained various strategies that they used to remedy a communication breakdown. CP 6 shares how she tries to notify PHL 6 when he misunderstands information in a group conversation.

“Yeah, sometimes when we are in company and hold his hand and press it. So that he realises when something is wrong. Sometimes in the conversation he misunderstands. I will correct him but not in front of people. I will do it softly so nobody hears.”

CP 3 depicts what happens when his partner pretends to hear when someone else is talking, “[PHL] pretends to hear, that’s when I know she’s missed out on information. I will then repeat the question or assist [PHL] to contribute to the conversation by asking the speaker to repeat the question”. CP 4 describes what strategy she uses to when other strategies don’t work. “I feel the hearing can cause a lot of misunderstanding...SMS also helps or writing things down help to express myself.”

Most CPs explained that their personal traits or perspective of the hearing loss was a strategy that helped them cope. Challenging situations required CPs to accept the circumstances in order to cope. CP 1 discloses, “Once you accept the medical problem, err things become much easier.” CP 4 shares a similar sentiment about her partners hearing loss, “I don’t feel different. I just accept it. It’s a normal thing. Lots of people have problems and disabilities. You just adjust.”

A sense of gratefulness and having a positive approach was a common sentiment that was echoed by a few CPs. CP 1 exhibited gratefulness by stating,

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“...thank goodness her hearing loss was not so great that there were major arguments or anything because of her hearing loss... I think with time, patience and with practice I think we will overcome it. There’s nothing that we cannot overcome. We just have to be patient.”

Similarly, CP 6 expressed,

“You think about what worse could go wrong, I just thank God for all the small mercies it could be worse. You have to have a positive attitude. And you have to be able to adjust to your lifestyle, in our way of life. It’s so good we’ve had such a good life thank God. We have to be grateful we have to adjust and we have to be positive.”

Humour played a pivotal role in accepting and dealing with the communication challenges. CP 4 commented,

“We used to laugh. It was also fun. It was funny. Joking also. Even my daughters used to laugh. We made it something nice, you know not make the person feel so bad. It’s the only way, otherwise they go into depression.”

Some CPs and PHLs mentioned adapting and adjusting numerous times to improve their communication skills. This can be viewed in CP 1s comments, “We adjusted to a lot of things, and now I know I mustn’t speak loud if she’s around with the hearing aid... It’s something we just have to adjust and learn to communicate in a different way.” CP2 also shared, “We adapted...I learnt to speak slower.” PHL 6 reveals how he has adjusted,

“I think what we’ve learnt now from past experience is basically. Try to get into a situation where there is one on one. 9 out of 10 there is background noise or wind it affects the hearing and I have to say can you repeat it. You develop strategies as you go along and most of them are where you put yourself in a situation where you can hear the other party. So, you try to get closer to them or you ask them to repeat themselves.”

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It was also noted how personality allowed CPs to deal with challenging situations better. CP 4 shared her response to dealing with challenging situations, “Agh I just, I’ve got a different personality. I’ve got...His got the stronger personality than me. I just take it as it comes.”

Attending the audiological rehabilitation sessions and working on the exercises together as a couple, included CPs on their partner’s rehabilitation journey. CP 4 describes how she was included and learnt to communicate with her partner through the exercises.

“I used to be like a teacher to him to teach him everything. I used to go with and then I used to do everything. It was like going to school again, starting with you know everything, a bit of everything. So, it’s not a problem for me because I got used to the situation already you see...We used to laugh. It was also fun.”

Empathy was a common trait observed among a few CPs. It appeared that empathy allowed the CPs to accept and cope with the challenging situations. CP 4 shares, “The person involved is more affected. We have to also you know...be more patient with him and so on. Because if you put yourself into that position, it’s not a nice position.”

The familiarity that the regular CP has with the PHL would allow the CP to modify their communication based on previous experiences and improve their communication. CP 3 mentioned strategies such as speaking in the better ear. The regular CP would have this prior knowledge to ensure the PHL hears the message. Intimate hand gestures that CP 6 stated such as squeezing the PHLs hand when he misunderstood the message would ensure successful communication in group conversations. CP 3 also learnt with experience that based on the answer the PHL gave would determine whether they received the message or not.

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Usability of the GPS tool

Once the participants completed the GPS tool, they were requested to answer questions regarding the tool's usability. The aim was to determine if the content, language and administration of the tool was usable and beneficial to the participants. Overall, the tool appeared to be usable by the participants, based on their ability to answer the questions. However, it demonstrated to be most beneficial when administered by the researcher as the researcher was able to obtain more detail from the participants answers which yielded more meaning for the participant. The details regarding the aspects of the tool are presented in the table below.

Table 2

Goal Sharing for Partners Strategy Tool Usability Questionnaire

Questions	Results
1. If you completed the GPS tool independently, did you find it easy?	14 out of 20 participants completed the tool independently without any assistance. Their answers were emailed to me. Three couples and one CP couples requested a video call whereby the researcher interviewed them and ask the questions.
2. If you completed the tool independently, did you require assistance? If yes, please elaborate.	14 out of the 20 participants who completed the tool independently stated that they did not require assistance. However, one couple required assistance to complete question five and six. The information provided when independently filled out by the participants appeared to be limited in comparison to when the researcher interviewed the participants.
3. Did you find the questions easy to understand (content)?	17 out of 20 participants mentioned that they found the questions easy to understand. However, during the interview, some participants found the questions repetitive. E.g., how hearing loss affects you and the problems experienced. Based on the answers provided it appeared as though the participants did not know how to answer question 4. In the interview, the researcher had to elaborate and provide examples.
4. Did you find the language of the questions easy to understand (translated language)?	19 out of 20 of the participants spoke English fluently and did not require the translated version. One Afrikaans speaking participant could read and write English.

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5. Do you think the questions asked, allowed you to fully express your thoughts and feelings?	18 out of 20 of the participants agreed that they were able to express their thoughts and feelings. One couple mentioned it was easier to fully express themselves verbally in the interview. It was noted that when individuals were asked “how the hearing loss affected them?” (Question 2) their answer comprised of what they do to accommodate the hearing loss, instead of their feelings. One CP felt that the questions were too superficial to provide a deeper insight into the impact on their relationship with the PHL.
6. Did you feel comfortable discussing your thoughts and feelings?	All participants mentioned that they felt comfortable.
7. Were the questions culturally appropriate?	All agreed they were culturally appropriate.
8. Did the questions apply to you and your chosen communication partner?	15 out of 20 of the participants felt that the questions applied. One couple felt that the questions were more directed at the PHL than the CP. The others felt the question was not applicable.
9. Do you feel the time to administer the tool was sufficient?	All the participants agreed the time was sufficient.
10. Do you feel this exercise has helped you?	15 out of the 20 participants felt it helped. Five felt that it didn't. Two couples mentioned that it didn't help as they had overcome most of their problems already.
11. Do you have a better understanding of the challenges that your partner goes through?	13 out of 20 of the participants mentioned that they have a better understanding. 4 of the 7 that stated 'no', felt that their problems had been managed already and was not applicable to their current context.
12. Do you feel your challenges as a communication partner were addressed?	8 out of the 10 CPs felt that their challenges were addressed. The one CP that answered no, did not experience many challenges with their partner.
13. Do you feel that the questions asked addressed some of the main problems with the challenges with hearing loss?	16 out of 20 of the participants felt that the questions were specific, however the couple that disagreed also felt that it was not applicable to their current context as they had managed to overcome the difficulties many years ago. Some of the CPs of the PHL fitted with the cochlear implant reported minimal communication difficulties and managed to adapt over the years.
14. Do you feel the goals that you have set together will be manageable to implement?	12 out of the 20 participants mentioned that this will be a difficult task to implement. The following was noted: Couple 1 had difficulty discussing goals. Couple 2, felt they have already worked on their problems and did not have any new goals. Couple 3 felt they did not need goals as they manage their challenges already. Couple 5 did not complete the goals due to constraints in their relationship. Couple 7, required assistance from

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	the researcher as they did not know how to identify solutions to their challenges.
15. How do you feel after conducting this exercise?	12 out of the 20 participants felt it was a positive experience and an insightful exercise that gave them a better understanding of their partners feelings. Other participants felt indifferent, these participants were fitted with PHLs with assistive devices for many years and their partners both felt they had dealt with their issues already.

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Discussion

This study aimed to describe the communication challenges that CPs of older adults with disabling hearing loss experienced and explore their management strategies. The four overarching themes identified from the interviews include: (1) daily life challenges from the CPs perspective and management strategies, (2) the emotional effect of communication breakdowns, (3) communication changes in the relationship and (4) general strategies to assist communication breakdowns. This chapter discusses these themes as well as the results from the questionnaire regarding the usability of the GPS tool.

Theme 1: Daily Life Challenges from the CPs Perspective and Management Strategies

The home environment was found to be the easiest to communicate with each other. The CPs would communicate through face-to-face interaction or move to the better ear of the PHL to ensure they are close enough for the PHL to hear. The close proximity and low level of background noise at home may be factors that increase the success of communication. This finding in the current study is similar to the results in a study by Roberts and Delich (2020) who found that a close proximity between communicators can improve communication. This also indicates how CPs assume the responsibility in the communication situation to ensure there is successful communication. Therefore, findings from the current study show that CPs need to be equipped by audiologists during the audiological rehabilitation process to take on this role.

In the current study, challenges communicating were experienced with and without the use of the assistive hearing device. Despite the use of assistive hearing devices, additional strategies were also required for successful communication. These results are in line with the meta-synthesis study by Barker et al. (2017) who reported that CPs experienced effective communication with their partners use of hearing aids, however, acknowledged that the

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hearing aids weren't as useful as hoped. Manchaiah et al. (2013) is also in agreement and

states the use of assistive devices by older adults with hearing loss does not solve all communication problems. Therefore, CPs still experience some challenges communicating with the PHL and require management strategies to assist (Manchaiah et al., 2013).

Therefore, it is important for audiologists to include CPs at the onset of the audiological rehabilitation process to learn communication strategies which will support the use of the hearing devices and enhance communication.

Social gatherings, restaurants, shopping and travelling in a car were challenging situations which would result in communication breakdowns due to the competing background noise. Despite the challenges reported, most CPs did not feel it prevented them from engaging in social events or travelling as they developed management strategies that allowed them to continue to participate in the activities. Contrary to the results in the current study, Govender et al. (2014) found that over 40% of their participants experienced problems and therefore avoided noisy environments, social gatherings and leisurely activities such as movies. However, they did report that the problems were mild to moderate in nature. The reasons for the differences in findings may be due to the strategies that the participants in the current study adopted to enable them to maintain a positive social life. Barker et al. (2017) explained this strategy as 'engaged coping' whereby the CP accepts and adjusts to the situations and displays willingness to continue regardless of the limitations. This finding indicates the importance of audiologists providing counselling in the initial stages of the audiological rehabilitation process to allow CPs and PHLs to develop coping strategies such as acceptance and various adjustment methods to maintain a healthy social life.

Telephonic conversations were also reported to be challenging situations to communicate in. At the time of data collection, one couple could not see each other face-to-

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face due to the restrictions imposed by COVID-19 and therefore, relied on telephonic conversation. Garg et al. (2021) documents the challenges that the PHL experiences communicating telephonically in the COVID-19 era, however there is a lack of focus on the difficulties the CP also experiences in the study. In the current study the challenge communicating with the PHL telephonically created an emotional distance in the relationship between the CP and the PHL. In a study by Preminger et al. (2015) participants echo the loss of intimacy due to not being able to communicate effectively with their PHL. This finding illustrates how hearing technology does not always provide complete support; therefore, audiologists need to explore more communication strategies to assist the CP and PHL in telephonic conversations. Furthermore, in the case where a PHL who's hearing loss impacts intimacy and emotional availability, audiologists should refer to a psychologist. Future research could focus on enhancing communication over communicative devices such as telephones and cellular phones.

Theme 2: The Emotional Effect of Communication Breakdowns

Most participants reported either frustration, irritation or annoyance due to communication challenges. Challenges in everyday communication have an effect on the PHL and their CPs (Hickson et al., 2016). Scarinci et al. (2012) mentioned that third-party disability was most prominent with regard to emotional problems such as frustration and anger, as well as the leading source of stress for spouses. Similarly, the results in the current study also demonstrate the participants experiencing these negative emotions, however, in contrast to the study by Scarinci et al. (2012) these emotions experienced were reported to be mild. This finding may be due to the apparent positive nature of the CPs and their acceptance of their partner's hearing loss. This view is in line with the participant's responses from Yorgason et al. (2007) study who also mentioned how frustrations can arise from the

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communication challenges, however couples focused on the positive aspects of life. Another reason may also be due to most of the CPs of PHLs who have been fitted with the assistive hearing devices for a long time, had managed to deal with their emotions when fitted with the hearing device and that the positive attitude of the CPs. Stark and Hickson (2009) also supports this reasoning as they mention that the PHLs hearing aid use decreases frustration and an improves the quality of life for CPs.

Feeling concerned for the PHLs wellbeing in dangerous situations was often mentioned in the current study. This result suggests dependency on the CP to listen out for warning signals in dangerous situations. Similarly, Nandurkar and Shende (2020) also reported a common feeling of concern with the CPs, especially for PHL with severe hearing loss. This finding indicates how CPs also assume the worry for their partner adding to the responsibility of caring for the PHL. Therefore, it is important that CPs are referred for group counselling with other CPs to manage third-party disability matters. The psychological implication of these challenges suggests that there is a need for a multidisciplinary approach in audiological rehabilitation with the involvement of psychologists. Furthermore, it would be important to advocate for the safety of PHLs through the implementation of safety training and emergency protocols in public spaces. Creating awareness in society of the impact of hearing loss on the safety of PHLs will accommodate PHLs and lessen the concern for their CPs. Future research could focus on the development of safety protocols for PHLs in public spaces.

Theme 3: Communication Changes in the Relationship

In the current study there were various ways in which the communication in the couple's relationship had changed due to the hearing loss. The way the CP changed their communication allowed them to cope with the hearing loss which also meant they were more

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responsible for the communicative exchanges due to the communication dependency imposed by their partners hearing loss. According to Scarinci et al. (2012) this 'burden' on the CP is considered as third-party disability. Communication burden was also the most statistically significant construct in a study by Schulz et al. (2017). However, contrary to the other studies, in the current study most CPs did not view this dependency as a burden or disability, it was accepted and viewed as a way to provide support for their partner. This is postulated to be due to the meaning that the couples attached to their experiences. The CPs perceived the dependency as part of the responsibilities of their relationship to support each other. Another reason may be due to the values and beliefs of the CPs that allowed them to adjust and adapt to the circumstances. Yorgason et al. (2007) supports both views by conveying that although there are challenges associated with hearing loss, the perceptions of the couples may not necessarily be negative, as couples also expressed acceptance and gratitude regarding their circumstances. The results indicate that the perceptions and beliefs of an individual contributes to their view of debility and therefore suggests how an individual may perceive their challenges determines the severity of their burden. Some CPs may not develop the same perceptions and therefore the burden may be more severe, suggesting that audiologists refer CPs for counselling to deal with any emotional burden they may encounter. Furthermore, the implementation of a person-centred care approach would prove to be more beneficial in audiological rehabilitation as each couple's beliefs and values differ. Audiologists should be aware of the differing values and beliefs to accommodate them in a customised approach and not a standardised approach to audiological rehabilitation. Further research into the beliefs and values that various cultural groups use to cope may provide more information to develop a customised approach to audiological rehabilitation.

Despite the changes in communication in the relationship, all the CPs reported that the hearing loss did not affect their relationship with each other. Comm challenges were

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navigated better didn't negate Yorgason et al. (2007) explains despite the adversity of the hearing loss they sustain positive adaptation overtime. Therefore, the findings of this study concur with Govender et al. (2014) who reported that more than 50% of their participants also did not experience changes in their relationship due to the hearing loss. The results suggest that the impact of the challenges of the disabling hearing loss on the relationship is dependent on the resilience of the couple's relationship. Therefore, in cases where the communication may impact the family relationship it would be necessary for audiologists to refer to psychologists for counselling therapy.

Theme 4: Coping Strategies

Various coping strategies were adopted by the CPs. Some strategies were to prevent misunderstandings, some were to remedy misunderstandings and some were the personal beliefs, values and adaptations to the hearing loss. The familiarity and experiences shared between the CP and PHL also demonstrated how this contributed to communication ease. Two factors that were apparent with regard to coping strategies included the CPs assuming responsibility for the communication situations and the PHL accepting their hearing loss. Most couples worked together to overcome the challenges experienced in their daily life. Barker et al. (2017) mentions that partners who work together to overcome stressful situations cope better. Therefore, suggesting that the influence of the effects of the hearing loss on the psychosocial wellbeing is dependent on the interaction between the CP and the PHL as well as their aligned coping strategies. This finding is mirrored in the current research as most couples mentioned how they adapted to the situations together and developed coping strategies over the years. Therefore, this suggests the health of the relationship is important to be able to work together and overcome the stressors in various situations.

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Some couples also attended the initial audiological rehabilitation sessions with their CPs which included them in their partner's journey. This inclusion provided the CP with an insight and understanding of what their partner was going through as well as a sense of purpose in their partners journey. Even though the inclusion of the CP was not aimed at the challenges that they experienced, it provided a support for the PHL which created a sense of unity in the relationship in a time of adversity. Ekberg et al. (2015) also emphasizes that successful rehabilitation is not only dependent on the PHLs ability but also the CPs willingness to participate in the rehabilitation communication practices. Therefore, highlighting the importance of including the CP in the audiological rehabilitation process by considering a training guide for CPs to care for PHLs.

Usability of the GPS Tool

Overall, the tool was easy for the participants to complete. However, most of the information was yielded through a verbal interview using the tool as a guideline. Using this tool as an interview guide can provide many benefits to including the CP in the audiological rehabilitation process. The tool showed to be most beneficial when used as an interview guide. Using the tool as a questionnaire for the participants to fill out independently proved to be limiting as the participants did not provide enough detailed information to obtain an insight into the challenges and coping strategies that were experienced. Therefore, for the current study, the information that was yielded from the GPS tool was dependent on the type of follow-up questions the researcher asked and the involvements of the CP in the interview. With regard to the content, the participants all mentioned it was understandable, however they also felt that the answers they provided for question one and the answers for question four were similar. The participants would discuss their easiest communication situations and

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challenging situations in question one. They found that these answers were similar to the answers they would provide for question four, 'problems that are experienced'. Therefore, it would be dependent on the audiologist's administration of the tool to prevent repetition.

The counselling process overall also requires more time. In an article by Hickson et al. (2016) it was mentioned how audiologists were discouraged by the use of the GPS tool due to the time it took to complete, however it was discussed that this tool was meant to be used as a conversation starter with a family centred approach. Therefore, when used as a platform to discuss rather than only obtain information, the tool can provide an opportunity to involve the CP and also create a setting for counselling.

The most challenging component of the tool for the participants was the implementation of goals. It was apparent that the phase of the audiological rehabilitation process that the couples were in, the assistive hearing device satisfaction for the PHL and the relationship between partners were aspects which determined their communication goals. It was also evident that the participants required assistance to generate these goals based on the problems that the couples experienced, as the participants were able to express their challenges but had difficulty identifying solutions. Therefore, the administration of the tool and involvement of the audiologist proved to be important. Furthermore, it was noted that when discussing emotions and impact of third-party disability with the PHL and CP separately, the couple may not be aware of each other's emotions. Therefore, the administration of the tool must be conducted in a careful manner through counselling as the information provided may impact the relationship of the couple.

The benefit of conducting the GPS tool was to gain insight into the perspective of the CPs. Additionally, the CPs also were made aware of some of the challenges the PHLs experienced and vice versa. This experience was also described by a patient in an article by

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Hickson et al. (2016). In the current study, the interview process when conducting the GPS

tool transformed into an unanticipated intervention session. Roberts and Delich (2020)

described the benefit of conducting interviews as the ‘elephant in the room’, as the interview

uncovered the rarely discussed but obvious issues by openly recognizing the impact of the disabling hearing loss in the relationship between the CP and PHL. Therefore, this

demonstrates the importance of the family centred approach and how creating an awareness

of both PHL and CPs challenges can assist in the decision process. It also highlighted an

increase of awareness of each partner’s difficulties can develop empathy for each other that

can decrease the emotional impact during challenging situations.

It was evident from the feedback on the GPS usability questionnaire, that the phase which the couple was at, within the audiological rehabilitation process as well as the satisfaction of their assistive hearing device was important for the GPS tool to have the most benefit. Some couples who began audiological rehabilitation many years ago disclosed that the tool would have been more beneficial then, as they did not feel the tool had helped them and the questions did not apply now. It was also evident that the couples whose PHLs were satisfied with the assistive hearing device, felt that it solved the communication problems previously. This finding is in line with the study by Wallace (2018) who also found a decrease in third-party disability following the PHL’s fitting of the assistive hearing device. Therefore, this feedback suggests that the implementation of the tool earlier on in the audiological rehabilitation process may be most beneficial for assisting with communication challenges.

Strengths and Limitations

The current study had several strengths and some limitations. A key strength in the study design was interviewing the participants qualitatively by asking open-ended questions

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instead of closed-ended questions. Open-ended questions allowed the researcher to delve deeper into the experiences and perceptions of the CPs. It was noted that the interviews that were done conjointly, some CPs may not have been comfortable to express themselves fully in the presence of their partner. Future research could be conducted by interviewing the CPs separately for a part of the interview, that involves the feelings and emotions of the participants. However, it is important to note that the purpose of the GPS tool is to involve both CPs and PHLs to discuss their goals together.

Another strength of the study was in the methodology in that the credibility of data collected was enhanced with two stages of member checking. The first stage was when the participants provided the information at the interview and the second stage was once the data was analysed, and themes were generated. Another strength in the current study was in the data collection instrument in that there was a pilot study to assess the appropriateness and exploring the usability of the GPS tool, which allowed the researcher to improve on the validity of the test materials as well as structure the main research project. From the apparent benefit in this research project, it would be advisable for future research to also conduct a pilot study.

Some of the limitations include that the study sample did not include a culturally diverse range of participants which may limit the information provided on the cultural appropriateness of the tool. Further research could include a more diverse sample, including participants from various cultural and socio-economic backgrounds. The inclusion of diverse cultures could provide more information on the cultural differences that South Africans with third-party disability experience, in comparison to other cultures. Furthermore, the couples that indicated that they were in the later stage of the audiological rehabilitation process did not have any current challenges or goals but provided management strategies that they

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adopted over the years. Even though their information was beneficial, future research could include participants that were earlier on in their rehabilitation journey, as they may provide more information regarding the challenges that they face.

Conclusion

In conclusion, the effects of disabling hearing loss are far reaching onto the CPs of older adults with disabling hearing loss. The impact resulted in daily life communication challenges for the CP. These challenges affected CPs emotionally as well as transformed the way they communicated in their relationships, however the values, beliefs and personality of the CPs allowed them to cope and develop resilience to the burden of third-party disability. Not all CPs may have the resilience to cope and thrive under adversity, hence the information in this study can be used to assist other CPs as well as enhance the success of audiological rehabilitation for PHLs. Therefore, the implementation of a family centred approach with emotional support for the CP will prove to be beneficial for all stakeholders.

The study demonstrated that the GPS tool was an appropriate tool to use when adopting a family centred approach to audiological rehabilitation and was most beneficial when implemented as an interview guide administered by an audiologist. It was evident that the questions on the GPS tool may require more specificity to initiate the conversation. Additionally, an audiologist may have to administer the tool by asking more probing questions to gain a deeper insight into the experiences of the PHL and CP to provide comprehensive support.

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Appendix A: Information Sheet



Good day, my name is Safoora Mustapha. I am a Masters student in Audiology at the University of Cape Town. As part of my degree, I am required to conduct a research project.

What is my research about?

My research explores the difficulties and coping strategies that communication partners of older adults with hearing loss experience. A communication partner is someone who speaks regularly to a person with hearing loss. Communication partners are often family members, carers, or friends.

Why have you been selected to participate?

You both have been selected to be a part of this research project as you meet the criteria for the study. The first criterion for the study is a person who is over the age of 65 years old and has a hearing loss. The second criterion for the study is, the partner of the person with the hearing loss should regularly communicate with the person with the hearing loss and be over the age of 18. You have also been selected to provide information about the difficulties and coping strategies you experience as a person who regularly communicates with an older adult with a hearing loss.

Other criteria for participation

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You both will be required to read and write.

How the information will be gathered from you?

1. The Goal Sharing for Partner's Strategy (GPS) tool is a questionnaire that you both will fill in together or fill in separately either telephonically, via email, WhatsApp or video call. This questionnaire has six questions. Questions one to four will be answered separately. Questions five and six should be discussed between you and the answers can be provided to me either telephonically, via email, WhatsApp or videocall.

2. If you choose to conduct the questionnaire telephonically or via video call, I will discuss your answers in an interview at the same time. If you choose to fill in the answers using email or WhatsApp, I will contact you at a separate time to discuss your answers with you in an interview.

3. After the interview, I will ask you some more questions about the GPS tool. This will evaluate it and determine if it can be used in South Africa. I will conduct this questionnaire in the same telephonic call or video call when I do the first interview or I can send the questionnaire to you via email or WhatsApp and you can send me the answers.

What is expected if you decide to participate?

The information for this study will be obtained through a communication medium that suits you (telephonic, video call, WhatsApp or email). The information will be gathered through two questionnaires and discussions. The first questionnaire is made up of six questions and the second questionnaire is made up of 15 questions.

The first interview can be conducted telephonically or via video call, whereby I will ask the person with hearing loss and the person who is regularly spoken to the questions one

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to four separately. I will discuss both answers separately as you provide them. Questions five and six, will require both of you to discuss with each other and then provide the answer to me. This can be done in one session, or the researcher can call back to obtain the answers. Telephonic and video calls will be audio recorded to analyse the data at a later stage in the study. If you both wish to be contacted via email or WhatsApp, then I will send you the questionnaire and you will be expected to fill out the answers separately for question one to four and together for questions five and six. I will call you back to discuss both your answers.

The second questionnaire will allow me to gain insight into both your experiences answering the questions in the first questionnaire. I can call you telephonically or via video call to ask you these questions, or I can send you the questions via WhatsApp or email and you can type out both your answers and send them to me.

If there are any difficulties that are identified with regard to hearing health care, you will be referred to your own audiologist.

Where and when will the research collection procedures take place?

The research collection process will take place at a time suitable for you. An appointment time will be set up to conduct the interviews. The discussion and questionnaire may be completed in two separate sessions depending on what is convenient for both of you. You can also be contacted separately in different sessions at a time that is suitable. The times will vary but not exceed 60 minutes.

What are the risks and benefits?

I understand that there may be some communication distress that may arise. I ensure to provide information counselling and refer both the person with hearing loss and partner to your respective audiologist for further management if necessary.

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I also understand there will be data costs incurred when communicating via WhatsApp/ video call or email. I will compensate the costs by providing R100.00 worth of data.

Are you allowed to refuse to participate?

Your participation in this study is voluntary. You are allowed to refuse or leave the study at any time without a problem. Your identity will be known by me (the researcher) and the direct supervisors only. Your identity will be protected and remain unknown during the project and in the research report.

How will your information be stored?

Any information that you provide will remain private. The material will be secure and privately managed by the researcher. Any identifying information such as email addresses, numbers or signatures will be kept separate to information collected. I will only have access to any contact information. At the end of the study, all contact information will be deleted. You will not be identified in any of the research reports. Each participant will be referred to by a number instead of a name. Any information that is written, will be typed out onto the computer and protected with a password. Any audio recordings will also be stored electronically and protected by a password.

What will be done with the information that you provide?

The information results from this research project will contribute to the development of hearing health care services. Specifically, services to assist the difficulties that partner who regularly communicate with persons with hearing loss experience. The information that you provide will show how the tool assists the communication partner share their difficulties in a

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South African setting. The results of the study will be written in a research report and submitted to academic journal.

If you have any further questions or queries please do not hesitate to contact me, Safoora Mustapha (0791645083 or email mstsaf001@myuct.ac.za) or my Supervisors, Lucretia Petersen (lucretia.petersen@uct.ac.za) or Vera Hlayisi (vera.hlayisi@uct.ac.za). If you have any queries regarding your rights and welfare as research subjects in the study, please contact the UCT FHS Human Research Ethics Committee (0214066338).

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

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Appendix B: Consent form



- I confirm that I have read and understood the information sheet provided for the above study.
- I have had the opportunity to consider the information, ask questions and have had the questions answered satisfactorily.
- I understand that my participation is voluntary and that I am free to withdraw at any time, without any negative consequences.
- I understand that participating in this study will not impact on the quality of service I receive from my audiologist.
- I understand that all identifiable information that I provide is treated as strictly confidential, and will not be released by the researcher in any form that may identify me. (Numbers will be assigned to the participants instead of names.)
- I understand that data collected during this study will be looked at by responsible individuals involved in conducting this research such as the researcher and her supervisors. I give permission to these individuals to have access to the data collected in this study.
- I agree that the research data gathered for the study may be published provided my name or other identifying information is not used.
- I agree to take part in the above research study.

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- Would you like to be informed about the findings of this study? Yes No
 - If you have ticked yes, please fill in your email address here_____.

Name of Participant: _____ Date: _____ Signature: _____

Researcher: _____ Date: _____ Signature: _____

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Appendix C: Consent form for voice recording



I hereby consent to audio recording of the interview. I understand that my confidentiality will be maintained at all times. The audio recordings will be transcribed and raw data will be destroyed.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

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Appendix D: Permission Letter



I, Safoora Mustapha, am a Masters student in Audiology at the University of Cape Town. I seek to obtain permission from your institute to conduct the following study.

The study explores the challenges that communication partners experience and the strategies that they use to assist them to manage communicating with older adults with hearing loss. The study will attempt to describe the challenges, and the strategies that are used to overcome these challenges that communication partners experience. A discussion tool called the Goal Sharing for Partner's Strategy (GPS) tool will be used to obtain the information. The study will also evaluate the GPS tool, to determine if it is suitable to use in a South African context.

Following ethical clearance from the UCT FHS Human Research Ethics Committee and permission from the institute and private audiology practice, the relevant head of the audiology departments at the institutes and practices will be approached. A briefing meeting will be held with the audiologists to discuss their role in the research study. The audiologists will be required to provide the researcher with contact details of clients who will be returning to the hospital at the soonest date, after obtaining their consent. The clients will be telephonically invited along with their communication partner. The telephonic invite will state the purpose of the study, inform the client of the compensation for funding data costs that may be incurred and obtain verbal consent. Written consent will be obtained via email or verbal consent will be acknowledged.

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The data collection procedures, will conducted via a communication medium that suits the participant (telephonic, video calls, WhatsApp or email).

The data for this study will be obtained in two parts. The first part, will require the person with the hearing loss and the communication partner to complete the GPS tool. Once the GPS tool is filled in, the researcher will discuss the answers with the participants in more depth, to understand the information provided.

Once the discussion is complete, the second part of the study will continue, whereby the participant will be required to complete a questionnaire. The questionnaire will comprise of questions related to the usability of the GPS in a South African context. The discussion and questionnaire will be completed in one or two sessions, but will not exceed a total of 60 minutes. The researcher will audio record the session to analyse the information at a later stage in the study. If there are any challenges that are identified with regard to audiological rehabilitation, the participant will be referred to their respective audiologist.

Ethical procedures will be applied to this study, whereby participation in this study is voluntary and the participant would be allowed to decline or withdraw from the study at any time without negative consequences. The participant's identity will be known by the researcher and the direct supervisors only. The participant's identity will be protected and remain anonymous during the project and in the research report. The risk of distress arising from communication difficulties that have not been addressed previously will be managed with information counselling provided by the researcher and referred to the participant's audiologist for further management if necessary. The information produced by the participant will remain confidential. Any written information will be transcribed and stored electronically. The material will be secure and confidentially managed by the researcher using password protected files.

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The information from this study's findings will contribute to the development of intervention strategies which will reduce the challenges that communication partners experience. The information obtained from the questionnaire regarding the usability of the Goal Sharing for Partners Strategy tool (GPS), will provide insight into how the tool assists the communication partner share their challenges in a South African context.

I, _____, grant permission to Safoora Mustapha to conduct the above-mentioned study at _____.

Signature: _____

Date: _____

If you have any further questions or queries please do not hesitate to contact me, Safoora Mustapha (0791645083 or email mstsaf001@myuct.ac.za) of my Supervisors, Lucretia Petersen (lucretia.petersen@uct.ac.za) or Vera Hlayisi (vera.hlayisi@uct.ac.za). If you have any queries regarding the rights and welfare of research subjects in the study, please contact the UCT FHS Human Research Ethics Committee (0214066338).

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Appendix E: Topic guide for discussing answers to GPS tool

Communication Partner

Where do you find communication most easy?

1.1. What makes the environment easy to communicate in?

1.2. Why do you find it easy to communicate in that environment?

1.3. In this case, which direction are you facing the speaker?

1. How does the hearing loss affect you?

2.1. How does it make you feel?

2.2. How do you assist in that situation if you can?

2.3. What strategies do you use to overcome the situation?

2. How does your hearing loss affect your partner?

3.1 Were you both aware of the effect the hearing loss has had on each other?

3.2. What do you do when you notice that the hearing loss is affecting your partner?

3.3. Has your relationship changed since the hearing loss?

3.4. How has it changed?

3.5: Have you had to take on more responsibility during communication? If so, how?

3. What problems do you both experience?

4.1. How does this make you feel?

4.2. How could it be different?

4. Discuss Shared Goals

What steps will you take to achieve the goal?

Person with Hearing Loss

Where do you find communication most easy?

1.1. What makes the environment easy to communicate in?

1.2. Why do you find it easy to communicate in that environment?

1.3. In this case, which direction are you facing the speaker?

1. How does the hearing loss affect you?

2.1. How does it make you feel?

2.2. How do you assist in that situation if you can?

2. How does the hearing loss affect your partner?

3.1 Were you both aware of the effect the hearing loss has had on each other?

3.2. What do you do when you notice that the hearing loss is affecting your partner?

3.3. Has your relationship changed since the hearing loss?

3.4. How has it changed?

3. What problems do you both experience?

4.1. How does this make you feel?

4.2. How could it be different?

What steps will you take to achieve the goal?

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Additional Comments.

Appendix F: Goal Sharing for Partners Strategy tool Usability Questionnaire

- If you completed the GPS tool independently, did you find it easy?
- If you completed the tool independently, did you require assistance? If yes, please elaborate.
- Did you find the questions easy to understand (content)?
- Did you find the language of the questions easy to understand (translated language)?
- Do you think the questions asked, allowed you to fully express your thoughts and feelings?
- Did you feel comfortable discussing your thoughts and feelings?
- Were the questions culturally appropriate?
- Did the questions apply to you and your chosen communication partner?
- Do you feel the time to administer the tool was sufficient?
- Do you feel this exercise has helped you?
- Do you have a better understanding of the challenges that your partner goes through?
- Do you feel your challenges as a communication partner were addressed?
- Do you feel that the questions asked addressed some of the main problems with the challenges with hearing loss?
- Do you feel the goals that you have set together will be manageable to implement?
- How do you feel after conducting this exercise?

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Appendix G: GPS Tool

DEVELOPING SHARED GOALS

<p>1 PHL: WHERE DO YOU FIND COMMUNICATION MOST EASY?</p> <hr/> <hr/> <hr/>	<p>CP: WHERE DO YOU FIND COMMUNICATION MOST EASY?</p> <hr/> <hr/> <hr/>
<p>2 PHL: HOW DOES THE HEARING LOSS AFFECT YOU?</p> <hr/> <hr/> <hr/>	<p>CP: HOW DOES THE HEARING LOSS AFFECT YOU?</p> <hr/> <hr/> <hr/>
<p>3 PHL: HOW DOES THE HEARING LOSS AFFECT YOUR PARTNER?</p> <hr/> <hr/> <hr/>	<p>CP: HOW DOES THE HEARING LOSS AFFECT YOUR PARTNER?</p> <hr/> <hr/> <hr/>
<p>4 WHAT PROBLEMS DO YOU BOTH EXPERIENCE?</p> <hr/> <hr/>	
<p>5 SHARED GOALS</p> <hr/> <hr/>	
<p>6 STEPS TOWARD GOAL</p> <hr/> <hr/>	

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Appendix H: Answers to Goal Sharing of Partners Strategy Tool

Question One	
<i>PHL: Where do you find communication most easy?</i>	<i>CP: Where do you find communication most easy?</i>
<p>PHL1:</p> <ul style="list-style-type: none"> • Around the dining table • When the speaker is opposite me <p><i>When is communication difficult?</i></p> <ul style="list-style-type: none"> • If someone is behind me or next to me and talk then it won't register. 	<p>CP1:</p> <ul style="list-style-type: none"> • When we are situated in front of each other and she can read my lips.
<p>PHL 2:</p> <ul style="list-style-type: none"> • Quiet environment • At home • In the same room. <p><i>When is communication difficult?</i></p> <ul style="list-style-type: none"> • It's difficult when there is background noise. • Avoid cocktail parties. • When there lots of people around the dinner table. 	<p>CP 2:</p> <ul style="list-style-type: none"> • Quiet environment • Outside of a crowd <p><i>When is communication difficult?</i></p> <ul style="list-style-type: none"> • Avoid noisy environments
<p>PHL 3:</p> <ul style="list-style-type: none"> • Indoors • Face to face <p><i>When is communication difficult?</i></p> <ul style="list-style-type: none"> • When its windy and in noisy environments 	<p>CP 3:</p> <ul style="list-style-type: none"> • Sitting on the right of the PHL • When PHL is able to lip read. <p><i>When is communication difficult?</i></p> <ul style="list-style-type: none"> • Restaurants with background noise. • In noisy environments
<p>PHL 4:</p> <ul style="list-style-type: none"> • Speaking directly to a person • Quieter environment <p><i>When is communication difficult?</i></p> <ul style="list-style-type: none"> • It's difficult to communicate with background noise • Communicating at functions • On the telephone 	<p>CP 4:</p> <ul style="list-style-type: none"> • At home will be. Direct contact communicating is much easier. • Quiet environment <p><i>When is communication difficult?</i></p> <ul style="list-style-type: none"> • Difficult at functions when its noisy • Move to quieter area to speak • Sit in quieter area at restaurant and arrange seating prior to arrival.

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<p>PHL 5:</p> <ul style="list-style-type: none"> • My [CP] tries to understand my problem and usually takes special care to make sure that I hear what she says. We mostly communicate by phone – I turn the speaker phone on. I have received a phone clip from Suren which works well. However, my [CP] sometimes finds the voice is too distant. She has visited me a couple of times during lockdown and the communication was easy and satisfactory • She articulates well and I really find communication with her very easy. <p><i>When is communication difficult?</i></p> <ul style="list-style-type: none"> • Difficult to communicate over the phone • Difficult to communicate with grand children • Communication when partner is in the other room. 	<p>CP 5:</p> <ul style="list-style-type: none"> • In person • no background noises • fewer people around • quiet area <p><i>When is communication difficult?</i></p> <ul style="list-style-type: none"> • communicating is difficult telephonically • difficult at family gathering • difficult in restaurants with background music
<p>PHL 6:</p> <ul style="list-style-type: none"> • One to one conversation • Where there is no background music or noise • When you are not in public places Restaurants, social gatherings, etc <p><i>When is communication difficult?</i></p> <ul style="list-style-type: none"> • Background noise • Social gatherings • Public spaces • Restaurants • wind 	<p>CP 6:</p> <ul style="list-style-type: none"> • When we looking at each other face to face at close proximity • When we have a conversation in a quiet environment <p><i>When is communication difficult?</i></p> <ul style="list-style-type: none"> • In moving transport, the noise of the vehicle makes it difficult to have a conversation even though we sitting next to each other • Difficult in the morning when the hearing aids are not in yet because PHL making smoothie. • Or when PHL swimming and I need to communicate.
<p>PHL 7:</p> <ul style="list-style-type: none"> • One on one directly facing each other • with little or no background noise <p><i>When is communication difficult?</i></p> <ul style="list-style-type: none"> • Background noise 	<p>CP 7:</p> <ul style="list-style-type: none"> • When we are sitting together, concentrating on a particular topic and looking at each other. <p><i>When is communication difficult?</i></p>

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<ul style="list-style-type: none"> • Crowds like around the dinner table with many people 	<ul style="list-style-type: none"> • When we are having dinner with other people and there are multiple conversations
<p>PHL 8:</p> <ul style="list-style-type: none"> • When the person is with or in front of me <p><i>When is communication difficult?</i></p> <ul style="list-style-type: none"> • Examples like in my room (fairly quiet environment) or at the supper table. 	<p>CP 8:</p> <ul style="list-style-type: none"> • When there is minimum background noise. • When he is aware that I am speaking to him it makes it easier. <p><i>When is communication difficult?</i></p> <ul style="list-style-type: none"> • It's difficult if he cannot see me talking to him, or my kids are busy making a noise.
<p>PHL 9:</p> <ul style="list-style-type: none"> • In a quiet environment <p><i>When is communication difficult?</i></p> <ul style="list-style-type: none"> • It's difficult when there is background noise and in noisy social environments 	<p>CP 9:</p> <ul style="list-style-type: none"> • Facing each other directly within 1.2 meters.
<p>PHL 10:</p> <ul style="list-style-type: none"> • When we are face to face, but we do also share a study where we are back-to-back at computers and I still hear my [CP] very clearly. • It's also easier well lit • Quiet environment • No echoes • No background noise 	<p>CP 10:</p> <ul style="list-style-type: none"> • When we are face to face with no masks or background noise. • When PHL is not tired. • Waits to communicate when there is quiet.
Question Two	
PHL: How does the hearing loss affect you?	CP: How does the hearing loss affect you?
<p>PHL 1:</p> <ul style="list-style-type: none"> • Makes me sad I can't hear my grandchildren • I get upset when my [CP] gets frustrated and calls me deaf • Felt there wasn't understanding from CP occasionally and I never spoke back. 	<p>CP 1:</p> <ul style="list-style-type: none"> • Feel frustrated • Feeling of going mad from having to repeat • Annoyed at times. • Would speak less in a restaurant to avoid speaking loudly. • Didn't feel there were major arguments over misunderstanding.

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	<ul style="list-style-type: none"> • Don't feel that the hearing loss is too severe otherwise there would be more problems.
<p>PHL 2:</p> <ul style="list-style-type: none"> • The hearing loss onset was in my 20's. I was more withdrawn and socialized less. • My choice of profession was limited because of the hearing loss. I couldn't be an advocate. • I battled to hear in movies. I still do, we watch movies with subtitles. • I can't hear whispers. Going to the theatre is still difficult, especially with the rapid dialogue. I can't ask my wife because I can't hear whispers 	<p>CP 2:</p> <ul style="list-style-type: none"> • I managed to adapt from the beginning. For example, I learnt to listen to two conversations, my conversation and the one my husband was having. In case he missed out on something, I could fill in for him. • Driving before was frustrating. • There was a loss of intimacy, but I got used to it. We couldn't have secret jokes. • My concern is at night when we are asleep and he is not wearing his CI.
<p>PHL 3:</p> <ul style="list-style-type: none"> • It makes me feel frustrated and affects my self-confidence. • Banking online is very difficult. • People with non-English accents are more difficult to understand. • I feel inadequate. • I rely on facial expression. • When I struggle to communicate, I ask them to repeat themselves. 	<p>CP 3:</p> <ul style="list-style-type: none"> • When [PHL] says "yes", I know she didn't hear me. • We have seating arranged at dinner parties. • We watch subtitled movies. • Asks to turn music off in restaurant if it's too noisy. • I walk on her right.
<p>PHL 4:</p> <ul style="list-style-type: none"> • It affects you badly as some people don't have patience to repeat things and get annoyed if they must repeat themselves. • Becoming increasingly difficult to run a business because sometimes people's tone of voice it's difficult to comprehend what they're saying. • When people speak with a bit of accent and they speak fast, then it's very difficult for me to comprehend what they saying over the phone. • [I] let my daughter speak for me. • So, I'm depending on my wife. To listen if there's a burglar or something like that. 	<p>CP 4:</p> <ul style="list-style-type: none"> • When I am around strangers and crowded places where there is noise. • I don't feel different. I just accept it. It's a normal thing. Lots of people have problems and disabilities • We have to also you know be more patient with him and so on. Because if you put yourself into that position, it's not a nice position.

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<p>PHL 5:</p> <ul style="list-style-type: none"> • I am sometimes sad because I cannot hear everything clearly. • I am an outgoing kind of person who loves company and I cannot function well in a group when more than one person speaks at the same time. • I also find that listening to music is not as enjoyable as it used to be. • I also have difficulty in hearing the conversations on TV. It is not always the same. It can be very frustrating as I love relaxing in front of the TV. 	<p>CP 5:</p> <ul style="list-style-type: none"> • I start getting those frights with loud noises even when she's not there. • I also get flustered when there's too much noise around me. • Irritated due to PHLs complaints. • Frustrated • Anxious • Sad that intimate conversations cannot be shared over the phone such as not being able to communicate when she is going through an ordeal, due to difficulties communicating over phone. • CP gets irritated with noise that connective machine makes when connected to telephone. • PHL dependent on CP for hearing and physical dependence. • Communicates on behalf of PHL in restaurants: translates from English to Afrikaans. Makes people aware of [PHLs] hearing loss. • CP takes over conversation. • Depends on CP for hearing assistance in crowds. Feels PHL is inquisitive. • Irritation due to PHL "zoning out" when she can't but does not inform CP. • Irritation when PHL zones out in group conversations.
<p>PHL 6:</p> <ul style="list-style-type: none"> • You do not always understand the CP because you only hear parts of the words. • When people whisper or speak softly, and you cannot hear. • Leads to frustration because you cannot hear what is being said and you interpret it incorrectly, resulting in you performing an incorrect task. • Before hearing aid: would bluff • Currently with hearing aid, PHL can participate in conversation 	<p>CP 6:</p> <ul style="list-style-type: none"> • It is tedious, frustrating, and irritating, because I must continuously repeat myself and raise my voice. • In moving transport, the noise of the vehicle makes it difficult to have a conversation even though we sitting next to each other. <p><i>How does it make you feel?</i></p> <ul style="list-style-type: none"> • I go 'crazy' when PHL is not wearing hearing aid and have to shout.

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	<ul style="list-style-type: none"> • Withdraw from making casual conversation when hearing aids not in. Only important information is communicated. • Frustrated when I have to respond to the doorbell because PHL hasn't heard it. <i>Is your partner dependent on you in anyway?</i> • Dependent to hear call for prayer in the morning. • When driving and other cars hooting. • Afraid at night when hearing aids are not in. I can't communicate if there is a problem. • CP feels overall the adjustments were not difficult to make.
<p>PHL 7:</p> <ul style="list-style-type: none"> • Cannot read lips • Causes much irritation as perceived messages are of the misunderstood. • Causes anxiety and feelings of inadequacy. • Results in mood swings difficult to control. 	<p>CP 7:</p> <ul style="list-style-type: none"> • When I speak to my partner and he doesn't concentrate on what I am telling him. • He often thinks ahead as I am speaking and then does not actually listen to what I am saying. <p><i>How does it make you feel?</i></p> <ul style="list-style-type: none"> • Frustrating when PHL interrupts flow of conversation and rules of conversation due to not hearing. • Annoyed and tiring when PHL doesn't concentrate on conversation and jumps to conclusions. • Frustrated when PHL assumes the topic of conversation and takes of conversation in the group. • Deal with it by sometimes walking away. <p><i>How do you assist your partner in the situations?</i></p> <ul style="list-style-type: none"> • Listening to conversation on behalf of PHL. Repeat information to PHL.

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	<ul style="list-style-type: none"> Assists PHL to order in restaurant by repeating what waitress says.
<p>PHL 8:</p> <ul style="list-style-type: none"> I used to put the T.V on loud when watching a program. My new hearing aids allow the T.V to connect to play through the hearing aids. <p><i>What do you do when you have difficulty communicating with your son?</i></p> <ul style="list-style-type: none"> I ask for repetition. <p><i>Are there any places your events you avoid because of the hearing loss?</i></p> <ul style="list-style-type: none"> I avoid big groups. When there are people over, I often am more comfortable to watch TV in my room. 	<p>CP 8:</p> <ul style="list-style-type: none"> I have to repeat myself multiple times or talk/speak at a high volume to get the attention of my dad when having a conversation. When you have to repeat yourself or speak at a higher volume, how does this make you feel? When I have to repeat myself, it does make me feel irritated. <p><i>Has your relationship with your [PHL] changed since the hearing loss?</i></p> <ul style="list-style-type: none"> Don't have a very verbal relationship
<p>PHL 9:</p> <ul style="list-style-type: none"> It causes loss of self-confidence. <i>When there is a communication breakdown, what do you do to assist or retrieve the message from the speaker?</i> Repetition <p><i>Are there any strategies you use?</i></p> <ul style="list-style-type: none"> Request to look at me while speaking, speak slowly not louder. <p><i>Which situations are difficult for you to communicate in? Do you avoid or withdraw from those situations?</i></p> <ul style="list-style-type: none"> Avoid noisy places (e.g., parties and crowds). If I have to be there, I withdraw. 	<p>CP 9:</p> <ul style="list-style-type: none"> I find it irritating sometimes. <p><i>Which situations do you find communicating most frustrating and irritating?</i></p> <ul style="list-style-type: none"> When [PHL] has her back to me and speaks softly. <p><i>How do you assist when there is a communication breakdown?</i></p> <ul style="list-style-type: none"> I wait for her to turn and face me and speak more slowly and clearly.
<p>PHL 10:</p> <ul style="list-style-type: none"> I occasionally get frustrated when I can't follow a conversation via at the moment on zoom and skype and when people are wearing masks. 	<p>CP 10:</p> <ul style="list-style-type: none"> Mostly not at all. Biggest problem is when I know I have not been heard and speak louder giving hearer the impression I am shouting.

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<p><i>When you get frustrated because you can't follow the conversation, what strategies do you use to overcome this challenge?</i></p> <ul style="list-style-type: none"> • I ask people to speak more slowly and to look at me. I also try to reduce background noise by switching off machines. 	<p><i>How do you feel when you have to shout to be heard?</i></p> <ul style="list-style-type: none"> • I try not to - don't want to give the impression of being angry <p><i>If you give the impression you are shouting, does this impact on your partners feelings?</i></p> <ul style="list-style-type: none"> • Both of ours <p><i>When your partner does not hear you, or others speak, besides increase the volume of your voice, do you use any other strategies to help her hear better?</i></p> <ul style="list-style-type: none"> • Just stay quiet and listen
Question Three	
PHL: How does your hearing loss affect your partner?	CP: How does the hearing loss affect your partner?
<p>PHL 1:</p> <ul style="list-style-type: none"> • He had to have a lot of patience to repeat things. • I wasn't aware of his frustrations • He sometimes used to say "can't you hear or something and it used to upset me" 	<p>CP 1:</p> <ul style="list-style-type: none"> • It was difficult for her to accept in the beginning that she's going deaf. • It affected [PHL] in completing tasks. e.g., ordering tablets. Due to not hearing the instruction. • Would not be able to hear from the garden. • Didn't feel the relationship changed. • She [PHL] would get frustrated when made aware of the hearing loss.
<p>PHL 2:</p> <ul style="list-style-type: none"> • She would get frustrated. • We adapted. • Partake in activities separately. 	<p>CP 2:</p> <ul style="list-style-type: none"> • Isolated • Led solitary lives, joined clubs alone.
<p>PHL 3:</p> <ul style="list-style-type: none"> • PHL feels CP is impatient 	<p>CP 3:</p> <ul style="list-style-type: none"> • Concentration is a problem. • Bluffs- pretends to hear.
<p>PHL 4:</p>	<p>CP 4:</p>

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<ul style="list-style-type: none"> • Patient and understanding • Its awkward at night when I don't have my device in and CP wants to communicate. • We communicate with humour. • Intimate communication affected. 	<ul style="list-style-type: none"> • Gets irritated on the phone • Experiences concentration difficulties when tired. • He was withdrawn after resigning from the community association due to hearing loss. • Relationship hasn't changed. Close couple that does everything together.
<p>PHL 5:</p> <ul style="list-style-type: none"> • CP finds telephonic communication distant. • CP copes with it very well. • CP has compassion and understanding. 	<p>CP 5:</p> <ul style="list-style-type: none"> • PHL never really adapted to hearing loss • Irritated with not being able to hear. • Difficult to hear at concerts. • Difficult to teach due to hearing loss. • Difficult to facilitate workshops with large groups of people. • Lost confidence in social settings. • Difficulty ordering in restaurants. • Difficulty hearing in crowds. • Frustrated and sulks when CP doesn't repeat what is being said by others. • Doesn't take part in conversations like before. "Zones out"
<p>PHL 6:</p> <ul style="list-style-type: none"> • Frustrated CP ignores me because of not hearing. 	<p>CP 6:</p> <ul style="list-style-type: none"> • Great strain and patience. • Relationship has changed for the better.
<p>PHL 7:</p> <ul style="list-style-type: none"> • Frustrated • Annoyed • Angry 	<p>CP 7:</p> <ul style="list-style-type: none"> • Difficult to converse in a group. • Annoyed when there are communicative misunderstandings.
<p>PHL 8:</p> <ul style="list-style-type: none"> • No impact on relationship • CP is probably frustrated 	<p>CP 8:</p> <ul style="list-style-type: none"> • Affected his confidence in social settings. but he seems to have been coping well so far. • In social situations he doesn't engage much with the company. • I assume it's probably too hard to follow the conversation then retreats to his room.
<p>PHL 9:</p>	<p>CP 9:</p>

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<ul style="list-style-type: none"> • Irritated • Frustrated from repeating 	<ul style="list-style-type: none"> • Frustrated and disillusioned • Continues listening to music despite PHL not hearing. • I enjoy it and she doesn't. I need to get on with my life so she must adjust to it. I feel I am not going to babysit her.
<p>PHL 10:</p> <ul style="list-style-type: none"> • Patient when communicating • CP tells PHL of conversations missed • Informs others of PHLs hearing loss 	<p>CP 10:</p> <ul style="list-style-type: none"> • PHL Is not affected. PHL pauses when its noisy and then speaks when conditions improve. • Aspects of life did change such as social aspects. • CP doesn't blame PHL. • Doesn't feel relationship changed.
Question Four	
What problems do you both experience?	
<p>COUPLE 1</p> <ul style="list-style-type: none"> • Cannot communicate when in different rooms • Speaking too loudly when hearing aid is on. • If PHL wasn't facing CP and she didn't respond to CP then CP would assume she didn't hear and not repeat. 	
<p>COUPLE 2</p> <ul style="list-style-type: none"> • Can't communicate in a quiet environment (e.g., Theatre) 	
<p>COUPLE 3</p> <ul style="list-style-type: none"> • Communicating when there are lots of people 	
<p>COUPLE 4</p> <ul style="list-style-type: none"> • Sometimes completely misunderstanding what is being said. • Many changes in our lives that we have to cope with regarding the loss at this age. 	
<p>COUPLE 5:</p> <ul style="list-style-type: none"> • PHL: Not clear what is meant by what you both experience...same kinds of problems? 	
<p>COUPLE 6:</p> <ul style="list-style-type: none"> • Frustration • - Due to the lack of hearing, both parties often feel frustrated. CP has a conversation with PHL and PHL does not hear the full story. CP then gets mad because CP requested PHL to do certain things and PHL did not do it. 	

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<ul style="list-style-type: none"> • Tolerance & Patience Lack of understanding my condition often results in the lack of patience between the partners.
<p>COUPLE 7:</p> <ul style="list-style-type: none"> • We both get very frustrated and irritable because I do not hear or misunderstand each other's speech. • We fail to practice hearing skills and talk around corners away from each other. • We do not practice reading lips. • Great lack of understanding of one another's perception of the 'spoken word'. • PHL: I have never been completely satisfied with the cochlear implant... This is probably the biggest contributor of the overall hearing difficulties over the years.
<p>COUPLE 8:</p> <ul style="list-style-type: none"> • Hearing and paying attention • Listening to understand and processing correctly. • Remembering what was discussed.
<p>COUPLE 9:</p> <ul style="list-style-type: none"> • Does not let hearing loss of PHL affect CP • Speak clearly and be aware of the problem • Communicating clearly with each other
<p>COUPLE 10:</p> <ul style="list-style-type: none"> • We communicate well together. The problem only comes talking with bigger groups, talking to our children over skype etc.
<p>Question Five</p>
<p style="text-align: center;">Shared goals</p> <p><i>Couple 1 had difficulty discussing goals. Did not know how to answer independently. Once probed they shared the following:</i></p> <ul style="list-style-type: none"> • To notify CP when hearing aid is on. • Speak in front of PHL when communicating. <p>Couple 2, felt they are already working on their problems, therefore had no new goals.</p> <p>Couple 3 felt they did not need goals.</p> <p>Couple 4:</p> <ul style="list-style-type: none"> • Sacrifice and be there for each other to cope with daily challenges. • To live with understanding. • To communicate better with understanding. <p>Couple 5 did not complete goal due to interpersonal communication difficulties.</p> <p>Couple 6:</p> <ul style="list-style-type: none"> • To communicate with each other without any frustration • To listen more attentively and confirm each other's requests • PHL: Make an appointment with an audiologist to alleviate my hearing loss.

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Couple 7 required assistance from researcher.

- Chatting on the same topic
- Including PHL in conversation
- Prevent miscommunications through anticipating what CP is going to say.
- Prevent miscommunications by assuming PHL has heard.

Couple 8

- To be able to hear conversations clearly and easily
- To be able to recall and remember what was discussed.
- To be able to improve and enjoy quality of life

Couple 9:

- Patience and understanding

Couple 10:

- Communicate effectively

Question Six

Steps towards the goal

Couple 1 (with assistance)

- When PHL doesn't respond then CP situates himself to be heard better.
- Have more patience.

Couple 4

- Have patience
- To support each other

Couple 6

- We set aside time to talk more attentively.
- Got myself a super-duper hearing aid – Widex. Now I can hear everything, even my phone ringing directly in my ears and watching TV with the sound on mute, cause my hearing aid allows the TV sound directly to my ears.

Couple 7 (with assistance)

- PHL: Use hand up gesture to partake in conversation.
- PHL not to jump ahead in conversation and pre-anticipate what CP is going to say (prevent miscommunication):
 - PHL has to practice this impulse.
- Prevent miscommunications by CP assuming PHL has heard:
- More face-to-face communication
- CP to be more aware of facial expression

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Couple 8

- Ge your attention before start talking
- Make sure there is enough light in the room
- Switch off or reduce background noise when engaging.

Couple 9

- Time and adapting

Couple 10

- Encourage others to speak up in groups
- Change the technology if needed
- Continuous process, working on all the time. Cochlear implant helped iron out most problems.

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Appendix I: Interview notes

- Some participants appear to have difficulty discussing challenges in detail with the partner present to avoid upsetting each other. PHL emailed researcher after the interview with more detail about the challenges. Another PHL waited for the CP to leave the call to include the challenges they experience.
- Conducting interviews telephonically and over video call prevents the researcher from establishing a rapport with the participant, therefore the answers to the questions may be limited to an extent.
- Reluctance of the CP 5 to discuss problems experienced with the PHL to prevent problems in their relationship further prevented them from completing the aspect of the GPS tool that required discussion between the CP and PHL (questions 4, 5 and 6)
- Based on the responses from PHL 5, they are not aware of the effect their hearing loss is having on the CP.
- The CPs that appeared to have a more easy-going personality in the interview had a more positive outlook on the challenges. They did not seem to be affected greatly by them.
- Couple 3: CP did not converse much in the interview; the answers were short and limited.
- Identifying goals and determining steps appear to be a challenge for most of the participants.
- Couple 7 required further discussion with the researcher to identify solutions to the challenges they experienced.

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- Participants often describe the difficulties being worse before the hearing aid fitting.
- There were contextual factors that contributed to the challenges, these experienced during the period of COVID-19. These being spending more time together at home resulting in more challenges, communicating with masks and having to communicate with their CP more over the telephone and video call.
- More detail added to participants responses when interviewed verbally.
- Strategies for communication and strategies to overcome miscommunication are noted.
- The answers for question 4 on the GPS tool appeared to often be the answers to question 1. This differs to the example of answers provided on the GPS tool.
- Limited information is yielded when the participants completed the GPS tool themselves. The topic guide generated more information through probing.

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Appendix J: Breakdown of themes

Theme	Code	Units
Daily life challenges from the CPs perspective and management strategies	At home	<p>Communicating from a different room of the house with the PHL would result in misunderstandings.</p> <p>Management strategies were:</p> <ul style="list-style-type: none"> • Using a cell phone when not in hearing range • When in hearing range shout and call to the same room to initiate conversation • Close proximity improved communication. <p>Some challenges experienced at home are still experienced without proactively managing the miscommunication. These are:</p> <ul style="list-style-type: none"> • Communicating verbal instructions to the PHL, however due to the hearing loss the instructions are not carried out. • When the CP is under the impression that the PHL is conversing on the same topic, but they are speaking about different topics. • Situations when the PHL is not wearing their hearing device (e.g., before bed, first things in the morning, when PHL is swimming) limits communication. This results in either CP shouting when device is on, or speaking normally when device is off and PHL not hearing.
	Social gatherings or dinner parties	<p>The background noise in social gatherings would make it difficult to have a conversation with the PHL.</p> <p>Some couples managed this by:</p> <ul style="list-style-type: none"> • Requesting to turn down the background noise, if this was possible. • Some would move to a quieter area to have a conversation such as the outskirts of the crowd. <p>Trying to communicate when there are multiple conversations happening at the same</p>

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		<p>time at a dinner party as the PHL relies on the CP for assisted listening.</p> <p>Some couples managed this by:</p> <ul style="list-style-type: none"> • Arranging seating to ensure the CP sits next to the PHL to assist them in conversation. • Another strategy mentioned was to limit the number of guests. • Avoiding cocktail parties.
	Restaurants	<p>Challenges were:</p> <ul style="list-style-type: none"> • Trying to converse in a restaurant with background noise. • One couple mentioned that the CP has to raise their voice to be heard and the rest of the patrons hear the conversation. This results in the CP speaking less. This was evident in CP 1 statement, “When we go to a restaurant, I would speak very little if I had to scream. I would rather just sit quietly.” <p>Some couples manage the background noise in restaurants by:</p> <ul style="list-style-type: none"> • Arranging their seating prior to arrival in a quiet area of the restaurant. <p>The PHL has difficulty communicating with the waiter due to the waiter speaking too fast or too softly.</p> <ul style="list-style-type: none"> • Some couples manage this by depending on the CP to assist with communication and some inform the waiter that the PHL has a hearing loss.
	Shopping	<p>Challenges were:</p> <ul style="list-style-type: none"> • When it is busy and there is background noise. This was managed by moving to an aisle that is quiet to communicate important information.
	Travelling	<p>The background noise of the vehicle makes it difficult to converse.</p>
	Leisure activities	<ul style="list-style-type: none"> • Watching movies together and due to the volume being too loud to accommodate the PHL this becomes unbearable for the CP. This is managed by enabling the subtitles and

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		<p>watching movies at a bearable volume.</p> <ul style="list-style-type: none"> • Being able to communicate in quiet environments such as theatres are also a problem as the PHL cannot hear the CP whisper. • Attending events without PHL initially, then partaking in separate social activities.
	Telephonic conversations	<ul style="list-style-type: none"> • Difficulty having a personal conversation with the PHL over the phone due to the interruptions of the phone with the hearing device.
The emotional effect of communication breakdowns	Feeling of frustration, irritation or annoyance	<ul style="list-style-type: none"> • Having to repeat themselves multiple times • Having to bridge the communication gap in group conversations, especially when having to explain a joke. • When the PHL pretends to hear. I. E. bluffing • When the PHL is not concentrating on the conversation. • When the CP realises that they have been speaking to each other about different topics because the PHL did not hear. • When the CP has communicated a message with the impression it has been received by the PHL, however it was not. The CP begins to doubt whether they communicated the message or not and describes this feeling as “going crazy”.
	Concern for partner	<ul style="list-style-type: none"> • Crossing the road • Driving • Sleeping and intruder is outside
Communication changes in the relationship	Dependent on CP	<ul style="list-style-type: none"> • Placing an order with the waiter at a restaurant due to the waiter either speaking too softly, fast or in an accent that is difficult for the PHL to understand. • Listening on behalf of the PHL in group conversations, and repeating, clarifying or rectifying information that has been conveyed by other group members. • Attending appointments with the PHL to provide supportive listening in the

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		<p>case that the PHL misses out on important information that the medical professional provides.</p> <ul style="list-style-type: none"> • Providing supportive listening in various situations such as: <ul style="list-style-type: none"> - In the morning when the call to prayer is being transmitted before the PHL has their hearing device on. - In the car when there are cars hooting. - Listening and attending to the door-bell at home.
	Other changes	<ul style="list-style-type: none"> • Communicative interactions such as whispers and intimate conversations conducted over the phone were aspects that also changed the way the PHL and CP communicated. CPs mentioned that they had to accept that they cannot whisper to their partner anymore. Therefore, jokes or communicating in a quiet space was an interaction that they could not partake in.
Coping strategies	Proactive strategies to preventing misunderstandings	<ul style="list-style-type: none"> • CP speaks from opposite PHL or on PHLs better ear • Ensure good lighting for visibility of lip reading and facial expression • Lower volume of any controllable background noise in the environment (music, tv) • Tapping PHL to get their attention first
	Remedying communication when there is a misunderstanding	<ul style="list-style-type: none"> • Repetition • Speaking loudly • Use of gesture • Facial expression • Writing message down or texting on cell phone • Speaking slower and not louder (cochlear implant users).
	Personal values and beliefs	<ul style="list-style-type: none"> • Gratefulness for hearing devices • Grateful for hearing loss not being worse • Learning to adapt

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		<ul style="list-style-type: none">• Having an easy-going personality• Having a sense of humour when misunderstanding happen.• Having patience• Having a positive attitude• Acceptance <p>Empathy</p>
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Appendix K: Ethical Clearance



14 November 2019

HRBC REF:638/2019

Ms. Lucretia Petersen
Division Communication Science and Disorders
Department of Health and Rehabilitation Sciences
F46
OMB GSH

Dear Ms. Petersen

PROJECT TITLE: THE CHALLENGES AND COPING STRATEGIES OF COMMUNICATION PARTNERS OF OLDER ADULTS WITH DISABLING HEARING LOSS. A SOUTH AFRICAN STUDY. (MSc DEGREE - MS S MUSTAPHA)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has formally approved the above-mentioned study.

Approval is granted for one year until the 30 November 2020.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/the/research/humanethics/forms)

Please note that for all studies approved by the HREC, the principal investigator must obtain appropriate institutional approval, where necessary, before the research may occur.

The HREC acknowledge that the student, *Ms S Mustapha* will also be involved in this study.

Please also note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC REF in all your correspondence.

Yours sincerely

PROFESSOR N. BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

HRBC 638/2019

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This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practices (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines.

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

CH ETHICS COMMITTEE