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FAMILY-CENTRED EHDI SERVICES: CAREGIVERS' EXPERIENCE AND EVALUATION OF THE PROCESS AND PRACTICES IN THE SOUTH AFRICAN CONTEXT

A RESEARCH THESIS SUBMITTED TO:

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BY

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DECLARATION

I, Ntsako Precious Maluleke, hereby declare that this submission is my own original work and that the assistance which I received is detailed in the Acknowledgments of this report. To the best of my knowledge and belief, this work contains no material that has been accepted for the award of any other degree or diploma at any university or other institute of higher learning, except where due acknowledgement has been made in the text. I am responsible for the study and conclusions reached.



10 February 2024

Ntsako Precious Maluleke **Date**

DEDICATION

A CHILD OF MINE

By Edgar A. Guest

I will lend you, for a little time, a child of mine, He said.

For you to love the while he lives, and mourn for when he's dead.

It may be six or seven years, or twenty-two or three.

But will you, till I call him back, take care of him for Me?

He'll bring his charms to gladden you, and should his stay be brief.

You'll have his lovely memories, as solace for your grief.

I cannot promise he will stay, since all from earth return.

But there are lessons taught down there, I want this child to learn.

I've looked the wide world over, in search for teachers true.

And from the throngs that crowd life's lanes, I have selected you.

Now will you give him all your love, nor think the labour vain.

Nor hate me when I come, to take him home again?

I fancied that I heard them say, 'Dear Lord, Thy will be done!'

For all the joys Thy child shall bring, the risk of grief we'll run.

We'll shelter him with tenderness, we'll love him while we may,

And for the happiness we've known, forever grateful stay.

But should the angels call for him, much sooner than we've planned.

We'll brave the bitter grief that comes, and try to understand.

ACKNOWLEDGEMENTS

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To kokwani, Daisy "Manana Mlangeni" Mlangeni. The impact of your choices and prayers have rippled into the opportunities and privileges I enjoy today, ndza mi khensa. Thank you for being an exceptional example. I carry your love and guidance in everything I do.

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To my supervisor, Professor Katijah Khoza-Shangase, this moment for me feels so surreal. The seed of one day obtaining my PhD was planted in 2006, when we were introduced you as our lecturer. To see a young, passionate, intelligent, Black, audiologist with a PhD in Audiology gave birth to a dream that had not existed until that point. I have had the privilege

and honour of having you as a supervisor for all three of my degrees! You are tough, I won't lie. Your time frames were near impossible and you demanded excellence, commitment and a work ethic like I have never seen before, because that is what you bring to the table. As strict as you were, you managed to be very supportive, understanding and my biggest cheerleader, which is truly amazing and I am in awe of how you balance the two. You have been more than a supervisor; you have gone far and beyond the call of your duties and responsibilities as a supervisor. Words fail to express my gratitude for you. There were times when I felt like giving up, but it was your unwavering belief and support that I can complete this research that forced me to push through. May you be blessed abundantly, in all aspects of your life and in everything you do.

SCHOLARLY ACTIVITIES

ARTICLES:

1. **Maluleke, N.P.,** Khoza-Shangase, K., & Kanji, A. (2019). Hearing impairment detection and intervention in children from centre-based early intervention programmes. *Journal of Child Health Care, 23*(2), 232-241. https://doi.org.10.1177/1367493518788477
2. **Maluleke, N.P.,** Khoza-Shangase, K., & Kanji, A. (2019). Communication and school readiness abilities of children with hearing impairment in South Africa: A retrospective review of early intervention preschool records. *South African Journal of Communication Disorders, 66*(1), a604. https://doi.org/10.4102/sajcd.v66i1.604
3. **Maluleke, N.P.,** Khoza-Shangase, K., & Kanji, A. (2021). An Integrative Review of Current Practice Models and / or Process of Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing. *Family and Community Health, 44*(1),59-71. https://doi.org/10.1097/FCH.0000000000000276
4. **Maluleke, N.P.,** & Khoza-Shangase, K. (2023). Embracing videoconferencing interview applications beyond COVID-19: Scoping-review-guided implications for Family-Centered EHDI services in South Africa. *Discover Health Systems, 2*, 20. https://doi.org/10.1007/s44250-023-00033-x
5. **Maluleke, N.P.,** Khoza-Shangase, K., & Kanji, A. (2023). EHDI services should be accessible! Caregivers' expectations of EHDI services in South Africa. Speech, Language and Hearing. https://doi.org/10.1080/2050571X.2023.2241219
6. **Maluleke, N.P.** (2024, in press). Early Hearing Detection and Intervention (EHDI) in South Africa: A Call for Pragmatic Considerations in Implementing Linguistic and Culturally Congruent Family-Centred EHDI programmes. *South African Journal of Communication Disorders*

7. **Maluleke, N.P.,** Khoza-Shangase, K., & Kanji, A. (Submitted). Caregivers' experiences of the Early Hearing Detection and Intervention (EHDI) process from detection to intervention in South Africa. *BMC Health Services Research*
8. **Maluleke, N.P.,** Khoza-Shangase, K., & Kanji, A. (Submitted). Barriers and facilitators to Early Hearing Detection and Intervention in South Africa: A narrative inquiry of caregivers' experiences. *BMC Pediatrics*
9. **Maluleke, N.P.,** Khoza-Shangase, K., & Kanji, A. (Submitted). Family-Centeredness of Early Hearing Detection and Intervention Programs in South Africa. *Brazilian Journal of Otorhinolaryngology*
10. **Maluleke, N.P.,** Khoza-Shangase, K., & Kanji, A. (Submitted). Caregivers' preferences for EHDI Services in South Africa: Evidence from a conjoint analysis. *Ear and Hearing*
11. **Maluleke, N.P.,** Khoza-Shangase, K., & Kanji, A. (Submitted). Early Hearing Detection and Intervention (EHDI) in South Africa: A call for pragmatic considerations in implementing linguistic and culturally congruent Family-Centred EHDI programmes. *South African Journal of Communication Disorders*

CHAPTERS:

1. **Maluleke, N.P.,** Chiwutsi, R., & Khoza-Shangase, K. (2021). Family-Centered Early Hearing Detection and Intervention. In K. Khoza-Shangase , & A. Kanji (Eds). *Early Hearing Detection and Intervention in Audiology* (pp. 196-218). Wits University Press.
2. Maluleke, N.P. (2022). Economic evaluation of EHDI programmes in South Africa: Putting EHDI on the political advocacy and resource allocation agenda. In K. Khoza-Shangase (Ed.). *Preventive audiology: An African Perspective* (pp.199-212). AOSIS Books. https://doi.org/10.4102/aosis.2022.BK209.10

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LIST OF ABBREVIATIONS

ABR : Automated Brainstem Response

AIDS : Acquired Immune Deficiency Syndrome

CBA : Cost-Benefit Analysis

CDC : Centers for Disease Control and Prevention

CEA : Cost-Effectiveness Analysis

COVID-19 : Coronavirus Disease-19

DALY : Disability-Adjusted-Life-Years

DPOAE : Distortion Product Otoacoustic Emission

ECD : Early Childhood Development

EFA : Education For All

EI : Early Intervention

EHDI : Early Hearing Detection and Intervention

FC-EHDI : Family-Centred Early Hearing Detection and Intervention

FCEI : Family-Centred Early Intervention

HCF : Healthcare Facility

HCP : Healthcare Professional

HIC : High-Income Country

HI HOPES : Home Intervention: Hearing and language Opportunities Parent Education Services

HIV : Human Immunodeficiency Virus

HPCSA : Health Professions Council of South Africa

JCIH : Joint Committee on Infant Hearing

LMIC : Low-and-Middle-Income Country

LYG : Life-Years-Gained

MPOC-56 : Measure of the Process Of Care-56

NHI : National Health Insurance

NHS : Newborn Hearing Screening

POPI : Protection Of Personal Information

QALY : Quality-Adjusted-Life-Years

SAJCD : South African Journal of Communication Disorders

SDG : Sustainable Development Goals

SMS : Short Message Service

UHC : Universal Health Coverage

UNHS : Universal Newborn Hearing Screening

WHO : World Health Organisation

UN : United Nations

UNAIDS : United Nations Programme on HIV/AIDS

UNICEF : United Nations International Children's Emergency Fund

USAID : United States Agency for International Development

CHAPTER 1

Early Hearing Detection and Intervention

Chapter 1 provides an overview of early hearing detection and intervention (EHDI) and family-centred early intervention (FCEI). The chapter also provides the statement of the problem, motivation for the study, statement of originality, conceptual framework, as well as the aim, sub-aims and research questions of the study. Lastly, this chapter provides an overview of the research methodology adopted in this study and overall outline of this thesis.

1.1 Background

The first few years of an infant's life form the foundation on which all future development is built (Deng et al., 2020; Robinson et al., 2017; Ward et al., 2019). The period from birth to 6 years encompasses early childhood development (ECD), and denotes a period where children undergo rapid cognitive, language, physical, emotional and social development which promote the realisation of their full potential (Albino & Berry, 2013; Mbarathi et al., 2016; Richter et al., 2019; WHO, 2018). Thus, the importance of ECD programmes is profound as these programmes seek to address inequalities and cushion children against the effects of inadequate healthcare and lack of education (Ashley-Cooper et al, 2019; Karisa et al., 2022), in the case of children with hearing impairment. Global evidence demonstrates that quality ECD programmes reduce the need for costly remedial interventions to address developmental lag and social problems in life (Albino & Berry, 2013; Ashley-Cooper et al., 2019).

An estimated 250 million children under the age of five years in low-and-middle-income countries (LMICs), like South Africa are at an elevated risk for not achieving their developmental potential (Black et al., 2017; Morelli et al., 2018; Richter et al., 2017). Within

the South African context, these children (73.3%) are believed to be at an elevated risk due to a lack of equitable access to quality ECD provision and resources including healthcare, social security and education (Ashley-Cooper et al., 2019). Protecting, promoting and supporting ECD programmes is essential to enable everyone to reach their full potential and forms part of the first sustainable development goal (SDG), which is to "ensure that all human beings can fulfil their potential in dignity and equality" (United Nations, 2015; 2019; Weiland et al., 2021). Accordingly, in response to the SDGs, various ECD programmes have been initiated within the South African context in order to meet the unique needs of young children; ensure that the most vulnerable families and children are reached; and reduce the risks associated with poor childhood development (Albino & Berry, 2013; Ashley-Cooper et al., 2019).

1.1.1 Early Hearing Detection of Hearing Impairment

One of the ECD initiatives implemented in South Africa for children with congenital or early-onset hearing impairment, in particular, is EHDI (Maluleke et al., 2021). The goal of EHDI is to ensure that all infants and newborns with hearing impairment are identified as early as possible and appropriate intervention initiated timeously (Joint Committee on Infant Hearing [JCIH], 2007; 2019; Health Professions Council of South Africa [HPCSA], 2007; 2018). EHDI is recognized as an undeniable right for children with hearing impairment and their families as a cost-effective solution to curb the widely reported communication, cognitive and academic challenges that are consequences of a late-identified hearing impairment (HPCSA, 2018; Khoza-Shangase et al., 2021; Pribanikj & Milkovikj, 2018; Wilson et al., 2017). Early detection of the hearing impairment through universal newborn hearing screening (UNHS) is the initial stage in any EHDI programme (Khoza-Shangase et al.,2017). UNHS is a cost-effective approach for the timeous and effective identification of hearing impairment (Tordrup et al., 2022; WHO, 2017); and has been regulated in many high-income countries (HICs) (Khoza-Shangase, 2019; Joshi et al., 2023). However, UNHS

is not mandated in LMICs, including South Africa (Bezuidenhout et al., 2019; Hussein et al., 2018).

Consequently, evidence within the South African context indicates significant delays in the ages of identification, diagnosis, and intervention for children with hearing impairment (Maluleke et al., 2018; 2019; Scheepers et al., 2014). Available reports reveal ages at identification between seven and 49 months; ages at amplification between 28 and 39 months; and ages at initial enrolment into early intervention (EI) services between 17 and 50 months (Maluleke et al., 2018; Scheepers et al., 2014; Storbeck & Young, 2016). These ages far exceed international benchmark indicators and HPCSA's (2018) guidelines, which state that all infants should be screened for hearing impairment by six weeks; diagnosed with hearing impairment no longer than four months of age; and enrolled in an EI programme before eight months of age.

The lack of mandated UNHS and suboptimal EHDI service provision exists in South Africa despite the high prevalence of paediatric hearing impairment in this context. Although, data on prevalence and epidemiology in South Africa is scarce, the estimated incidence of congenital or early-onset hearing impairment is about 6 in every 1000 live births or 20 babies born daily (Bezuidenhout et al., 2018; Haile et al., 2019; Manyisa et al., 2022; Wilson et al., 2017). The challenge with implementing UNHS in South Africa is linked to contextual barriers such as scarcity of financial, human and physical resources; locations of audiologists mainly in the private sector; newborn hearing screening (NHS) services not forming part of the birthing package or institutional policy; low coverage rates; burden of disease challenges; health priority challenges; and reliance on international guidelines from HICs which are not contextually relevant or responsive to a LMIC context (Bezuidenhout et al., 2018; Kanji, 2021; Kanji & Khoza-Shangase, 2021; Khan et al., 2018; Pillay et al., 2020). As a result, paediatric hearing impairment is viewed as less urgent because it relates more to quality of

life than to survival and has consequently received lesser financial attention and political will from the Department of Health (Khoza-Shangase & Michal, 2014; Petrocchi-Bartal et al., 2021; Petrocchi-Bartal & Khoza-Shangase, 2016).

In order to ensure timely diagnosis of hearing impairment in the South African context it is recommended that EHDI programmes be contextually relevant and responsive (Khoza-Shangase, 2019; Maluleke et al., 2021a). Thus, there is a need for EHDI services to be contextualised in terms of the feasibility of adopting different screening approaches (including targeted newborn hearing screening); and implementing newborn screening programmes at various levels of service delivery, including primary healthcare clinics, community health centres, district hospitals, and tertiary hospitals through task shifting and de-centralising the services where necessary (Bezuidenhout et al., 2018; De Kock et al., 2016; Kanji, 2021; Petrocchi-Bartal et al., 2021). Undoubtedly, one of the main benefits arising from the implementation of UNHS programmes is early detection of hearing impairments in children (Kuschke et al., 2020; WHO, 2016; Yoshinaga-Itano et al., 2021). However; hearing screening in newborns and infants is only an important first step in the EHDI process, and does not necessarily guarantee optimal outcomes. Early access to amplification and quality EI services have been identified as critical components of successful EHDI programmes (JCIH, 2019).

1.1.2 Family-Centred Early Intervention

EI represents the purpose and goal of the entire EHDI process (Devi, 2023; Yoshinaga-Itano, 2014); and focuses on optimizing the development and well-being of the child with hearing impairment and their family (HPCSA, 2018; Kanji & Casoojee, 2021; Yoshinaga-Itano, 2014). Central to the principles of EI as delineated in the principles and guidelines for EI (Yoshinaga-Itano, 2014) is the family of the child with hearing impairment. Thus, the best way to meet the needs of the child with a hearing impairment is to

acknowledge the needs of the family members as well, through FCEI (Dirks et al., 2022; Moeller et al., 2013). FCEI is a family-professional partnership that places the needs of the child in the context of their family (MacKean et al., 2005; van der Zee & Dirks, 2022) in order to optimise the child's developmental outcomes (Iversen et al., 2003; Moeller et al., 2013). FCEI is the preferred term in paediatric care, where families are most involved with their children (Moeller et al., 2013). It is mainly a philosophy, belief and values from which professionals support the development and capacities of families in order to promote the progress of the child with disabilities (Dalmau et al., 2017).

FCEI is based on the following principles: (1) the client is the child patient and their family rather than just the child (Epley et al., 2010; Kuo et al., 2012); (2) caregivers are invited to become involved in their child's care and have the opportunity to share their opinions, needs and preferences with professionals (Moeller et al., 2013; Yoshinaga-Itano, 2013); (3) information sharing between the professional and caregiver is open, objective and unbiased in order to ensure that families can make appropriate decisions that best fit the needs, strengths and values of the child and family (Kuo et al., 2012; Moeller et al., 2013); (4) caregivers are encouraged to collaborate with professionals to acquire knowledge and competencies that allow them to mediate or extend the intervention for their child with a hearing impairment, conversely, professionals acknowledge the family as the expert of their child's development (Turan, 2012; Moeller et al., 2013); and (5) social opportunities through parent-to-parent support which affords families of the child with a hearing impairment an opportunity to network and meet other families of children with a hearing impairment (Yoshinaga-Itano, 2013; Henderson et al., 2014).

Decades of research have demonstrated positive effects on child outcomes through strengthening the family role and responsibility; through allowing caregivers their rightful position as advocates, decision makers and partners with EI professionals (Sass-Lehrer et al.,

2015). However, FCEI is a broad concept, and different stakeholders have emphasized different aspects of this philosophy. Consequently, an international consensus statement became available in 2013 to articulate tenets of the philosophy and promote wider implementation of validated, evidence-based principles of FCEI with children with hearing impairment and their families (Moeller et al., 2013). A better understanding of which components of FCEI lead to positive outcomes can allow for more targeted development of effective interventions (Gallo et al., 2016). The consensus statement highlights 10 principles guiding FCEI as follows (Moeller et al., 2013, pp. 430-443):

- *Principle 1:* Early, timely, and equitable access to services- screening and confirmation of the hearing impairment is effective when linked to immediate, timely and equitable access to appropriate interventions.
- *Principle 2:* Family/provider partnerships- the goal is to develop a balanced partnership between families and health care professionals, characterized by reciprocity, mutual trust, respect, honesty, shared tasks, and open communication.
- *Principle 3:* Informed choice and decision making- families gain the necessary knowledge, information, and experiences to make fully informed decisions.
- *Principle 4:* Family social and emotional support- families are connected to support systems so they can accrue the knowledge and experiences that can enable them to function effectively on behalf of their child with hearing impairment.
- *Principle 5:* Family-infant interaction-families and healthcare professionals work together to create optimal environments for language learning.
- *Principle 6:* Use of assistive technologies and supporting means of communication- providers must be skilled in the tools, assistive devices, and mechanisms necessary to optimally support the child language and communication development.

- *Principle 7:* Qualified providers- healthcare professionals must possess the core competencies to support families in optimizing the child's development and child-family well-being.
- *Principle 8:* Collaborative teamwork- an optimal FCEI team focuses on the family and includes professionals with experience in promoting early development of children with hearing impairment.
- *Principle 9:* Progress monitoring- FCEI must be guided by regular monitoring /assessment of child and family outcomes.
- *Principle 10:* Programme monitoring- FCEI programmes must evaluate healthcare professional's adherence to best practice and include quality assurance monitors of all programme elements.

FCEI is particularly relevant to South Africa where access to EHDI programmes is not only affected by the barriers delineated in section 1.1, above. However, South Africa's multicultural and multilinguistic population poses a challenge to accessing linguistically and culturally-congruent EHDI programmes, as recommended by the HPCSA (2018). South Africa has 11 official languages, but English is the predominant language in accessing EHDI services owing to a largely white, female, English- or Afrikaans-speaking staff complement (Constitution of South Africa, 1996; Khoza-Shangase, 2019; Pillay et al., 2020). This practice does not respond to the needs of 11 million South Africans who do not receive healthcare services in their home language (Khoza-Shangase & Mophosho, 2018; Mophosho, 2018). Global evidence on health indicates that patients who do not form part of the dominant language and culture have worse health outcomes than patients who do (Flood & Rohloff, 2018; Steinberg et al., 2016); South Africa is no exception (Mtimkulu et al., 2023).

1.2 Statement of the Problem

Challenges with access to EHDI programmes within the South African context underscore the need for context-specific studies to be conducted, in order to guide best practice that is relevant to contextual realities (Khoza-Shangase, 2021; Khoza-Shangase et al., 2017; Kanji & Khoza-Shangase, 2021). Contextualised intervention approaches would also facilitate FCEI, and benefit from the role families and caregivers play in the implementation, integration and carry-over of care (Khoza-Shangase, 2022; Maluleke et al., 2021a; Moeller et al., 2013). FCEI recognises caregivers as important co-drivers of any intervention programme, facilitates active caregiver engagement and involvement, and promotes self-efficacy in caregivers (Dalmau et al., 2017; Khoza-Shangase, 2019; MacManus et al., 2020; Henderson et al., 2014).

Active caregiver engagement and involvement are essential in EI and result in higher rates of follow-through, greater participation in and adherence to EHDI, improved outcomes for children with hearing impairment, and mitigation of the inequities associated with access to healthcare (HPCSA, 2018; Khoza-Shangase, 2022; Moeller et al., 2013; Yoshinaga-Itano, 2014). Caregivers and families also provide a linguistic and cultural environment in which children can develop (Balton et al., 2019; Schlebusch et al., 2016). Hence, provision of EHDI services in the family's home language would mitigate the language barriers experienced by caregivers when accessing EHDI programmes (Khoza-Shangase, 2019). Furthermore, linguistically and culturally congruent EHDI services would ensure that the child with hearing impairment is not distanced linguistically and culturally from the rest of their family or community (HPCSA, 2018; Khoza-Shangase & Mophosho, 2018).

In recent years, literature has demonstrated that for EHDI programmes to be effective, it is not enough to consider the availability, quality and equity of care provided, it is also necessary to consider the adoption of the FCEI approach (Deng et al., 2018; Khoza-Shangase,

2019, 2022). Although there is an increasing awareness of caregivers' role in EI, limited attention is given to their opinions, their views, and their role in the EHDI process, by both the clinical and the research communities (Khoza-Shangase, 2019). Caregivers are the individuals within the child's family who play the most significant role in day-to-day child rearing and caregiving (Maluleke et al., 2021b; Masuku & Khoza-Shangase, 2018). However, limited research focus has been placed on caregivers as the key co-drivers of any intervention programme, in South Africa and other LMICs (Khoza-Shangase, 2019). Exploring caregiver views and experiences would lead to EHDI programmes that are contextually-relevant and responsive; evidence-based; and are cognizant of child, caregiver and family needs; and ultimately contribute to positive patient outcomes within this context (Gillian et al., 2013; Khoza-Shangase, 2019; Fitzpatrick et al., 2016).

1.3 Motivation for the Study

As the implementation of EHDI programmes in many countries gathers pace, attention is shifting from arguments for UNHS and subsequent EI to closely focus on the evaluation of the practice and process of these programmes (Fitzgibbons et al., 2021; Naidoo & Khan, 2022). Available literature on studies conducted in the South African context is limited to investigations of risk factors for hearing impairment (Kanji & Khoza-Shangase, 2012; le Roux et al., 2014), the status of EHDI programmes (Bezuidenhout et al., 2018; Kanji, 2018; Khoza-Shangase et al., 2021; Moodley & Storbeck, 2015; Meyer et al., 2014), the feasibility and efficacy of implementing NHS programmes at various levels of healthcare service provision (Butler et al., 2015; Kanji & Khoza-Shangase, 2016; Khoza-Shangase & Harbinson, 2015; Petrocci-Bartal & Khoza-Shangase, 2016;); as well as the barriers and facilitators of EHDI (Khoza-Shangase, 2019; Naidoo & Khan, 2022; Maluleke et al., 2023). These studies only focus on validation of early hearing detection programmes and the development of contextually feasible models of service delivery.

Furthermore, services for children with disabilities have tended to focus mainly on the child; consequently, the priority was to deal with the consequences of the disability by adopting a habilitation approach. Working with families was usually disregarded and perceived as a complement to the work carried out with the child (Dalmau et al., 2017). The past four decades have seen an increasing shift towards emphasizing the importance of the child's family taking an active role in the habilitation process, thorough FCEI programmes (Ingber & Dromi, 2010). Thus, a need exists to assess the perceptions of caregivers regarding the services received, interventions provided, and the changes that could be made to improve them (Campana et al., 2019).

Only few studies exist that focus on caregivers' own accounts of how they interpret the experience of, or journey through the EHDI process, the concepts they use to make it meaningful and the criteria they generate against which such programmes can be evaluated (Hagedorn, 2015; Kanji & Noorbhai, 2021; Maluleke et al., 2023). Thus, attempts to consider caregivers' experience, to use their reports, reflections, understandings, and analyses of the process are essential as it is they who determine their quality (Campana et al., 2019). This is also crucial in terms of identifying gaps and incongruence in knowledge, beliefs, and practices that might be grounded in linguistic, cultural and socioeconomic diversity of the South African population – which has significant clinical implications.

Therefore, the current study has significance towards building on the 'indigenous' knowledge base for children with hearing impairment and their families, and provides a foundation for formulating and implementing a framework for FCEI within the South African context.

1.4 Statement of Originality

According to the HPCSA (2018), EI services following diagnosis of hearing impairment must be family-centred within a community-based model of service delivery that

is culturally congruent. This call presented a unique opportunity for this study, which aimed to explore caregivers' experiences of the EHDI process and practices within the South African context in order to gather contextually relevant evidence that will guide FCEI practices that are contextually relevant and contextually responsive.

This study is the only study within the South African context that sought to understand EHDI processes and practices from detection to intervention through a) caregivers' own perspectives through a narrative enquiry, thus amplifying caregivers' voices; b) through utilizing the MPOC-56 to determine the family-centredness of EHDI programmes; and c) through utilizing the conjoint analysis strategy to obtain caregivers preferences for characteristics associated with EHDI programmes. The MPOC-56 and conjoint analysis are quite unique and allowed caregivers, who present with a unique first-hand experience of EHDI programmes to share their overall satisfaction with various aspects related to the provision of EHDI programmes. Consequently, this study allowed caregivers to participate in the decision making, regarding designing and evaluating these programmes, which are aimed at meeting their needs and those of their child with hearing impairment. Hence the novelty of the current study.

The comprehensive mixed methods of collecting and analysing data undertaken in this study enabled the researcher to identify gaps and incongruence between recommended best practice and current practices; and this has not been done before in this field. Implications of the findings of this study include justifying the need for effective EHDI programmes across the geographically varied healthcare settings in the South African context (Khoza-Shangase & Harbinson, 2015). Findings form this study also support the researcher's recommendation for mandating UNHS which will a) inform policy and the relevant

stakeholders and b) ensure systematic implementation of family-centred EHDI[1] (FC-EHDI) programmes that are contextually relevant and responsive to the South African context. The researcher believes that systematic implementation of FC-EHDI programmes for children with hearing impairment and their families can mitigate the inequities associated with access to these programmes and ensure that these children develop to their potential.

1.5 Conceptual Framework

This research will be framed within the conceptual framework of ECD, and positioned within EHDI and the Developmental Systems Framework, particularly Bronfenbrenner's Ecological Systems Framework of social development.

The centrality of the ECD framework is the developmental initiatives including the 2030 SDGs and the Education For All (EFA) goals, which the South African government subscribes to. It is founded on the growing body of evidence that a nation's development depends on the extent to which it can unlock the potential human capital inherent within its youngest population (Department of Social Development, 2015; Wertlieb, 2019). Consequently, the South African government recognises ECD as a fundamental human right and has committed to the provision of ECD programmes as a necessity to equalise the developmental deficits experienced by infants and young children vulnerable to risk factors for developmental deficits (Britto et al., 2011; Department of Social Development, 2015). The ECD period presents a window of opportunity to address inequality and improve outcomes later in life (Neuman & Devercelli, 2013). This opportunity extends beyond the child's inherent potential to include caregivers, families support for families, an enabling environment for caregivers, families and the community, and an enabling social, economic, political, climatic, and cultural context (Black et al., 2017; Farnsworth et al., 2014).

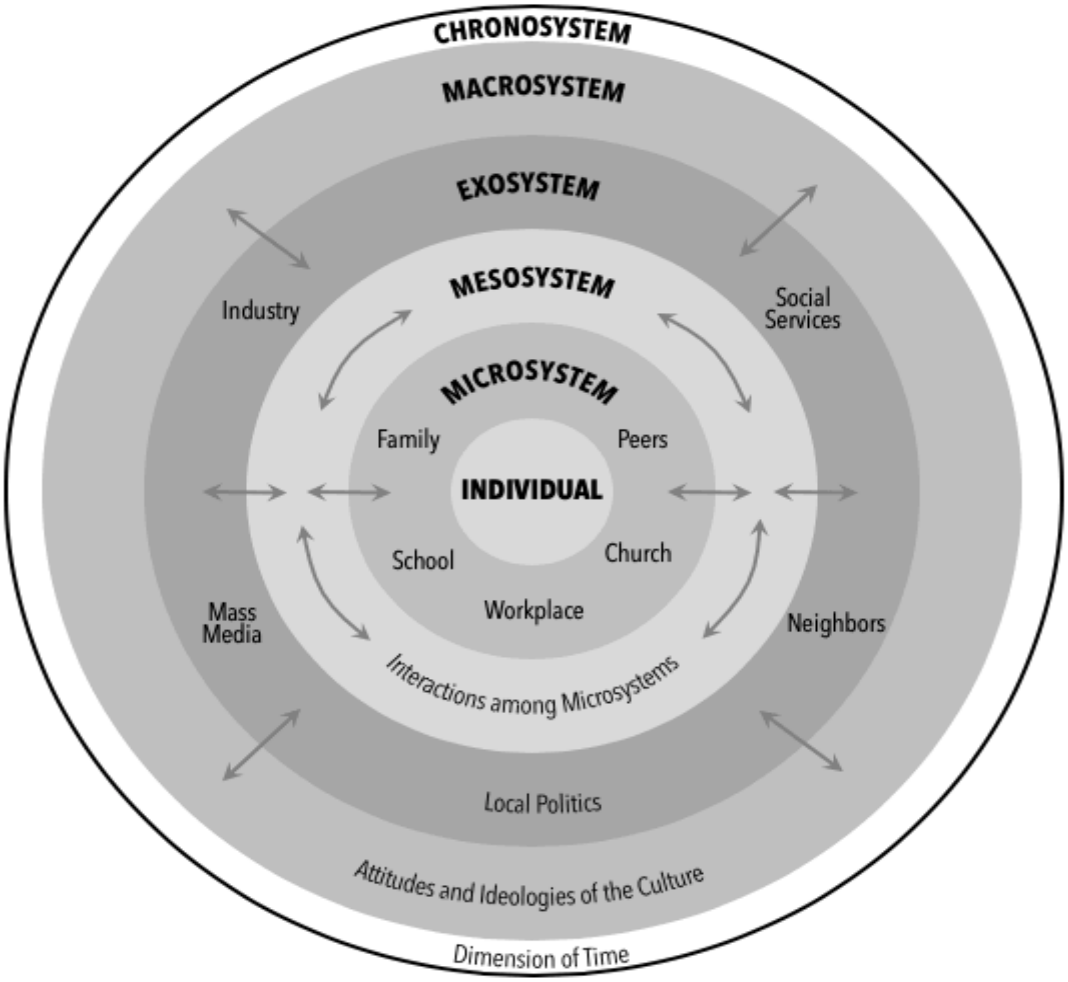
[1] FC-EHDI is discussed in Chapter 2

The ECD period is a maturational and interactive process, resulting in an ordered progression of perceptual, motor, cognitive, language, socio-emotional, and self-regulation skills (Black et al., 2017; Sameroff, 2009). As a result, ECD programmes refer to the broad range of support for young children and their families including; health, early learning and education, family support, and attention to social protection (Britto et al., 2011). Hence, the ECD framework demonstrates the South African government's recognition that the child's parents are as important part for the child's care, development and wellbeing through the provision of a nurturing and caring environment. Furthermore, the government recognises that caregivers must have access to and receive the information, support and necessary service to enable them to fulfil their responsibilities (Department of Social Development, 2015).

The importance of a nurturing and caring environment is best described by Bronfenbrenner's Ecological Systems Framework, depicted in Fig. 1.1; which looks at the child's development within the context of the system of relationships that form part of their environment. Each layer of the environment has an effect on the child's development. Thus, the interaction between the child's maturing biology, their immediate family, community and societal landscape fuels and steers the child's development (Bronfenbrenner, 1994; Berk, 2000). According to this framework, the developing child is contained within four systems: the microsystem (caregiver, family, school), the mesosystem (interactions between systems), the exosystem (local government, extended family) and the macrosystem (social norms, culture, economic system). The interaction between the child and the mesosystem, exosystem and microsystem indirectly influence the developing child; however, the interaction between the child and the microsystem influences them directly (Bronfenbrenner, 1979; El Zaatori & Maalouf, 2022).

Figure 1.1

Bronfenbrenner's Ecological model of human development



Note. Reprinted from Davis & Francis (2023

Thus, based on the ECD and Ecological Systems Frameworks, it is through the family that children are born, socialised and cared for until they become independent (Department of Social Development, 2013). Hence, caregivers and families provide the most effective and economical system for fostering and sustaining the child's development (Bronfenbrenner, 1994; Maluleke et al., 2021a; Mantri Langeveldt et al., 2019).

1.6 Main Aim

The primary aim of this study was to explore caregivers' experiences and evaluation of the EHDI process and practices in Gauteng, South Africa.

1.7 Research Objectives

1. Describe caregivers' expectations of the EHDI process, from detection to intervention.
2. Describe caregivers' experience of the EHDI process from detection to intervention.
3. Evaluate the success or failure of the EHDI process in relation to caregivers' expectations.
4. Identify barriers and facilitators to the EHDI process from caregivers' perspectives.
5. Describe caregivers' level of satisfaction with current EHDI programmes.
6. Determine caregivers' perceptions of the extent to which the EHDI services they received are family-centred.
7. Explore the association between personal, family and socio-demographic factors and caregivers' perceptions of family-centeredness of the EHDI services they received.
8. Explore caregivers' preferences for characteristics associated with EHDI services.

1.8 Research Questions

1. What are caregivers' expectations of the EHDI process, from detection to intervention?
2. What is caregivers' experience of the EHDI process from detection to intervention?
3. What is the success or failure of the EHDI process in relation to caregivers' expectations?
4. What are the barriers and facilitators to the EHDI process from caregivers' perspectives?

5. What is caregivers' level of satisfaction with current EHDI programmes?
6. What are caregivers' perceptions of the extent to which the EHDI services they received are family-centred?
7. What is the association between personal, family and socio-demographic factors and caregivers' perceptions of family-centeredness of the EHDI services they received?
9. What are caregivers' preferences for characteristics associated with EHDI services?

1.9 Overview of Research Methodology

This section provides an overview of the research methodology that was used in this study. Given that all manuscripts that form part of this thesis have detailed methodology sections, only a brief outline of the methods used in this study will be discussed in this section.

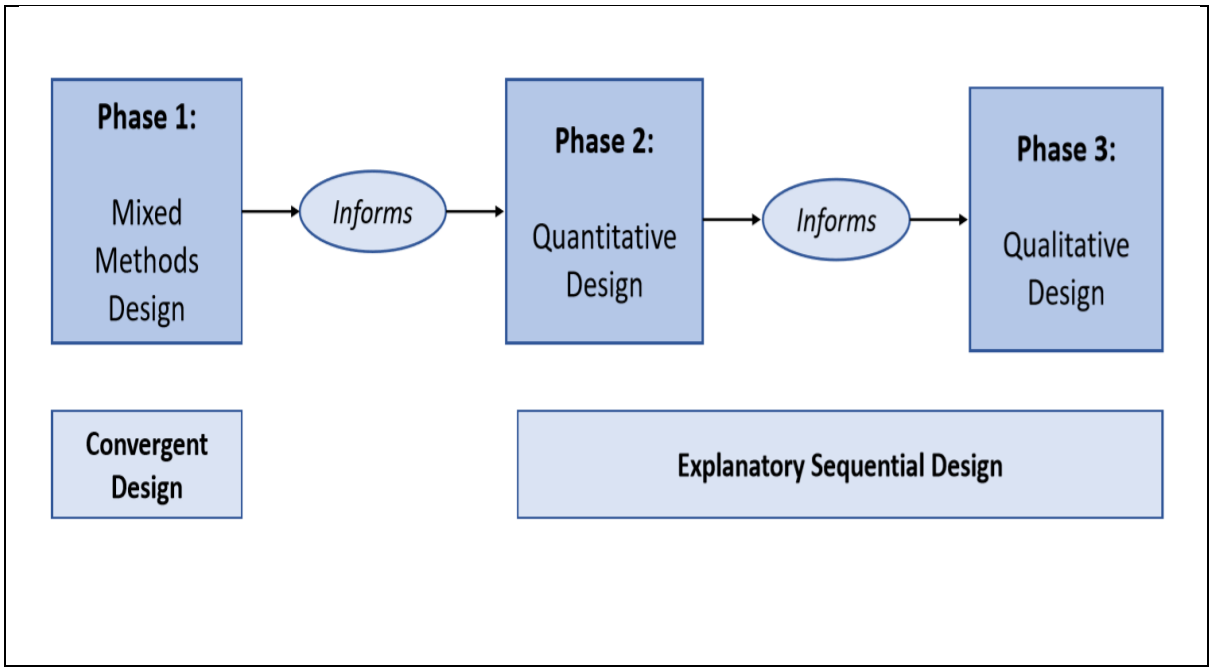
1.9.1 Research Design

The research design is the procedure that was followed for collecting, analysing, interpreting and reporting of data in this study. The research design served as a useful guide for the methods and decisions that the researcher made during the study, and established the logic by which the researcher interpreted the findings of the study (Creswell & Plano Clark, 2018).

For the purpose of answering the predefined research questions, this study employed a mixed methods evaluation design (also referred to as mixed methods multiphase, mixed methods multistage evaluation design), as depicted in Figure. 1.2.

Figure 1.2

Diagram of mixed methods evaluation design for this research



A mixed methods evaluation design is a process evaluation design which systematically integrates quantitative and qualitative methods into a single evaluation, potentially at every stage of the evaluation process (USAID, 2013). This design is characterized by a core design within another methodology and is typically used in programme evaluation design in which quantitative and qualitative approaches are used over time to support the development, adaptation, and evaluation of a specific programme, intervention, an organization, or policies (Plano Clark & Ivankova, 2016; Creswell & Plano Clark, 2018).

Variations of the mixed methods evaluation design exist, which reflect the different contexts in which researchers work. Variations include the number and order of phases that are employed (Creswell & Plano Clark, 2018). For the purpose of this study, the programme evaluation comprised a needs assessment (Phase 1), developing an instrumentation for caregivers to evaluate programme activities, conducting a survey regarding caregivers'

preferences for characteristics associated with EHDI services using the developed instrument (Phase 2), as well as follow-up and refinement of the survey results through a focus group interview (Phase 3).

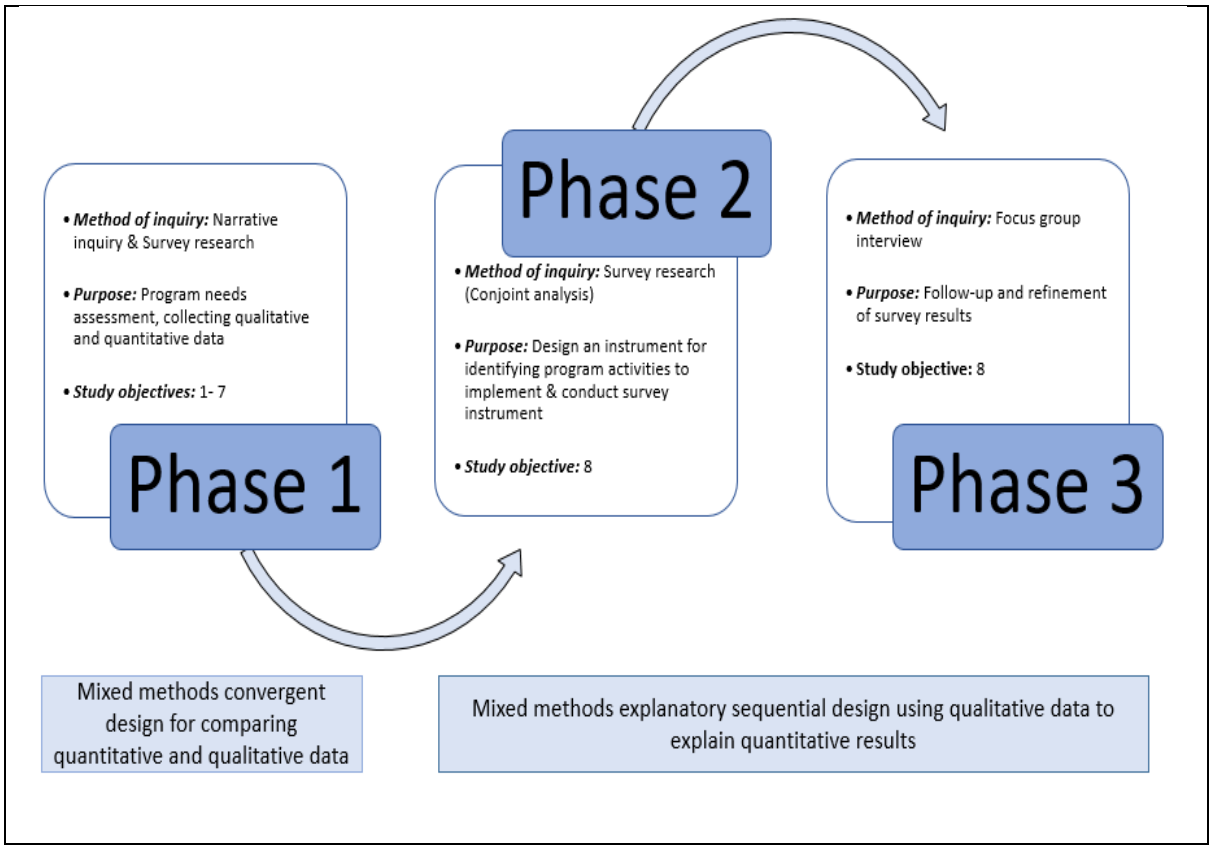
For the purposes of this study, the evaluation design comprised of a convergent design, which merged the quantitative and qualitative results within phase 1 of the study. The results obtained from Phase 1 (Objectives 1-7[2]) informed Phase 2 and 3 (Objective 8: Conjoint analysis[3]). Phase 2 and 3 adopted the framework of an explanatory sequential design, as depicted in Figure. 1.3.

[2] Objectives 1 and 2 explored caregivers' expectation and experiences with the process and practices of EHDI in the South African context; while objectives 3-7 allowed caregivers to evaluate the process and practices of EHDI in the South African context. These are the two main aspects that informed the aim of this study. Furthermore, objective 6 assessed the five FCEI principles outlined on page 30; as well as principles 1-8 as outlined on pages 31-32.

[3] Objective 8 also formed part of caregivers' evaluation of the process and practice of EHDI in the South African context through conjoint analysis which is a two-phase process that was carried out in Phase 2 and phase 3.

Figure 1.3

Diagram indicating the steps implemented in this programme evaluation design



This design was attractive to the researcher as it incorporates the flexibility needed to use any mixed method design elements required to address the interconnected research questions of this study (Creswell & Plano Clark, 2018). Furthermore, incorporating multiple methods into a single evaluation resulted in a stronger, more complete evaluation than conventional evaluation approaches that rely on only one method. Furthermore, incorporating multiple method increased confidence in the validity and reliability of the evaluation results (USAID, 2013).

A discussion of the core design for each phase of this study is provided below.

1.9.1.1 Mixed Methods Convergent Design. A mixed methods convergent design was employed for objectives 1-7. In this convergent design, the researcher implemented the

qualitative and quantitative strands of the research study at the same time and the results of the two stands are converged for interpretation (Creswell & Plano Clark, 2018). The intent of the convergent design was to obtain different but complementary data on the same phenomenon in order to best understand the research problem (Creswell & Plano Clark, 2018). This research design enabled the researcher to gather both types of data in one day and give equal emphasis to both strands of the study.

A narrative inquiry was conducted for the qualitative strand and survey research was conducted for the quantitative strand of Phase 1 of the study.

1.9.1.1.1 Narrative Inquiry. Objectives 1-5 were explored using a narrative inquiry, a research method whereby participants tell stories of their lived experiences as a storied phenomenon (Johnson & Christensen, 2017). Narrative inquiry is a way for researchers to understand participants' experiences and explore the meanings that the participants derive from their experiences (Wang, Geale, 2015). The narrative inquiry was based on the notion that experiences are continuous and interactive, and if intentionally reflected upon, they may be educative (Lindsay & Schwind, 2016).

The purpose of the narrative inquiry was to reveal the meaning on the individuals, as opposed to objective, decontextualized truths (Wang & Geale, 2015). Thus, it encompassed enquiry into the institutional, social, cultural, familial, and linguistic narratives in which each participant's experiences are embedded and that shape the individual's experience (Johnson & Christensen, 2017). The narrative inquiry amplified voices that may have otherwise remained silent (Wang & Geale, 2015) and has the potential to inform care practices not only in EHDI, but across the healthcare system and beyond (Lindsay & Schwind, 2016).

1.9.1.1.2 Survey Research. Objectives 6 and 7 were investigated using survey research, a non-experimental research design in which questionnaires were used to gather

information with the goal of understanding the characteristics of a population based on sample data (Johnson & Christen, 2017). Surveys depict how things are at a specific time, with no attempt to control conditions or manipulate variables (Kaliyadan & Kulkarni, 2019). The aim of the survey research was to examine a situation by describing important factors associated with the situation such as demographic data, socio-economic data, and caregivers' perceptions of the extent to which the EHDI services they received were family-centered.

1.9.1.2 Explanatory Sequential Design. Objective 8 was investigated in two phases, using an explanatory sequential design. The explanatory sequential design is a mixed methods design with two distinct phases, starting with the collection and analysis of quantitative data, followed by the collection and analysis of qualitative data in order to explain, elaborate or expand the quantitative data (Creswell & Plano Clark, 2018). The results of the quantitative data, informed the follow-up qualitative data, thus emphasis was placed on the initial quantitative data (Creswell & Plano Clark, 2018). Mixing of the quantitative and qualitative data occurred at two points; mixing of the quantitative and qualitative data initially occurred when the two strands were connected after the completion of the quantitative strand and beginning of the qualitative strand, and again when the results of both strands were interpreted together (Plano Clark & Ivankova, 2016).

This research design appealed to the researcher because of its strong quantitative orientation (Creswell & Plano Clark, 2018). This design was also easy to implement due to the straightforward, chronological sequence of the two strands (Plano Clark & Ivankova, 2016; Creswell & Plano Clark, 2018). Furthermore, it provided an opportunity for the exploration of initial quantitative results or unexpected results in detail (Plano Clark & Ivankova, 2016). A conjoint analysis was conducted for Phase 2, which was the quantitative strand of this design and a focus group interview was conducted for Phase 3, which was the qualitative strand of this design.

1.9.1.2.1 Conjoint Analysis. A conjoint analysis is an evaluation approach that uses survey methods to elicit trade-offs among attributes and attribute levels to determine respondents' preferences for alternative products (Al-Omari et al., 2022; Hauber et al., 2016; Marshall et al., 2010). It is a method of eliciting stated preferences from patients that goes beyond traditional health outcome measures to account for non-health outcome attributes in the process of delivery of healthcare services (Ali & Ronaldson, 2012; Al-Omari et al., 2021). The underlying theory of a conjoint analysis is that a product or service can be described by its characteristics or attributes (Eggers et al., 2018; Ryan & Farrar, 2000).

This survey method provides an estimation of the relative importance people attribute to various components of care, measures how individuals are willing to trade between these characteristics, and estimates the overall satisfaction they gain from various forms of health service provision (Fitzpatrick et al., 2018). A conjoint analysis offers a mechanism for patients to participate in decision making and how different stake holders may value outcomes (Bridges et al., 2011; Eggers et al., 2018). Thus, helping decision makers understand the health service choices of communities, the perspectives of different user segments or the unique preferences of individual patients (Al-Omari et al., 2021; Cunningham et al., 2010).

1.9.1.2.2 Focus group Interview. A focus group interview design is a qualitative research design whereby a moderator leads a group discussion with a small group of individuals to examine how the group members think and feel about a topic; as well as illuminate differences in the perspectives of groups of individuals (Johnson & Christensen, 2017). Thus, a focus group interview is very important in generating in-depth discussion (Dilshad & Latiff, 2013). A focus group interview design was attractive to the researcher as it can generate large amounts of data in a relatively short time span (Nyumba et al., 2018). Furthermore, group interaction between members of the target population during the focus

group interview encouraged participants to make connections to various concepts through the discussion that may not occur during individual interviews (Nagle & Williams, 2013). The focus group interview was used to clarify the results from the conjoint analysis that was conducted in Phase 2 of the study.

1.9.2 Research context

Three EI preschool Centres (The Children's Communication Centre in Johannesburg, Whispers Speech and Hearing Centre in Pretoria, and Eduplex School in Pretoria) were approached for potential inclusion of caregivers, of their current or former preschoolers, in this study. Only Two EI preschool centres; The Children's Communication Centre and Whispers Speech and Hearing Centre, granted the researcher permission to conduct the study.

The Children's Communication Centre caters for children between two-and-half years and seven years, who present with speech, language and/or hearing impairment and who are felt to have the skills to benefit from the social-pragmatic small-group programme that they offer. The Children's Communication Centre's philosophy and approach is the belief that "language learning starts at birth and occurs in a dynamic and integrated manner". They follow "a social-pragmatic approach to language learning, where language learning takes place through engagement and meaningful interaction". The Children's Communication Centre's philosophy and approach is based on existing evidence that "communication difficulties arising from specific speech, language and/or hearing impairments can be significantly reduced during the pre-school years through intensive and appropriate interventions" (www.thecentre.org.za).

Whispers Speech and Hearing Centre provides a full developmental stimulation programme for children aged 18 months to five years who present with a hearing impairment and/or developmental challenges language learning difficulties, or any developmental

challenges. Whispers Speech and Hearing Centre's mission is "to foster and support the development of functional language in children with any degree of hearing impairment, using any type of hearing technology, who may also have one or more additional challenges. Working with a natural developmental pattern, in collaboration and respecting the parent's role as their child's primary decision maker. To allow each child to become the unique talented person they were meant to be" (www.whisperscentre.co.za).

1.9.3 Participants and Sampling Strategy

Participants are the individuals who actually participate in the research study (Johnson & Christensen, 2017). Non-probability, purposive sampling was used to recruit and select participants throughout this study. Non-probability, purposive sampling is a non-random sampling procedure whereby the researcher specifies the characteristics of a population of interest and then recruits the individuals who have those characteristics (Johnson & Christensen, 2017; Kaliyadan & Kulkarni, 2019). The selected individuals can provide the necessary information to understand the central phenomenon (Creswell & Plano Clark, 2018). This sampling strategy is based entirely on the judgement of the researcher, in that a sample is composed of elements which contain the most characteristics, representative or typical attributes of a population (Obilor, 2023; Strydom & De Vos, 2011). Results obtained from this sampling strategy are not generalizable to entire population; however, this strategy is optimal when the goal is to recruit a sample with a relatively low prevalence rate in the general population (Campbell et al., 2020), as is the case with the participants in this study.

In order to gain access to the participants, the researcher obtained written permission from the two EI preschool centres (Appendices A &B), allowing the researcher access to the preschool files such that potential participants can be identified. However, when the new Protection of Personal Information (POPI) Act came into effect on 1 July 2021 (Government

Gazette, 2013; www.popia.co.za), the EI preschool centres compiled the list of potential participants and their contact details, once they had obtained permission from the potential participants to be recruited for this study.

Then, a poster (Appendix C) outlining the study, recruitment strategy, participant inclusion and exclusion criteria, data collection methods, and researcher's contact details was placed at the reception at each preschool centre. Participants were recruited telephonically, subsequent to which participant information letters and informed consent forms were emailed to them after they indicated their willingness to participate in this study.

1.9.4 Inclusion and Exclusion Criteria

Participants were required to meet the inclusion and exclusion criteria outlined below in order to participate in any of the phases of this study.

1.9.4.1 Inclusion Criteria.

- Caregivers had to be 18 years old and older.

  Eighteen in the legal age of majority status whereby an individual is able to conclude valid contracts without parental assistance (Fokala & Rudman, 2020; Strode et al., 2010).
- Caregivers had to be the primary caregiver of the child with hearing impairment.

  Primary caregivers are defined as the biological parents, legal guardians of the child with hearing impairment. They are the individuals who care for, nurture, care and look after the child (UNICEF, 2008). Primary caregivers are the co-drivers of intervention programmes (Khoza-Shangase, 2019) and are crucial to the success of EHDI programmes (Larsen et al., 2012).

- Caregivers of children diagnosed with a mild to profound, bilateral or unilateral hearing impairment.

  Children with a congenital or early-onset, bilateral hearing impairment are at an increased risk of speech and language delays compared to their hearing peers extending from early childhood to school age (Vohr et al., 2012). A moderate or greater degree of hearing impairment can have significant effects on a child's language, speech, academic, social-emotional development and social inclusion (JCIH, 2007; 2019; Eriks-Brophy et al., 2012; Whittingham, 2012). Furthermore, studies have shown that children with unilateral hearing impairment are also at risk for language and academic concerns (Fitzpatrick et al., 2018).

- Caregivers of children with hearing impairment who have been fitted with amplification devices such as hearing aids and/or cochlear implants in order to compensate for the hearing impairment.

  EHDI encompasses benchmark indicators of hearing screening at birth, provision of amplification devices by three months of age and enrolment in EI services by six months (JCIH, 2007; 2019). Intervention services emphasize using the child's residual hearing through amplification, to develop and maintain normal language skills in keeping with their cognitive development (Monshizadeh et al., 2019; Yoshinaga-Itano, 2014).

1.9.4.2 Exclusion Criteria

Participants with the following factors will be excluded from the study.

- Caregivers of children with no confirmed hearing impairment. This exclusion criterion is based on the proposed study's focus on the processes and practices of current EHDI services for children with hearing impairment

- Caregivers of children with hearing impairment who were enrolled at EI preschool centres prior to 2010.

  A ten-year period (2010-2020) was used in this study in order to ensure that the researcher had access to a large enough population from which to recruit participants, given the limited number of children with hearing impairment who attend early intervention preschool centres in South Africa.

1.9.5 Materials and Equipment

Due to the mixed methods approach of this study, the researcher collected both forms of quantitative and qualitative data. The methods of inquiry for each phase of the study are outlined below.

1.9.5.1 Phase 1: Narrative Inquiry. A narrative inquiry is a method of inquiry in which the researcher attempts to illuminate the meaning of personal stories and events (Wang & Geale, 2015). It is a fluid kind of research inquiry with no set procedures or steps to be followed but is open to where the participants' stories take the researcher (Johnson & Christensen, 2017). Thus, the inquiry started with an open-ended request for participants to share their experience of the research phenomenon (Lindsay & Schwind, 2016). The researcher only asked questions, as outlined in the interview script (Appendix D), that would help them interpret and experience the world of the participant rather than try to explain or predict the world (Wang & Geale, 2015). By listening, paraphrasing back to ensure understanding and asking clarifying questions, the researcher formulated a research puzzle that carried with it a sense of a "re-search" that suggested a sense of continual reformulation", rather than framing a research question with a precise expectation of the answer (Lindsay & Schwind, 2016; Johnson & Christensen, 2016). The narrative inquiry was conducted in the participant's preferred location (in-person interviews), time and language.

1.9.5.2 Phase 1: Survey Research. Survey data was collected using a demographic questionnaire and a modified version of the Measurement of Processes of Care-56 (MPOC-56).

The demographic questionnaire (Appendix E) consisted of two sections. Section A comprises of caregivers' demographic questionnaire such as ethnicity, home language, age, marital status, educational level, economic status, etc. While Section B comprises of demographic information of the child with hearing impairment such as age, gender, age at identification of hearing impairment, home language, and language used to access audiology services, etc.

The following modifications were made to the MPOC-56 (Appendix F), in order to make it more suitable to the South African context.

- *General:* All reference to "we" were changed to "I" i.e. "I would like to…" instead of "We would like to…"
- *Introductory section:* reference to parents was expanded to include caregivers i.e., "…measure the experiences of parents who have children…." was modified to "…measure of the experiences of parents and/or caregivers who have children…".
- *Introductory section:* The sentence "The questions in this section are based on what parents, like yourself, have told us about the way care is sometimes offered" was changed to "The questions in this section are based on what parents and/or caregivers, like yourself, have said about the way care is sometimes offered".
- *Introductory section:* The list of heath care people was expanded to include audiologists i.e. "The audiologist, psychologist, ….".

- *Question 5:* The word "relationship" was placed in parenthesis next to rapport i.e., "take the time to establish rapport (relationship) with you and your child when changes occur in your services?
- *Question 31:* The word "disability" was replaced with "hearing impairment" i.e., "treat you as an individual rather than as a "typical" parent of a child with hearing impairment?
- *Question 33:* The words "mama" and "papa" were added i.e., "treat you as an equal rather than just as the parent of a patient (e.g., by not referring to you as "Mom" and "Mama" or "Dad" and "Papa")?
- *Question 42:* The sentence was changed from "…treat you and your family as people rather than as a "case" e.g., by not referring to you by diagnosis, such as "the spastic diplegic?" to "…treat you and your family as people rather than as a "case" (e.g., by not referring to you by your child's diagnosis).
- *Question 51:* The word "disability" was replaced with "hearing impairment" i.e., "provide support to help cope with the impact of childhood hearing impairment (e.g., by advocating on your behalf or informing you of assistance programmes)?
- *Question 53:* The word "disability" was replaced with "hearing impairment" i.e., "have information available about your child's hearing impairment (e.g., its cause, how it progresses, future outlook)?

The survey research was conducted in English in accordance with the participants' preferences.

1.9.5.3 Phase 2: Conjoint Analysis. A conjoint analysis was conducted in this phase of the study. The underlying theory of a conjoint analysis is that a product or service can be described by its characteristics or attributes (Al-Omari et al., 2021; Ryan & Farrar, 2000). A

conjoint analysis provides an estimation of the relative importance people attribute to various components of care, measures how individuals are willing to trade between these characteristics, and estimates the overall satisfaction they gain from various forms of health service provision (Fitzpatrick et al., 2018). Understanding how patients and other stakeholders value different aspects of an intervention is vital to both the design and evaluation of programmes (Bridges et al., 2011; Eggers et al., 2018).

The survey for the conjoint analysis (Appendix G) was conducted in English in accordance with the participants' preferences.

1.9.5.4 Phase 3: Focus Group Interview. A focus group interview was conducted in this phase of the study. The focus group interview was conducted in English in order to eliminate the loss of pertinent information during the discussion through translation of participants' responses (van Nes et al., 2010). The aim of the focus group interview was to clarify and/or expand on the results of the conjoint analysis that was conducted in Phase 2 of this study. This was achieved through a descriptive narrative, thus the concepts and topics that were discussed during the focus group interview were not fully specified (Creswell & Plano Clark, 2018). The researcher started the focus group interview with an open-ended question for participants: " Do these results reflect your preferences for characteristics associated with EHDI services?". Then, the researcher only asked questions, as outlined in the interview script (Appendix H) for clarity.

1.9.6 Data Collection Procedures

Prior to commencement with data collection, the researcher obtained ethical clearance (Appendix I) from the University of the Witwatersrand Human Research Ethics Committee (Medical) (Protocol number :H19/06/16). Permission to conduct the study was sort from the three EI preschool centres and was provided by only two of the centres.

Once ethical clearance and permissions were granted, posters outlining the study, the recruitment strategy, participant inclusion and exclusion criteria, and data collection methods, and researcher's contact details were placed in the reception area of each EI preschool centre. Once the researcher obtained permission from the two EI preschool centres, the researcher compiled a list of all possible participants and their contact details. However, when the POPI Act came into effect, the EI preschool centres compiled the list of potential participants and their contact details, once they had obtained permission from the potential participants to be recruited for this study. All participants were recruited telephonically, subsequent to which information letters and informed consent forms were emailed to them after they indicated their willingness to participate in the study. Participants' preferred language for the narrative interview and the survey were established telephonically in order to ensure that the narrative enquiry is conducted in their preferred language and the modified MPOC-56 can be translated accordingly.

Due to the mixed methods approach of this study, the researcher collected both forms of quantitative and qualitative data for the purpose of integrating the information in the interpretation of the overall results (Creswell & Plano Clark, 2018). Thus, the researcher employed various methods of enquiry according to the three phases; namely, narrative inquiry and survey research in Phase 1, conjoint analysis in Phase 2, and a focus group interview in Phase 3.

1.9.6.1 Phase 1: Narrative Interview and Survey Research. Once informed consent (Appendix J) was obtained from the participants, interview dates, location (in-person interviews) and times were finalized with the participants. The researcher used short message services (SMS) to send a reminder a week prior to the scheduled interview as well as on the day of the interview, prior to the arranged time. The study had aimed to conduct data collection through in-person interviews only, however, these plans had to be changed to

accommodate COVID-19 restrictions (National Department of Health, 2020). Three in-person interviews were conducted from January to February 2020, prior to the World Health Organisation (WHO) declaring COVID-19 a pandemic (WHO, 2020); while telephonic (2) and videoconferencing (4) interviews were conducted from March to June 2020. Of the three in-person interviews, one was conducted at the participants home and two were conducted at the participants' place of work. All the interviews were audio-recorded.

Following the interview, participants were required to complete a demographic questionnaire and the modified MPOC-56.

1.9.6.2 Phase 2: Conjoint Analysis. The conjoint analysis comprised of two parts, the development of the conjoint analysis questionnaire and conducting survey research using the developed questionnaire. Development of the conjoint analysis survey questionnaire was done in three stages, as outlined by Fitzpatrick et al. (2018).

Stage 1: Establishing the attributes of services

This stage involves identifying the principal attributes and features or characteristics of the services. The qualitative and quantitative findings in Phase 1 were used to inform the content of the survey questionnaire. These findings were used to select the principal attributes of services identified by the participants and defined the features or characteristics of the services, such as the levels of care. Thus, the key themes from the narrative interviews were used as the main attributes. In addition, a literature review was conducted in order to supplement the identified characteristics. Five attributes were included in order to ensure that questionnaire was manageable.

Stage 2: Determining level of attributes

In this stage, levels of care were defined for each attribute. The level represented a choice that described an attribute, and each attribute was defined by three levels, resulting in the creation of scenarios.

Stage 3: Creating scenarios

This last stage involved framing questions around the attributes. All the possible attributes and levels would render the questionnaire unmanageable, thus the combinations were reduced to nine scenarios by using the Sawtooth Software. The Sawtooth Software is a survey software tool that specializes in conjoint analysis. The 'reduced' scenarios formed part of the survey questionnaire whereby participants were required to choose the clinical scenario that would provide them with the most satisfaction in caring for their child with hearing impairment. Before distribution, the survey instrument was reviewed by the researcher for appropriateness and clarity. Subsequently, a final step of revisions and pilot testing of the survey instrument for clarity and ease of completion was conducted.

Upon completion of developing the survey questionnaire (Appendix G) potential participants were invited to partake in the second part of Phase 2 of this study (Appendix K). Once informed consent was obtained from the participants (Appendix L), the survey instrument was sent to them via email. The researcher sent three SMS and email reminders to participants if they had not responded by the set return date. The researcher sent the reminders at the end of week one, and another one at the end of week three. The third reminder was sent at the end of week 5 to the remaining participants.

1.9.6.3 Phase 3: Focus Group Interview. Participants who took part in either Phase 1 or 2 of this study were invited to partake in this phase of the study (Appendix M). Once informed consent was obtained from the participants (Appendix N), the focus group

interview date and time were finalized with the participants. The researcher sent SMS and email reminders a week prior to the scheduled focus group interview as well as on the day of the interview, prior to the scheduled time. The researcher conducted the focus group interview using videoconferencing in accordance with participants' preference. The focus group interview was audio-recorded, transcribed and analysed accordingly.

1.9.7 Data Management

All the narrative and focus group interview data were recorded on a Phillips Voice Tracer audio recorder. The online survey research results were recorded into Microsoft Excel Spreadsheets. All the electronic data were saved in a password-protected folder created for the purpose of this study. Only the researcher had access to the computer and passwords. The computer was kept in a secure place. Hard copies were kept in in a locked cabinet in the researchers' home. No one had access to this data except the researcher and the supervisors.

1.9.8 Data Analysis

The analysis strategies that were employed in this study reflect the integration of the quantitative and qualitative data which is the hallmark of a mixed methods investigation (Creswell & Plano Clark, 2018). Detailed analysis methods are discussed in each manuscript of this thesis. In general, narrative interview data were analysed using reflexive thematic analysis and research survey data was converted into Microsoft Excel Spreadsheets and converted into STATA version 15.2 for analysis.

Measures of central tendency indicate the middle and commonly occurring points in a data set. The three main measures of central tendency, mode, median and mean were used (Chakrabarty, 2021). The mode is the value most frequently occurring within the data set. The mode is important for describing a data set when one value occurs frequently, and it is not affected by extreme values (Kaliyadan & Kulkarni, 2019). On the other hand, the median

is the value that is in the exact middle of the sample when the measurements are arranged in order of magnitude and the mean is the average of the dataset (Kaliyadan & Kulkarni, 2019; Siedlecki, 2020).

In addition to measures of central tendency, measures of dispersion were used to analyse the raw data. Measures of dispersion indicate the distribution of the individual values or range of values of a data set (Siedlecki, 2020). The measure of dispersion used in this study was frequency distribution. Frequency distribution is based on the distribution of the data (Chakrabarty, 2021). It involves organizing raw data into ungrouped and grouped data and offering a description of the number of participants in each possible option (Kaliyadan & Kulkarni, 2019).

Furthermore, the association between personal, family and socio-demographic factors and caregivers' perceptions of family-centeredness of the EHDI services they received was established using the chi-squared statistic. A chi-squared statistic is nonparametric test used when the data to be analysed are frequency counts for different categories (Carlson & Winquist, 2014; Salkind, 2014). In this study, the chi-squared test of independence was used in order to determine if the relative frequencies within the categories of one variable are associated with the relative frequencies within the categories of a second variable (Carlson & Winquist, 2014). The association between caregivers' perceptions of family-centeredness of the EHDI services they received and the following factors were investigated: age, home language, marital status, occupation, child's degree of hearing impairment, and child's age at enrolment in EHDI programme, language used to access services.

The Possible attributes and attribute levels for the conjoint analysis were determined using logistic regression analysis. Logistic regression analysis studies the association between categorical-response variables and independent (explanatory) variables (Ranganathan et al.,

2017). For this study, a multinomial logistic regression analysis was conducted. A multinomial logistic regression analysis is used in a case whereby the dependent variable has three or more categorical values such as married, single, divorced, widowed, etc. (Ranganathan et al., 2017). Its objective is to obtain an odds ratio in the presence of more than one explanatory variable. Thus, the result illustrates the impact of each variable on the odds ratio of the observed event of interest (Shafieezadeh-Abadeh et al., 2015; Sperandei, 2014).

The multinomial logistic regression analysis allowed multiple explanatory variables to be analysed simultaneously, while reducing the effect of confounding variables (Sperandei, 2014), and thus enabled the researcher to establish the attributes and levels of attributes of EHDI services that caregivers may prefer. These results were then be used to compile the survey questionnaire that was completed by the participants. The logistic regression analysis was computed using the Stata software.

Results of the conjoint analysis evaluation instrument were analysed using descriptive statistics as outlined above.

Table 1.1 provides a summary of the study.

Table 1.1

Summary of the study, data collection techniques and data analysis methods

Objectives	Phase	Study design	Data collection technique	Data collection tool	Data analysis	Chapter where results are reported
1. Describe caregivers' expectations of the EHDI process, from detection to intervention.	Phase 1	Mixed methods convergent design	Narrative inquiry	Participant interview	Reflexive Thematic Analysis	Chapter 5
2. Describe caregivers' experience of the EHDI process from detection to intervention.	Phase 1	Mixed methods convergent design	Narrative inquiry	Participant interview	Reflexive Thematic Analysis	Chapter 6
3. Evaluate the success or failure of the EHDI process in relation to caregivers' expectations.	Phase 1	Mixed methods convergent design	Narrative inquiry	Participant interview	Reflexive Thematic Analysis	Chapter 5
4. Identify barriers and facilitators to the EHDI process from caregivers' perspectives.	Phase 1	Mixed methods convergent design	Narrative inquiry	Participant interview	Reflexive Thematic Analysis	Chapter 7
5. Describe caregivers' level of satisfaction with current EHDI programmes.	Phase 1	Mixed methods convergent design	Narrative inquiry	Participant interview	Reflexive Thematic Analysis	Chapter 6
6. Determine caregivers' perceptions of the extent to which the EHDI services they received are family-centred.	Phase 1	Mixed methods convergent design	Survey research	Modified MPOC-56	Descriptive statistics	Chapter 8

Objectives	Phase	Study design	Data collection technique	Data collection tool	Data analysis	Chapter where results are reported
7. Explore the association between personal, family and socio-demographic factors and caregivers' perceptions of family-centeredness of the EHDI services they received.	Phase 1	Mixed methods convergent design	Survey research	1. Demographic questionnaire 2. Modified MPOC-56	Chi-squared statistic	Chapter 8
8. Explore caregivers' preferences for characteristics associated with EHDI services.	Phases 2	Mixed methods explanatory sequential design	Conjoint analysis	Development of conjoint analysis instrument	Multinomial logistic regression analysis	Chapter 9
	Phase 2		Conjoint analysis	Conjoint analysis survey instrument	Descriptive statistics	
	Phase 3		Focus group interview	Group interview	Reflexive Thematic Analysis	

1.9.9 Ethical Considerations

This study adhered to the Helsinki Declaration of 1975, as revised in 2013 (World Medical Association, 2013). To this end, all procedures adhered to the relevant national and institutional guidelines for conducting research involving human subjects. The following ethical principles were adhered to throughout the study namely; respect for communities and persons, participants' right to confidentiality and anonymity, beneficence, and justice.

1.9.9.1 Respect for Communities and Persons. Respect for communities and persons requires a commitment to ensuring the autonomy of research participants (British Psychological Society, 2010). This aspect was achieved through informed consent. Permission letters were issued to all EI preschool centres from which participants were recruited from. Information letters and consent forms were also issued to all potential participants who indicated a willingness to participate in the study. This was done in order to ensure that all potential participants had an understanding of what participating in the study entailed so they could decide in a conscious, deliberate way whether they wanted to participate in this study or not (Xafis et al., 2019). All the information letters outlined the topic, objectives, potential benefits and risks of the study.

1.9.9.2 Confidentiality and Anonymity. In order to uphold participant's rights to privacy, the participant's identity was kept anonymous and confidential information was not included during data collection and analysis. The researcher ensured participants' anonymity by ensuring that data recording forms and transcriptions did not include any identifying information and are kept in a secure area with limited access, in the researcher's possession. Anonymity essentially means that participants will remain anonymous throughout the study, even to the researcher (APA, 2003; Leedy & Ormrod, 2013). Anonymity was ensured by using participant reference numbers instead of the participant's names. However, the nature

of narrative interviews and focus groups is such that anonymity could not be guaranteed, only confidentiality of the research data.

1.9.9.3 Beneficence. Beneficence requires a commitment to minimizing the risks associated with research and maximizing the benefits that accrue to research participants and the wider community (Polit & Beck, 2010). The researcher utilized a research design that minimized the possibility of harm to the participants and obtained approval from the University of Witwatersrand Research Ethics Committee prior to commencement of the study. Furthermore, the researcher conducted the study in a field where there is limited research available in the South African context, thus ensuring that the research is beneficial to the wider community of children with congenital or early-onset hearing impairment.

1.9.9.4 Justice. Justice requires fairness and equity in research. Justice requires inclusiveness of individuals or groups in the research study and ensures that individuals or groups are not excluded on the basis of attributes such as culture, language, gender, race, ethnicity, age and disability; unless there is a basis for such an exclusion (Gill & Redwood, 2013). For the purpose of this study, the researcher ensured justice through treating all the participants fairly and equally.

1.9.9.5 Dissemination of Results. The researcher will inform the participants of the research results, in a manner that they will understand. Secondly, all participating institutions will be provided with the results.

1.10 Outline of thesis

Chapter 1: Background

Chapter 1 provides an overview of EHD and FCEI. The chapter also provides the statement of the problem, motivation for the study, statement of originality, conceptual framework, as well as the aim, sub-aims and research questions of the study. Lastly, this

chapter provides an overview of the research methodology adopted in this study and overall outline of this thesis.

Chapter 2: Literature review

Chapter 2 provides a comprehensive and critical review of the literature with focus on FC-EHDI, particularly in South Africa; with due recognition of the unique concept of what constitutes a family in this context, the multilingual and multicultural nature of society, as well as power and decision-making dynamics. The chapter also outlines the principles of FC-EHDI and provides a discussion of current evidence and practice in the field; as well as the economic evaluation of EHDI programmes with recommendations for the implementation of FC- EHDI programmes in the African context.

Chapter 3: Paper 1: An Integrative Review of Current Practice Models and/or Process of Family-Centered Early Intervention for Children who are Deaf or Hard of Hearing

This chapter explores and documents evidence reflecting trends in FCEI for children with hearing impairment by identifying and describing current practice models and/or processes of FCEI for these children.

Chapter 4: Paper II: Embracing Videoconferencing Interview Applications Beyond COVID-19: Scoping Review-guided Implications for Family-Centered EHDI Services in South Africa

This chapter reviews current practices of videoconferencing in healthcare and how these can be applied to FC-EHDI within the South African context.

Chapter 5: Paper III: EHDI Services Should Be Accessible! Caregivers' Expectations of EHDI Services in South Africa

This chapter describes caregivers' expectations of EHDI services, and evaluates the success and/or failure of the EHDI services in relation to these expectations.

Chapter 6: Paper IV: Caregivers' Experiences of the Early Hearing Detection and Intervention (EHDI) Process from Detection to Intervention in South Africa

This chapter describes caregivers' experience of the EHDI process from detection to intervention, within the South African context.

Chapter 7: Paper V: Barriers and Facilitators to Early Hearing Detection and Intervention in South Africa: A Narrative Inquiry of Caregivers' Experiences

This chapter identifies barriers and facilitators to EHDI services in South Africa, based on caregivers' experiences.

Chapter 8: Paper VI: Family-Centeredness of Early Hearing Detection and Intervention Programs in South Africa

This chapter determines caregivers' perceptions of the extent to which the EHDI services they received were family-centered, and explores the association between caregivers' demographics and their perceptions of family-centeredness of the services they received.

Chapter 9: Paper VII: Caregivers' Preferences for EHDI Services in South Africa: Evidence from a Conjoint Analysis

This chapter explores caregivers' preferences for characteristics associated with of EHDI services.

Chapter 10: Paper VIII: Early Hearing Detection and Intervention in South Africa: A Call for Pragmatic Considerations in Implementing Linguistic and Culturally Congruent Family-Centred Programmes

This chapter extends a clarion call improving access to EHDI programmes through linguistic and culturally-congruent FC-EHDI services for children with hearing impairment.

Chapter 11: Synthesis of Findings

This chapter provides a summary and integration of the papers presented in Chapter 3 to Chapter 10. The aim and objectives of the study are reviewed, including a discussion of the integration of the findings of the eight papers included in this thesis. This chapter also offers a discussion of how this research contributes to the body of knowledge in the field of EHDI, particularly in relation to FC-EHDI in South Africa. Furthermore, the study's theoretical and practical contribution to the field of audiology, its design and methodological limitations, and recommendations for future research are presented.

1.11 Roles and Responsibilities

The researcher conceptualized the study in consultation with the supervisor and co-supervisor. The researcher also drafted the research proposal, in consultation with the supervisors and submitted it to the University Human Research Ethics Committee (Medical) for ethical clearance.

Upon obtaining ethical clearance and permission from the two EI preschool centres, the researcher, as the primary and sole investigator collected and analysed all data for this study. The researcher further sought guidance for the statistical analysis required in this study. Due to the significant contribution by the researcher to the research process, the researcher is the first author in all publications, the supervisor is the second author and the co-supervisor is the third author.

The researcher's role in this study included making substantial contributions in conceptualising data collection and analysis, as well as writing all the manuscripts. The supervisors provided critical theoretical and technical feedback on aspects of the research process. Corrections were conducted in accordance with the supervisors' feedback. Both supervisors provided supervision, guidance and critical feedback on all the work produced in this study, except for the sole author paper (Chapter 10).

CHAPTER 2

Complexities of Implementing FC-EHDI within the South African Context

This chapter discusses FC-EHDI in South Africa, with due recognition of the unique concept of what constitutes a family in this context; the multilingual and multicultural nature of society; as well as power and decision-making dynamics. The chapter also outlines the principles of FCEI and provides a discussion of current evidence and practice in the field; as well as the economic evaluation of EHDI programmes with recommendations for the implementation of FC-EHDI programmes in the South African context.

2.1 Introduction

The concept of family-centred practice made an appearance in discussions about EI in the early 1980s and has become an integral principle guiding the design and delivery of service models since then (Kokorelias et al., 2019; Kuo et al., 2012). Consequently, over the past few decades, there has been an increasing shift towards emphasising the importance of the child's family taking an active role in the habilitation process, through FCEI programmes. In the case of EI services for children with hearing impairment identified through early hearing detection initiatives, the term 'FC-EHDI' is used (Moeller et al., 2013).

Deliberations around FC-EHDI are crucial because, according to the WHO (2021), around 1.5 billion people worldwide have disabling hearing impairment. Approximately three percent of these individuals are children aged zero to nine years. It is estimated that the number of disabling hearing impairment cases will increase to over 2.5 billion by 2050, with nearly 80% of these individuals living in LMICs (WHO, 2021). The high prevalence of hearing impairment in LMICs such as South Africa has significant implications given the resource constraints within this context and the substantial economic costs to society (Chorozoglou et al., 2018). The WHO (2021) states that unaddressed hearing impairment

costs an annual global amount of 980 billion US dollars. Thus, initiatives to prevent, identify and provide early intervention for hearing impairment in a family-centred context are cost-effective and can bring great benefits to individuals, families and societies (Maluleke, 2022). Thus, there is an urgent need for the development and implementation of early holistic multidisciplinary services and resources, taking into account the unique South African context and the needs of the caregiver and family of the child with hearing impairment. Before further exploring the concept of FC-EHDI, we establish what a family is in the South African context.

2.2 The African Family Defined

Family is an essential factor without which no society can function. The child's development of personality and independence is facilitated through the family's provision of physical and emotional care, security, appreciation and affection, positive communication, time spent together and spiritual well-being. The family also acts as a protective buffer against risk behaviours in order to promote resilience and coping during difficult times (Aldersey, 2012).

Despite being a foundational social institution, the concept of family is difficult to define, especially in the South African context (Department of Social Development, 2013). This is primarily because family structures and functions are in a constant state of flux due to:

- population migration as a result of high unemployment rates and limited economic opportunities, especially in rural contexts, with many African women working as domestic workers and raising their employers' children
- the high prevalence of HIV/AIDS, which has resulted in many women having to take on the roles of both breadwinner and caregiver in challenging circumstances of high unemployment

- the absence of parents due to the HIV/AIDS epidemic, resulting in grandparents and older children caring for their grandchildren or younger siblings, respectively, with child-headed households being common.

The concept of family may differ from culture to culture and based on the social context. Given the multilingual and multicultural nature of South Africa, no standard definition of family is comprehensive enough to cover the various kinds of families that exist. However, for the purpose of legislative frameworks, the Department of Social Development (2013, p. 11) defines the family as 'a societal group that is related by blood (kinship), adoption, foster care or the ties of marriage (civil, customary or religious), civil union or cohabitation, and go beyond a particular physical residence'. Thus, in this context, family constitutes a wider circle of relatives than just the nuclear family with its biological or adopted children. Instead, members of the extended family automatically become part of the immediate family: paternal and maternal grandparents, uncles, aunts, nephews, nieces, cousins, sons- and daughters-in-law (Chataika & McKenzie, 2011).

In patriarchal contexts, the roles of various family members are often hierarchical and gendered. In the case of some South African cultures, males are generally considered the heads of the family, and females play the most significant role in day-to-day child rearing and caregiving (Masuku & Khoza-Shangase, 2018). However, as a collective, family members can take responsibility for caring for relatives when it comes to provision of shelter, clothing, food, tuition fees and health care. Similarly, hospitality and mutual aid towards one's relatives are important cultural values (Chataika & Mc Kenzie, 2011).

Despite differences in family structures in the South African context versus the diverse conceptualisation of family constellations in western societies of contexts over the past decade , children are an important factor in any family (Luck & Castren, 2018). Their care and upbringing are of concern not only for the biological parents, but also for relatives

and extensive networks such as the community. Based on the adage ‘your child is mine and my child is yours’, communities in this context assist in raising children to ensure they follow community values, norms and religious beliefs. This brings a sense of unity in the community. Children belong to the whole community and community members are there to ensure that they become significant members of the community. Thus, in this context, the concept of family-centred may be viewed as community-centred or village-centred, particularly in rural areas. Khoza-Shangase (2019) argues that the philosophy of ubuntu and the cultural belief that a child is raised by the whole village should thus form part of any conceptualisation of intervention plans or initiatives to ensure that they are culturally congruent.

2.3 Family-Centred EHDI

Decades of research have demonstrated positive effects on child outcomes through strengthening the family role and responsibility; through allowing caregivers their rightful position as advocates, decision makers and partners with EI professionals (Sass-Lehrer et al., 2015). Thus, research investigating FCEI, in the past decade, has focused on various principles of the consensus statement outlined in Chapter 1.

Studies from LMICs highlight the challenges associated with achieving timely access to services (Principle 1). In Adedeji et al.’s (2015) and Merugamala et al. (2017) studies, the late identification, diagnosis and initiation of EI services for children with hearing impairment reported in these studies was attributed to a lack of attention to early hearing detection in Nigeria and India, respectively. Thus, making early intervention elusive. Similarly, in South Africa, children with hearing impairment are late-identified (Storbeck & Young, 2016; Maluleke et al., 2018). The South African context is characterized by a quadruple burden of disease whereby the HIV/AIDS epidemic co-exists with a burden of tuberculosis, high maternal and child mortality, high levels of violence and injuries, as well

as a growing burden of non-communicable diseases (Maphumulo & Bhengu, 2019; Parliamentary Monitoring Group, 2016; The Presidency, 2018). Within this context, infant hearing impairment is viewed as less urgent and has consequently received lesser financial attention and political will from the Department of Health (Khoza-Shangase & Michal, 2014; Naidoo & Khan, 2022; Petrocchi-Bartal & Khoza-Shangase, 2015; Storbeck & Young, 2016).

The lack of attention to EHDI in South Africa, India and Nigeria raises implications for systematic planning and implementation of international level gold standard EHDI programmes at various levels of service delivery. Urgent implementation of wide spread and accessible EI services would serve as a concrete step to equalize opportunities for vocational and societal contexts for children with hearing impairment (Maluleke et al., 2019).

For EI services to be successful, it is crucial that the caregivers, who are a powerful influence on the child's early development are included in the habilitation process (Ingber & Dromi, 2010; Larsen et al., 2012). Without caregiver or family involvement, intervention is likely to be unsuccessful, and what few effects are achieved are likely to disappear once the intervention is discontinued (Bronfenbrenner, 1994; Balton et al., 2019). Accordingly, principle 2 outlines the need for a caregiver/family-professional partnership in FCEI. Two studies have investigated this aspect, with the aim to explore emotional and motivational characteristics' influence on caregiver involvement as well as the behaviours and practices associated with caregiver involvement. Ingber et al, (2010) investigated the contribution of maternal characteristics in explaining mothers' involvement in EI for their children with hearing impairment, in Israel. In Ingber et al.'s (2010) study, increased curiosity, motivation and perceived social support, as well as decreased pessimism about a child's potential resulted in increased caregiver involvement in EI. However, increased anger resulted in decreased caregiver involvement. Generally, services that reduce the burdens and stressors

families experience are believed to make it easier for caregivers to focus on the needs and care of their child (Adebiyi et al., 2022; Turan, 2012).

Through FCEI, these stressors can be reduced, thus promoting optimal levels of family interaction and developmental outcomes (Dirks & Szarkowski, 2022; Guralnick, 2011). When families are empowered with knowledge through FCEI programmes, this acts as a buffer against the stress and anxiety commonly reported by caregivers, which in turn allows them to extend the intervention for their child with a hearing impairment; thus, improving developmental outcomes. These findings have implications for clinical practice, especially in the South African context. Caregivers may further experience discomfort and reluctance seeking information from a healthcare professional from a different linguistic and cultural background (Mophosho, 2018). Moreover, different cultural groups have vastly different perceptions of the causes of disability and disease, which influence their health seeking behaviour (Babik & Gardner, 2021; Wegner & Rhoda, 2015). Thus, it is imperative for professionals to be cognizant of caregivers' health seeking behaviour which includes consulting a traditional healer with the same linguistic and cultural background in conjunction with biomedical options (Moshabela et al., 2016; Town et al., 2014).

Inger et al.'s (2010) study also reported pessimism about their child's potential and perceived social support as having an influence on caregiver involvement. Similar results may be expected in the South African context. The current state of the Department of Health and the Department of Basic Education do not arouse optimism about the potential of a child with hearing impairment or availability of social support. Teachers in schools for the Deaf are not fluent in Sign Language; only a few deaf learners are reported to have progressed beyond grade 12; and only a few schools have audiology equipment and audiologists (DeafSA, 2018; Ngobeni et al., 2020; Parliamentary Monitoring Group, 2013). Some estimates indicate that more than 70% of all deaf adults have no jobs, the few adults who are employed work in non-

professional jobs (DeafSA, 2018; De Villiers, 2010). Furthermore, the shortage of health care professionals (HCPs) in this context has resulted in most communities not having the services of audiologists in the public sector (Khoza-Shangase & Mophosho, 2018).

Families provide a rich cultural context in which children learn and develop; thus, intervention approaches that can be easily incorporated into their daily lives and are congruent with their beliefs and practices are warranted (Balton et al., 2019). Through linguistic and culturally appropriate FCEI, caregivers and families can be guided to resolve challenges associated with anger, motivation, pessimism and perceived support services. Thus, audiology programme's curricula for audiologists should incorporate the effects of ethnicity and culture on clinical decision making (Mophosho, 2018). Furthermore, through FCEI, the reported barriers with access to healthcare due to a shortage of professionals can also be minimized.

Caregiver involvement has been reported to be multifaceted (Ersabi et al., 2018). Furthermore, it incorporates a broad range of behaviours and practices which include:

a) Caregivers' work behind the scenes which includes creating an optimal environment for habilitation and learning at home and helping the child adapt to hearing technology as well as managing the use and maintenance of the devices;

b) Caregivers as case managers, which includes arranging and attending appointments/meetings, communicating with various professionals, educating others and advocating on behalf of their child;

c) Caregivers support their child's language development by giving up work or reducing work load so as to help their child achieve successful communication outcomes, incorporating interactive activities into daily routines, and encouraging their child to use communication strategies;

d) Caregivers' role extends to advocacy for all children with hearing impairment through contributing to education and support for other families with children with hearing impairment, and participating in research to improve product and services;

e) Parenting, which includes showing affection and being responsive to their child's needs, involving their child in daily and weekly routines, encouraging and supporting their child to explore new things, as well as participating in school activities and helping with school work.

Ersabi et al.'s (2018) study is one of a few that seeks to understand caregiver involvement from their own perspective. The reported findings highlight the fact that the construct of caregiver involvement is more extensive than previously reported and provides a more comprehensive understanding of the various roles that caregivers of children with hearing impairment fulfil in their children's daily lives. However, caution needs to be exercised in the South African context, in order to ensure that epistemic knowledge of developed contexts is not used as the norm, without incorporating knowledge obtained from the South African context (Khoza-Shangase & Mophosho, 2018). This raises implications for exploring constructs of caregiver involvement within this context; in order to ensure that caregivers are adequately capacitated within this context to influence their child's development.

In order for caregivers to be involved in the habilitation process for their child with hearing impairment, they need to gain the necessary knowledge and information to make fully informed decisions (Principle 3). Information sharing and coaching should be provided in an open, objective and unbiased manner (Kou et al., 2012). For a successful caching relationship; clear expectations must be established between caregivers and HCPs, intervention goals must be mutually agreed upon, the coaching relationship must be balanced

with reciprocal coaching exchange, information sharing and coaching must adjust in response to caregivers' information and support needs, and caregivers should be allowed time to practice and absorb the information given (Dalmau et al., 2017; Noll et al., 2022; Watermeyer et al., 2017). Four studies investigated information sharing with caregivers. Of these four studies, two studies focused on the information provided to caregivers following a failed hearing screening or confirmation of hearing impairment and two studies focused on the informational resources that caregivers preferred or found to be useful.

In Elpers et al.'s (2010) study, conducted in rural Kentucky in USA; caregivers reported poor communication of the hearing screening results. The hearing screening results were reportedly communicated to caregivers a few days or weeks after discharge from the hospital via telephone or posted mail. In Larsen et al.'s (2012) study, conducted in the Utah State in USA only 48% of the caregivers reportedly received resources pertaining to paediatric hearing impairment.

In Jackson (2011) and Findlen et al.'s (2019) studies caregivers across USA reported that they found the following resources most useful during information sharing a) written materials; b) verbal/visual demonstrations; c) hearing aid resources; d) discussion with other caregivers of children with hearing impairment; e) internet sources; f) explanations provided by professionals; g) parent-friendly books; h) discussion with adults with hearing impairment; i) Videos and DVDs; j) brochures and pamphlets and; k) detailed professional books.

The information provided to caregivers is essential in order to ensure caregivers' involvement in the intervention process. Information sharing dispels any misconceptions and emotional turmoil associated with a confirmed hearing impairment. This information enables caregivers to make informed decisions jointly with professionals (Kuo et al., 2012; Malar et

al., 2013). Therefore, audiologists need to decide what information is essential to include in feedback sessions, as both the type and amount of information presented may impact caregiver recall (Watermeyer et al., 2012). The degree of accurate recall and understanding of information has significant implications for follow-up of treatment options, as well as commitment and adherence to treatment recommendations (King & Hoppe, 2013; Laws et al., 2018). Thus, studies investigating caregivers' preferred mode of information sharing is vital, especially in low literacy populations such as South Africa where 3.7 million adults, 20 years and older are illiterate (Khuluvhe, 2022).

In addition to caregivers receiving the necessary knowledge and information, Principle 4 outlines that caregivers and families must be connected to support systems that will enable them to obtain the knowledge and experience that will enable them to function effectively. HCPs' expertise, experience and content knowledge cannot substitute the joys, needs, worries, feelings and experiences caregivers possess. Thus, social opportunities for networking and meeting other families with children with hearing impairment empowers caregivers to fully participate in the EI programme. These support systems also act as a buffer against the stress and isolation faced by many parents of children with a hearing impairment. Three studies reported on support services for caregivers and families of children with hearing impairment.

In Larsen et al.'s (2012) study discussed above, only 33% of the caregivers were reportedly informed about available caregiver support organizations. Of the three studies, two studies reported the support needs of caregivers and families. In Decker and Valloton's (2016) study, caregivers reported the need to access support services following confirmation that their child presents with hearing impairment. Similarly, in Jackson et al.'s (2010) study, caregivers reported a need to connect with other caregivers of children with hearing impairment, as well as additional support for family life. Connecting families to parent-to-

parent and community-based support systems provides vital knowledge and experiences. This support positively impacts family well-being and enables caregivers to effectively advocate for their child with hearing impairment (Moodie et al., 2016). Such support services are essential in the South African context, where there is poor access to healthcare services. Parent-to-parent and community-based support systems offer decentralization of access to hearing healthcare services. Furthermore, it may reduce the barrier to accessing healthcare services due to linguistic and cultural incongruence. Thus, parent-to-parent and community-based support systems must be explored as an alternative model of service delivery.

Principle 5 states that families and HCPs should work together to create optimal environments for language learning. This can be achieved through caregiver coaching, which has been shown to empower and prepare caregivers to function effectively in their social contexts, daily life and as a result promote their quality of life (Dalmau et al., 2017). The two studies that addressed caregiver coaching provided commentary for caregivers during assessment or intervention tasks conducted by the professional, as well as feedback on caregiver-child interaction. Ekberg et al.'s (2018) study provides a description of how caregiver-directed commentaries during therapy appointments can be used to enhance caregivers' knowledge of habilitation procedures and facilitate FCEI. Similarly, Sacks et al.'s (2014) study provides a description of how linguistic feedback provided for caregiver-child interactions resulted in increased Adult Word Count, Conversation turn Count and Child vocalization Count. These studies were conducted in Australia and Chicago in USA, respectively.

Caregiver coaching is central to FC-EHDI, to equip and empower caregivers with the knowledge and skills to improve language interactions with their child with hearing impairment and extend the therapy environment into the home environment (Noll et al., 2021; Soulek, 2022). However, studies conducted in the South African context have

demonstrated poor caregiver recall and understanding of information provided by professionals. Furthermore, studies also highlighted a lack of tailoring of information-giving towards the communicative needs of the individual caregivers (Watermeyer et al., 2012). Moreover, the use of an interpreter has been shown not to necessarily address the challenges associated with multilingualism and multiculturalism (Mophosho, 2018). Thus, a multi-pronged approach is required to address this challenge as follows: a) aligning approaches to information sharing and coaching to include individualized, collaborative, and context-driven coaching practices (Noll et al., 2021; 2022; Watermeyer et al., 2017); b) the Department of Health should invest in recruiting trained interpreters to assist HCPs (Mophosho, 2018); c) induction of all newly-appointed HCPs should include introductory knowledge on the language and culture of the community which they serve (Khoza-Shangase & Mophosho, 2018); d) additional opportunities for clarification through the initiation of support group structures (Watermeyer et al., 2017); e) transformation of the admission criteria to increase accessibility to African language speaking students and a curriculum that incorporates cultural awareness and cultural competence (Khoza-Shangase & Mophosho, 2018).

Timely provision of amplification devices for hearing impairment forms part of the benchmark indicators for EHDI programmes (HPCSA, 2018). When children with hearing impairment receive sensory devices timeously, they have the potential to receive the necessary linguistic information to reach speech and language competencies similar to their hearing peers (Harrington et al., 2010). Accordingly, Principle 6 promotes the use of assistive technologies and supporting means of communication to support the child's language and communication development. In Jackson et al. (2010) and Jackson (2011), caregivers reported the need for information pertaining to available technology. Caregivers' need for information pertaining to available technology implies a lack of provision of these devices following confirmation of the hearing impairment or delayed provision of such

devices. Suboptimal provision of amplification devices between 18 and 52 months, has been reported in the South African context (Maluleke et al., 2018). Suboptimal provision of amplification devices demonstrates poor adherence to the HPCSA guidelines for best practice, which recommend provision of amplification devices within one month of identification of the hearing impairment (HPCSA, 2018). Provision of amplification devices as soon as possible after a child has been identified with the hearing impairment is of crucial importance as lack of auditory stimulation has an effect on the development of the child's speech and language abilities (Meyer et al., 2014). In addition to mandated UNHS, necessary budget provisions are required to ensure that children identified with hearing impairment are provided with amplification devices, timeously.

In addition to providing assistive technologies, HCPs must possess the core competencies to support families in optimizing the child's development and child-family well-being (Principle 7). Three studies investigated this aspect in FCEI. In Elpers et al.'s (2010) study, caregivers reported that paediatricians or HCPs did not expedite the hearing healthcare and ignored their concerns about their infant's hearing impairment and that the paediatrician was unaware of EI programmes offered which resulted in the child not receiving timely treatment. In Merugamala et al.'s (2017) study, caregivers reported that they had been referred for a hearing evaluation from a general children's clinic, but had to "wander around looking for the right people". Moreover, in Khoza-Shangase's (2019) study, 48% of the caregivers reported that the professional did not seem to know or understand what was wrong with their child.

For FCEI initiatives to be effective and efficient, services must be easily accessible to the clients that it aims to serve. HCPs' lack of knowledge pertaining to paediatric hearing impairment highlights the need for EHDI programmes to be mandated in South Africa and other LMIC contexts. This will facilitate support and education of all HCPs involved in

paediatric care (Petersen & Ramma, 2015). Thus, potential prospects for effective trans-disciplinary teamwork by ensuring sufficient awareness of congenital or early-onset hearing impairment by HCPs involved in paediatric management exist (Maluleke et al., 2018).

The hallmark of FCEI is collaborative team work between families and healthcare professionals, as outlined in Principle 8. In Ingber and Dromi's (2010) study, caregivers expressed satisfaction with HCPs' attitude and practices towards family participation in the intervention programme. The caregivers reported that professionals were willing to collaborate with them and encouraged them to participate in their child's intervention. Caregivers' self-reported levels of satisfaction acknowledges their actual experience with FCEI programmes and makes them the most suitable informants to improve accountability of actual screening, diagnosis, and intervention practice (Dirks & Szarkowski, 2022; Maluleke et al., 2020). This finding has significant implications for the South African context due to its sociopolitical history. Through FCEI programmes that are linguistically and culturally sensitive to the child with hearing impairment and their families, the cycle of exclusion of the patient and family from receiving effective treatment or care can be broken; enabling caregivers to work collaboratively with HCPs. Thus, validating the need for multi-pronged approach to address the challenges with multilingualism and multiculturalism (Mophosho, 2018), as discussed above.

Principles 1 to 8 focus on benchmark indicators of FCEI programmes; however, Principles 9 and 10 focus on regular monitoring and/or assessment of child and family outcomes (Principle 9) and quality assurance monitors of all programme elements (Principle 10). Four studies investigated Principle 9. In Jackson et al.'s (2010) study, caregivers reported improved family interaction, parenting and support following access to FCEI. Similarly, In Findlen et al.'s (2019) study, 86% of the caregivers reported overall satisfaction with services provided during annual multidisciplinary assessment and monitoring

appointments. Investigation of caregiver satisfaction with current EHDI initiatives in South Africa is warranted so as to identify gaps and incongruence in knowledge, beliefs, and practices that will ensure that FC-EHDI programmes that are implemented are grounded on the linguistic, cultural and socioeconomic diversity of the South African population.

Caregivers in Constanescu's (2012) study expressed satisfaction with EI services provided via computer-based video-conferencing. Eighty-nine percent of the caregivers reported that receiving EI services via videoconferencing was a better alternative to travelling for regular face-to-face sessions. However, 61% of the caregivers reported experiencing technical difficulties that required trouble shooting during the session.

According to the WHO (1998), telehealth is the delivery of health care services by HCPs through the use of information and communication technologies, where distance is a critical factor (Monaghesh & Hajizadeh, 2020). Telehealth is viewed as a solution to the shortage of EI providers and challenges with providing services to geographically dispersed families (Havenga et al., 20156; Monaghesh & Hajizadeh, 2020). Tele-audiology, which is a sub-set of telehealth may be a valuable vehicle for delivering FCEI services to various communities with no or limited access to health care in the South African context. However, it is crucial that its feasibility is investigated with regards to cost-effectiveness; installation, use and maintenance of videoconferencing devices; as well as the associated technical support required. Moreover, access within the South African economically unequal society needs careful deliberation.

The various changes and advances in EHDI call for the evaluation of not only the outcomes, but also the quality of the services provided (Campana et al., 2019). Programme monitoring and evaluation of any programme determines how well the programme is working, and whether programme activities have been implemented as intended and resulted

in desired outputs (Diaz et al., 2018). However, there is a dearth of documented studies investigating Principle 10 of the consensus statement over the past decade (Deng et al., 2016), especially in the South African context. In Reynolds et al.'s (2023) study which investigated caregivers' experience of the journey of hearing impairment diagnosis, amplification and intervention, caregivers reported mixed performance of EHDI programmes' adherence to best practice guidelines. Findings in this study revealed that caregivers either received timely and coordinated EHDI services resulting in their child with hearing impairment developing average and above-average spoken language skills; or delayed EHDI services due to HCP's lack of knowledge pertaining to hearing impairment services, lack of local services, resulting in their child with hearing impairment developing low average or below-average spoken language skills. Feedback, regarding specific and all aspects of EHDI, is crucial in order to increase caregiver satisfaction, caregiver involvement, policy formation, and to facilitate better developmental outcomes for children with hearing impairment.

In addition to evaluating the quality of health interventions , there is a need for decision makers in the healthcare sector to consider the cost impact in adopting healthcare interventions and technologies (Lakdawalla et al., 2018), EHDI included.

2.4 Assessing the Value of EHDI within the Healthcare Sector

Assessing the economic value in healthcare is not a new concept (Doshi & Willoke, 2017). Health economics is the leading interdisciplinary science that bridges the gap between the theory and economics and practice of healthcare. Its earliest roots date back to 1932, during the cold war with the establishment of the Bureau of Medical Economics by the American Medical Association. However, the first publication of this science as "health economics" was in 1958 (Jakovlejevis & Ogura, 2016). Since then, this field has

experienced great development from its earliest roots into extensive diversification into the various sub-disciplines available today (Blumnschein & Johannesson, 1996; Jakovlejevis & Ogura, 2016). The importance of economic value in healthcare has risen to prominence in recent years in the wake of the universal health coverage (UHC) movement (Cookson et al., 2017), and as health policy makers across the globe are facing difficult financial decisions of having to balance a large unmet and rising demand for health services, ambitious international guidelines and severely constrained health budgets (Remme et al., 2017).

Confronting choices about how to spend society's limited resources on healthcare is not an easy task (Neumann & Sanders, 2017). Furthermore, although prevention programmes such as EHDI can be the most cost-effective way to maintain the health of the population in a sustainable manner, concerns about the upfront costs and intangibility of outcomes frequently leads to a lack of action and continued investment in increasingly expensive curative approaches (WHO, 2014). Consequently, health economics evaluation frameworks have been proposed and refashioned in order to measure and/or rank the value of new interventions (Doshi & Willke, 2017; Mandellblatt et al., 2017), and provide useful evidence about health equity impact and trade-offs (Balinsky et al., 2017). Various health economics evaluation frameworks exist namely, cost-benefit analysis, cost-effective analysis, and conjoint analysis.

2.4.1 Cost-Benefit Analysis

Cost-benefit analysis (CBA) provides a universal metric to support decision-making that allocates scarce resources, at the fundamental level of where to invest and in the marginal analysis of how much to invest (Robertson et al., 2019). It is used evaluate the economic value of interventions by providing a monetary value for both cost and outcomes or benefit of the intervention (WHO, 2003; McNamee et al., 2016). This method, thus, allows for direct

calculation of the net monetary cost of achieving a health outcome (WHO, 2003; Robertson et al., 2019). However, the techniques used to value health outcomes in monetary terms is somewhat controversial, thus limiting the use of this method of economic evaluation to trial-based or modelled applications in healthcare (Mosadeghrad et al., 2022; WHO, 2003). A trial-based analysis uses the incremental benefits and use of resources in a clinical trial to calculate the net incremental cost-effectiveness of gaining an incremental health benefit over another treatment; however, this may not be as relevant to the use of the intervention as it would be in the real-world. Furthermore, a modelled analysis is used to apply the benefits and use of resources to a local clinical situation, and to extend the time frame beyond that of a clinical trial. However, the benefits of treatment may not be realized until sometime in the future (Thomas & Chalkidou, 2016).

2.4.2 Cost-Effectiveness Analysis

Conversely, Cost-effectiveness analysis (CEA) compares the costs and effectiveness of two or more health interventions (Marseille et al., 2015). It involves a more comprehensive evaluation of intervention outcomes. While cost is measured in monetary terms, effectiveness is determined independently and may be measured in terms of clinical outcomes such as life-years-gained (LYGs), quality-adjusted life-years (QALYs) or Disability-Adjusted Life-Years (DALYs) in order to account for quality-of-life outcomes (Augustovski et al., 20178; McGregor, 2003; WHO, 2003). CEA is the recommended method of economic evaluation in health care as it is better suited to address the UHC objectives and for allocating scarce healthcare resources (Culyer & Chalkidou, 2019). Furthermore, the WHO strongly advocates for the use of CEA to help governments set healthcare priorities in both HIC and LMIC (Saunders et al., 2015). The underpinning objective of CEA is maximizing total health in the general population. Items included on the cost side of the economic evaluation include any resources that have an opportunity cost as a result of being associated with the healthcare

programme, while the benefit side includes the health effects and other impacts of individual's wellbeing (Lau 2017; McIntosh et al., 1999).

A limited number of CEA of various audiological services have been conducted over the years. These include a) investigating the cost-effective approach of hearing screening in a general population of older veteran (Liu et al., 2011); b) cost-effectiveness of neonatal hearing screening programmes in China (Tobe et al., 2013); c) cost and outcome of conducting hearing screening programmes using a 2-step DPOAE screening protocol (Ramkumar et al., 2018); d) cost-effectives of bone-anchored hearing devices (Peter et al., 2011), e) compared cost-effectiveness of deaf education versus cochlear implants for children with severe-to-profound sensorineural hearing impairment using DALYs in low resource environments (Saunders et al., 2015); f) cost-effectiveness of booklet-based vestibular rehabilitation with and without telephone support for chronic dizziness, compared to routine care (Yardley et al., 2012); and g) cost-effectiveness of telehealth to reach patients in remote and/or rural settings with lack of healthcare facilities or personnel (Swanepoel & Hall, 2010).

2.4.3 Conjoint Analysis

Another method used in health economics that can used in evaluating EHDI, particularly in the South African context, is the conjoint analysis. A conjoint analysis is an evaluation approach that uses survey methods to elicit trade-offs among attributes and attribute levels to determine respondents' preferences for alternative products (Hauber et al., 2016; Marshall et al., 2010). It is a method of eliciting stated preferences from patients that goes beyond traditional health outcome measures to account for non-health outcome attributes in the process of delivery of healthcare services (Ali & Ronaldson, 2012; Soekhai et al., 2018).

The underlying theory of a conjoint analysis is that a product or service can be described by its characteristics or attributes (Eggers et al., 2021; Ryan & Farrar, 2000). This survey method provides an estimation of the relative importance people attribute to various components of care, measures how individuals are willing to trade between these characteristics, and estimates the overall satisfaction they gain from various forms of health service provision (Fitzpatrick et al., 2018). A conjoint analysis offers a mechanism for patients to participate in decision making and how different stake holders may value outcomes (Al-Omari et al., 2022; Bridges et al., 2011). Thus, helping decision makers understand the health service choices of communities, the perspectives of different user segments or the unique preferences of individual patients (Cunningham et al., 2010; Steigenberger et al., 2022).

In the field of audiology, only one conjoint analysis has been conducted thus far. In Fitzpatrick et al.'s (2019) study, they used conjoint analysis to quantify parent's preference for service attributes for children with mild bilateral or unilateral hearing impairments. Results of the study indicated that preference for speech-language support compared with support for amplification use. According to our knowledge, this study is the second study to use the conjoint analysis to elicit caregivers' preferences for characteristics associated with EHDI services.

2.5 Summary

The nuclear family is a foreign concept in the African context, where the term 'family' includes a wider circle of paternal and maternal grandparents, uncles, aunts, nephews, nieces, cousins, sons- and daughters-in-law. Family structures and functions are in a constant state of flux due to various factors. However, the roles of various family members are still patriarchal and hierarchical. Men and senior members of the family have the power to

make decisions on behalf of the family, but are significantly less involved in day-to-day child-rearing activities than women.

Family-centred EHDI is a viable option for decentralised service delivery in the South African context given the overburdened health care system, South Africa's socio-political history and dynamics, and the reported poor access to health care services, especially by vulnerable populations. Thus, an analysis of the healthcare costs associated with EHDI programmes is essential in order to ensure that policy makers have an understanding of the costs or budgetary implications of these programmes, particularly in the current climate of budgetary constraints in healthcare. Furthermore, for these programmes to be effective, the following factors need to be considered:

- the linguistic and cultural diversity of the South African population and its influence on access to health care, health care-seeking behaviour and decision-making dynamics
- aspects of family-centred EHDI programmes such as caregiver involvement, information and support needs, and caregiver satisfaction with current early intervention services
- tailoring of current caregiving programmes for OVC with regards to caregiver training and the caregiving process in order to ensure that these children also benefit from family-centred EHDI
- alternative and feasible service provision avenues, such as tele-audiology, that mitigate the reported barriers associated with access to health care, in order to ensure contextually relevant and responsive care of children with hearing impairment.
- aligning EHDI outcomes with the SDGs, especially UHC

- demonstrating the substantial effects of EHDI programmes beyond the healthcare sector into interrelated sectors such as education, social services, and economic productivity
- careful tailoring of EHDI programmes based on what the buyer-patient, payer or society can afford.

In chapter 3, a comprehensive and critical review of the literature focusing on trends, practice models and/or processes of FCEI for children with hearing impairment is provided. The search strategy, data extraction and data synthesis methods used for this review are also presented.

Chapter 3

An Integrative Review of Current Practice Models and/or Process of Family-Centred Early Intervention for Children who are Deaf or Hard of Hearing

(Reprinted with permission, Appendix O)

3.1 Abstract

Background: Over the past few decades, there has been an increasing shift towards emphasizing the importance of the child's family taking an active role in the habilitation process, through Family-Centered Early Intervention (FCEI) programs. Accordingly, the Health Professions Council of South Africa (2018) recommends that early intervention services following confirmation of hearing loss must be family-centered within a community-based model of service delivery that is culturally congruent.

Aim: The aim of this study was to explore and document current evidence reflecting trends in FCEI for children who are deaf or hard of hearing (DHH) by identifying and describing current practice models and/or processes of FCEI for these children. This study describes our first steps in formulating a framework for FCEI for children who are DHH in South Africa.

Methods: An integrative literature review was conducted. Sage, Science Direct, PubMed, and Google Scholar databases were searched for studies published in English between January 2009 and January 2019 reporting on FCEI programs for children who are DHH. Studies that focused on speech and language outcomes of children, youth and adults who are DHH; education for children who are DHH; universal newborn hearing screening; professionals' roles in early hearing detection and intervention; diagnosis of hearing loss; and sign language were excluded from the study. Kappa statistics was performed to determine agreement between reviewers. Twenty-two studies were included in the review.

Results: Cohen's kappa revealed a substantial agreement (k=0.8) between reviewers for data extraction and synthesis in terms of the articles that met the criteria for inclusion in the review. Findings were discussed under five themes: caregiver involvement, caregiver coaching/ information sharing, caregiver satisfaction, challenges with FCEI, and telehealth. Generally, there is sufficient evidence for FCEI with caregivers indicating the need for full involvement in their children's care. Methods of caregiver involvement involving caregiver coaching/information sharing need to be culturally and linguistically appropriate, with sensitivities around time and manner. This increases caregiver satisfaction with intervention programs and improves outcomes for children who are DHH. Challenges identified by the studies raise implications for EHDI programs, as well as Departments of Health and Social Welfare. These challenges included logistical challenges; professional related challenges; and caregiver related challenges.

Conclusion: Various aspects of FCEI have been reported in the review. Findings of these studies have significant implications for the formulation of quality FCEI programs to ensure contextually relevant and contextually responsive care of children who are DHH in South Africa.

Keywords:

FCEI, early hearing detection and intervention, deaf or hard of hearing, early intervention

3.2 Introduction

The concept of family-centred practice made an appearance in discussions about early intervention (EI) in the early 1980s and has become an integral principle guiding the design and delivery of service models since then (Epley, Summers & Turnbull, 2010). Consequently, over the past few decades, there has been an accelerating shift towards emphasizing the importance of the child's family taking an active role in the habilitation process, through Family-Centred Early Intervention (FCEI) programs (Ingber & Dromi, 2010). Family-Centred Early Intervention is a family-professional partnership that places the needs of the child in the context of their family (MacKean et al., 2005) in order to optimise the child's developmental outcomes (Iversen, Shimmel, Ciacera & Prabhakar, 2003). Family-Centred Early Intervention is the preferred term in paediatric care, where families are most involved with their children, and its purpose is to educate, support and empower family members and the family system of the child who is deaf or hard of hearing (DHH) (Moeller, Carr, Seaver, Stredler-Brown & Holzinger, 2013). Recognising the centrality of family-child interactions represents a paradigm shift from viewing the caregiver as a peripheral player in child-focused interventions to a service delivery model where professionals focus on strengthening family interactions (Woods, Wilcox, Friedman & Murch, 2011). This position fundamentally challenges the care paradigm of unilateral responsibility for decision-making by the professional (Kuo, Houtrow, Arango, Kuhlthau, Simmons & Neff, 2012).

Family-Centred Early Intervention is a philosophy, belief and values from which professionals support the development and capacities of families in order to promote the progress of the child with disabilities (Dalmau et al., 2017; Epley et al., 2011). It is based on the following principles: (1) the client is the child and their family rather than just the child, therefore the best way to meet the needs of the child who is DHH is to acknowledge the needs of the family members as well; (2) caregivers are invited to become involved in their

child's care and have the opportunity to share their opinions, expertise, needs and preferences with professionals; (3) information sharing between the professional and caregiver is open, objective and unbiased in order to ensure that families can make appropriate decisions that best fit the needs, strengths and values of the child and family; (4) caregivers are encouraged to collaborate with professionals to acquire knowledge and competencies that allow them to mediate or extend the intervention for their child who is DHH, conversely, professionals acknowledge the family as the expert of their child's development; and (5) social opportunities through parent-to-parent support which affords families of the child who is DHH an opportunity to network and meet other families of children who are DHH.

In South Africa, early intervention (EI) services following diagnosis of a child's hearing loss must be family-centered within a community-based model of service delivery that is culturally congruent (HPCSA, 2018). The authors of this paper agree with the Health Profession's Council of South Africa's [HPCSA] (2018) recommendations and argue that establishing FCEI programs for children who are DHH can mitigate the inequities associated with access to health care (Nkonki, Chopra, Doherty, Jackson & Robberstad, 2011; Khoza-Shangase & Mophosho, 2018). This is particularly relevant to South Africa where access to health care services is significantly affected by an over-burdened health care system, linguistic barriers between healthcare professionals and patients, as well as cultural diversity. Typically, these challenges mostly affect the already vulnerable members of the population, in rural and poverty-stricken black communities (Nkoki et al., 2011; Storbeck & Young, 2016; Khoza-Shangase & Mophosho, 2018).

The South African context is characterized by a quadruple burden of disease whereby the HIV/AIDS epidemic co-exists with a burden of tuberculosis, high maternal and child mortality, high levels of violence and injuries, as well as a growing burden of non-communicable diseases (Swanepoel et al, 2009; Petrocchi-Bartal & Khoza-Shangase, 2015).

Within this context, infant hearing loss is viewed as less urgent and has consequently received lesser financial attention and political will from the Department of Health (Khoza-Shangase & Michal, 2014; Petrocchi-Bartal & Khoza-Shangase, 2015).

In addition to an over-burdened health care system, South Africa has 11 official languages which the constitution states must all enjoy equal esteem and treatment (Constitution of the Republic of South Africa, 1996). However, English is the prominent language in the political, educational and social settings (Pascoe, Klop, Mdlalo & Ndhambi, 2018). This is despite the fact that English is spoken by 10% of the population as their home language (Statistics South Africa, 2016) and is thus viewed as a language of power and prestige (Pascoe et al., 2018). This effect creates and perpetuates a structural paradox, which does not respond to the population's needs (Mophosho, 2018); with over 11 million black South Africans receiving health care services in a language that is not their home language (Khoza-Shangase & Mophosho, 2018). Moreover, language is closely tied to identity and culture (Irina, 2011; Pascoe et al., 2018). Wegner and Rhoda (2015) define culture broadly as a people's way of life, interaction with the world, and behaviour in certain situations. They argue that culture can be considered as a combination of religious beliefs, socially accepted norms, and traditions (Wegner & Rhoda, 2015). In South Africa, audiologists are largely female, white, English or Afrikaans speaking and thus do not represent the cultural diversity of the country's population (Pascoe & Norman, 2011).

In post-apartheid South Africa, these cultural differences replicate historical power dynamics which may result in clients not feeling confident to request clarification or indicate when they have not understood some information (Watermeyer, Kanji & Cohen, 2012). Most importantly, evidence on global health indicates that groups who do not form part of the dominant culture have worse health outcomes than the dominant populations (Flood & Rohloff, 2018). This effect creates a cycle of exclusion of the patient and family from

receiving effective treatment or care (Mophosho, 2018). However, FCEI programs have the potential to eliminate this cycle of exclusion, as the family roles and responsibility is strengthened; allowing caregivers their rightful position as advocates, decision makers and partners with EI professional (Sass-Lehrer, Porter & Wu, 2015). Children spend a significant amount of time with their caregivers and families; thus, the family is the most effective and economical system for fostering and sustaining the child's development. Hence, FCEI programs can ensure that EI efforts provide optimal benefit for clients and do not distance them linguistically and culturally (Mophosho, 2018). This paper forms part of a larger doctoral research project, and describes our first steps in formulating a framework for FCEI for children who are DHH in South Africa; by identifying and describing current practice models and/or processes of FCEI for these children.

3.3 Methods

An integrative literature review for the development of concepts (Broome, 2000) was conducted to explore and document current evidence reflecting trends in FCEI for children who are DHH. Although integrative in nature through the inclusion of experimental and non-experimental studies, (Broom, 2000) this study was conducted with the same rigor as a systematic review in terms of an academic database search with clear parameters.

3.3.1 Search Strategy

A comprehensive search was conducted of papers on family-centered early intervention services for children who are DHH. A computer-aided search of four online journal databases, including Sage, Science Direct, PubMed, and Google Scholar was undertaken. The following keywords were used "Family centered care", "Family-centered early intervention", "Early Intervention", "Early hearing detection and intervention" and "Hearing loss". The Boolean operator "AND" was used between the phrases. MeSH terms

were used in addition to author keywords. The databases used were chosen based on their content matter and accessibility to the researcher.

Searches were supplemented with a rigorous manual review of the reference lists of the papers included in order to obtain additional papers. All published, peer-reviewed studies within the last 10 years (January 2009-January 2019) were considered for review. A period of 10 years was chosen in order to ensure that the information was current evidence because the aim of the study was to review current evidence that would allow for the formulation of a framework for FCEI for children who are DHH in South Africa; through identifying and describing current practice models and/or processes of FCEI for these children. Furthermore, this time frame was selected as this is the period post-apartheid South Africa, where the main study to which the current study is linked is located, where early intervention started receiving much attention. It is acknowledged that the timeframe selected could have limited inclusion of seminal studies in the field, which might have influenced current findings; hence the importance of being cognizant of this limitation in the interpretation. The researcher identified all the articles for review. Two additional reviewers reviewed all articles that were included or excluded from the review in order to ensure the reliability and validity of the process of identifying the relevant articles. Kappa statistics was performed to determine agreement between reviewers.

3.3.2 Inclusion Criteria

Articles selected for inclusion in this study were original pieces of scientific work or reports published in peer reviewed scientific journals. The focus was on FCEI services for children who are DHH. All the articles were published in English. Grey literature was not included in this review.

All the articles selected for inclusion were independently identified by all investigators using pre-defined abstraction. Disagreements on papers selected for inclusion were resolved through discussion and consensus among all authors of this paper. Where consensus was not reached, the leading author made the final decision. Secondly, authors provided a narrative synthesis of the findings from the studies that met the inclusion criteria. Cohen's kappa revealed a substantial agreement (k=0.8) between reviewers for data extraction and synthesis in terms of the articles that met the criteria for inclusion in the review.

3.3.3 Data extraction and Synthesis

Twenty-three thousand, six hundred and forty-five articles that contained the search keywords were screened. Sixty-one of these were based on FCEI services for children who are DHH, while 23 584 investigated speech and language outcomes for children, youth and adults who are DHH; education for children who are DHH; universal newborn hearing screening (UNHS); professionals' roles in early hearing detection and intervention (EHDI); diagnosis of hearing loss; and sign language. Thirty-nine out of the 61 articles were excluded because they focused on ages for initiation of EHDI services, as well as the nature of services received; causes of the hearing loss, medical management and strategies to optimize hearing; history of UNHS and the progress made; and health related quality of life. Nineteen of the excluded articles were literature reviews, scoping reviews or systematic reviews.

Eventually, twenty-two peer-reviewed, research studies were included in this review. These included 16 surveys, four exploratory cohort studies, one prospective short-term longitudinal pretest-post-test design, and one retrospective research design study. The synthesis included the research focus, context, method of implementation and format, and outcomes. Table 3.1 outlines the process of selecting studies for inclusion in this review is

included. The studies included in this review were heterogeneous as they included quantitative, qualitative and mixed methods studies, hence the integrative nature of the study (Broome, 2000).

Table 3.1

Description of the search results identifying articles for the integrative review

Procedural steps	No. articles	Description
Records identified in the database search	23 713	4 electronic databases used (Sage, Science Direct, PubMed and Google Scholar)
Records after duplications removed	23 636	77 duplications removed
Additional records through identified other sources	9	Reviewed reference lists of articles included in the review to identify additional, relevant records.
Records screened	23 645	Articles that contained the search keywords.
Records excluded	23 584	Articles investigated speech and language outcomes for DHH children, youth and adults; education for DHH children; universal newborn hearing screening (UNHS); professionals' roles in EHDI; diagnosis of hearing loss and sign language.
Full-text articles assessed for legibility	61	Articles based on FCEI services for DHH children
Full-text articles excluded	39	focused on ages at identification of hearing loss and initiation of EI services, as well as the nature of services received; causes of the hearing loss, medical management and strategies to optimize hearing; history of UNHS and the progress made; and health related quality of life
Studies included in the review	22	Articles forming part of the integrative review.

3.4 Results and Discussion

The range of FCEI services provided for children who are DHH included in this paper are summarized in Appendix P – depicting the research focus, methods of implementation and formats, and outcomes. With a total sample size of 22 papers, data synthesis revealed five themes. Ten of the 22 articles were relevant to more than one category or theme, resulting in a total sample of 32 articles. Percentages were calculated on the total number of 32 articles. The five themes that were identified are: caregiver involvement (n=5; 16%); caregiver coaching/information sharing (n=12; 38%); caregiver satisfaction (n=4; 13%); challenges of FCEI (n=11; 34%); and telehealth (n=3; 9%). Below, the studies are reported and discussed within each of the identified themes.

3.4.1 Caregiver Involvement

A caregiver is defined as the person responsible for providing care to the child on a daily basis, which includes biological caregivers, legal guardians or family members (Tanco et al., 2018). Caregivers are widely accepted to make the greatest difference to children's achievements (Harris & Goodall, 2008). Thus, they are crucial to the success of early hearing detection and intervention initiatives (Larsen, Munoz, DesGeorges, Nelson & Kennedy, 2012).

Five studies on caregiver involvement were included in this review. These studies sought to explore emotional and motivational characteristics' influence on caregiver involvement; influence of the setting in which EI services were received on caregiver involvement; behaviours and practices associated with caregiver involvement; as well as determining effective facilitative language techniques used by the caregiver. Ingber, Al-Yagon and Dromi (2011) investigated the contribution of maternal characteristics in explaining Hebrew-speaking mothers' involvement in EI for their child who is DHH, in

Israel. In Ingber et al.'s (2011) study, increased curiosity, motivation and perceived social support, as well as decreased pessimism about a child's potential resulted in increased caregiver involvement in EI. However, increased anger resulted in decreased caregiver involvement. In another study, Harrison et al. (2016) examined the influence of the setting in which EI services were received on caregiver involvement. Caregivers of children who are DHH enrolled in EI services at various centres through USA participated in a telephonic interview. Results of the study indicated that family involvement was significantly more likely to occur when services were delivered in the home.

Generally, services that reduce the burdens and stressors families experience are believed to make it easier for caregivers to focus on the needs and care of their child (Turan, 2012). Findings from these two studies have implications for establishing FCEI, especially in the South African context. Curiosity, motivation and anger may be perceived incorrectly by professionals given the power dynamic created by South Africa's sociopolitical history. Caregivers may experience discomfort and reluctance seeking information from a healthcare professional from a different linguistic and cultural background (Mophosho, 2018). Moreover, different cultural groups have vastly different perceptions of the causes of disability and disease, which influence their health seeking behaviour (Wegner & Rhoda, 2015).

Furthermore, providing intervention in the family's home has been shown to be an effective strategy for improving child development and parenting in vulnerable families (Tubach et al., 2012). In addition, the home visit may increase the family's sense of control and comfort; allowing them to get the most benefit from the service; and allows service providers to offer a more tailored approach to service delivery, thus increasing caregiver participation (Peacock et al., 2013). Home visiting during the perinatal period has also been shown to be efficacious in improving caregiver and child health outcomes when delivered by

nurses and community health workers (CHW) in low- and middle-income countries such as South Africa (Rotheram-Borus et al., 2017). However, African countries, South Africa included, have the lowest per capita health budgets and fewer health professionals, globally (Ferguson, 2018). Thus, feasibility of home visits and collaboration with CHW during EHDI services for children who are DHH requires further exploration. Moreover, EI professionals must be cognizant of caregivers' health seeking behaviour which includes consulting a traditional healer or spiritual guide with the same linguistic, cultural and religious background in conjunction with biomedical options (de Andrade & Ross, 2005; Pillay & Moonsamy, 2018).

Inger et al.'s (2011) study also reported pessimism about their child's potential and perceived social support as having an influence on caregiver involvement. Similar results may be expected in the South African context. The current state of the Department of Health and the Department of Basic Education do not arouse optimism about the potential of a child who is DHH or availability of social support. Approximately 80% of teachers in schools for the Deaf are unable to use sign language; only a few learners who are DHH are reported to have progressed beyond grade 12; and only a few schools have audiology equipment and audiologists (Parliamentary Monitoring Group, 2013). Some estimates indicate that more than 90% of all adults who are DHH have no jobs, the few adults who enter the open labour market do so in non-professional jobs such as office administration, upholstery, cosmetology, construction and hospitality (De Villiers, 2010). Furthermore, the shortage of health care professionals in this context has resulted in most communities not having the services of audiologists in the public sector (Khoza-Shangase & Mophosho, 2018). Consequently, caregivers have to travel long distances to access such services.

The authors of this paper argue that, through linguistic and culturally appropriate FCEI, caregivers and families can be empowered with knowledge to optimize their child's

developmental outcomes and be guided to resolve challenges associated with anger, motivation, pessimism and perceived support services. Thus, audiology program's curricula for audiologists should incorporate the effects of ethnicity and culture on clinical decision making (Mophosho, 2018). Furthermore, through FCEI the reported barriers with access to healthcare due to a shortage of professionals can also be minimized.

In Ersabi et al.'s (2018) study, conducted in Queensland, Australia; findings revealed that caregiver involvement is multifaceted. Furthermore, it incorporates a broad range of behaviours and practices which include a) caregivers' working behind the scenes to create an optimal environment for habilitation and learning at home and helping the child adapt to hearing technology as well as managing the use and maintenance of the devices; b) caregivers as case managers, which includes arranging and attending appointments/meetings, communicating with various professionals, educating others and advocating on behalf of their child; c) caregivers supporting their child's language development by giving up work or reducing work load so as to help their child achieve successful communication outcomes, incorporating interactive activities into daily routines, and encouraging their child to use communication strategies; d) caregivers' role extends to advocacy for all children who are DHH through contributing to education and support for other families with children with hearing loss, and participating in research to improve product and services; f) parenting, which includes showing affection and being responsive to their child's needs, involving their child in daily and weekly routines, encouraging and supporting their child to explore new things, as well as participating in school activities and helping with school work.

This study is one of a few that seeks to understand caregiver involvement from their own perspective. The reported findings highlight the fact that the construct of caregiver involvement is more extensive than previously reported and provide a more comprehensive understanding of the various roles that caregivers of children who are DHH fulfil in their

children's daily lives. However, caution needs to be exercised in the South African context, in order to ensure that epistemic knowledge of developed contexts is not used as the norm, without incorporating knowledge obtained from the experiences of South African families (Khoza-Shangase & Mophosho, 2018). This raises implications for exploring constructs of caregiver involvement within this context. In order to ensure that caregivers are adequately capacitated within this context to influence their child's development.

In Cruz et al.'s (2013) study, the researchers evaluated the effects of facilitative language techniques and word types on oral language development over three years post cochlear implantation for children who are DHH. Higher level facilitation techniques such as parallel talk, open-ended questions, expansion, expatiation and recast were more facilitative than lower-level facilitative techniques such as linguistic mapping, comment, imitation, labelling, directives and closed ended-questions. Similarly, in Ambrose et al.'s (2015) study conducted in USA, examined quantity and quality of caregivers' talk-directed to children who are DHH as compared to children with typical hearing at 18-months and 3 years. Caregivers exposed children who are DHH to greater proportions of directing utterances as compared to children with normal hearing at 18 months. Furthermore, children who are DHH were exposed to fewer words and lower quality input from their caregivers compared to children with typical hearing at three years. Findings from these studies highlight that the quality of caregiver involvement during caregiver-child interactions plays a major role on language development for the child who is DHH (Moeller, 2000; Niparko et al., 2010). FCEI programs highlight the important role that families and caregivers play in facilitating language development in children who are DHH (Iversen et al., 2003; MacKean et al., 2005). Thus, this raises implications for ensuring that during caregiver coaching and or information sharing, emphasis is placed on the need for caregivers' linguistic input to be varied with utterances that are appropriate and facilitate their child's language development.

3.4.2 Caregiver Coaching/ Information Sharing

Information sharing refers to the exchange of information in an open, objective and unbiased manner (Kou et al., 2012). Caregivers should be guided and coached through information that supports their ability and confidence to care for their child and provide learning opportunities that have a positive impact on their development without threatening self-confidence, and cultural, religious or familiar traditions (Bruder, 2000; Turan, 2012; Dalmau et al., 2017).

Twelve studies addressing caregiver coaching and/or information sharing were included in this review. Further analysis led the authors of this paper to divide this theme according to the following sub-themes: caregiver coaching (n=3; 25%); information provided to caregivers (n=5; 42%); and information needs of caregivers (n=4; 33%).

3.4.2.1 Caregiver Coaching. The role of the EI practitioner as a 'coach' to support families of children with disabilities is a critical practice of FCEI, allowing more opportunities to foster the child's development through family-implemented activities during their daily routines (Korfmacher et al., 2008; Rush & Sheldon, 2011). The three studies that addressed caregiver coaching provided commentary for caregivers during intervention tasks, as well as feedback on caregiver-child interaction. Ekberg et al.'s (2018) study demonstrated how caregiver-directed commentaries during therapy appointments conducted by the professional can be used to enhance caregivers' knowledge of habilitation procedures and facilitate FCEI in Australia. In their study Ekberg et al. (2018), revealed that when EI professionals provide caregiver-directed commentaries during child-directed activities in therapy, caregivers' knowledge of habilitation procedures and goals was enhanced. Furthermore, the EI professional-caregiver interaction cultivates a positive partnership with the caregiver.

In Sacks et al.'s (2014) study, caregiver education and linguistic feedback or review of video-recorded caregiver-child interactions resulted in increased Adult Word Count, Conversation turn Count and Child vocalization Count post-intervention scores. Similarly, Lam-Cassettari et al.'s (2015) study demonstrated increased parental sensitivity, parental structuring, parental non-hostility, parental self-esteem, child responsiveness and child involvement following video-feedback intervention for caregiver-child interaction during free play. Sacks et al. (2014) and Lam-Cassettari et al.'s (2015) studies were conducted in Chicago in the United States of America (USA) an in the United Kingdom (UK), respectively.

Caregiver coaching has been shown to empower and prepare caregivers to function effectively in their social contexts, daily life and as a result promote their quality of life (Dalmau et al., 2017). Caregiver coaching through modelling and provision of linguistic feedback is essential in order to ensure that caregivers are adequately equipped to extend the therapy environment into the home environment. However, studies conducted in the South African context have demonstrated poor caregiver recall and understanding of information provided by professionals. Furthermore, studies also highlighted a lack of tailoring of information-giving towards the communicative needs of the individual caregivers (Watermeyer et al., 2012). Moreover, the use of an interpreter has been shown not to necessarily address the challenges associated with multilingualism and multiculturalism (Mophosho, 2018). The authors of this paper argue that a multi-pronged approach is required to address this challenge as follows: a) the Department of health should invest in recruiting trained interpreters to assist health care professionals (Mophosho, 2018); b) induction of all newly-appointed health care professionals should include introductory knowledge on the language and culture of the community which they serve (Khoza-Shangase & Mophosho, 2018); c) additional opportunities for clarification through the initiation of support group

structures (Watermeyer et al., 2017); d) transformation of the admission criteria to increase accessibility to African language speaking students and a curriculum that incorporates cultural awareness and cultural competence (Khoza-Shangase & Mophosho, 2018).

3.4.2.2 Information Provided to Caregivers. Of the twelve studies that focused on caregiver coaching and/or information sharing, five studies investigated information provided to caregivers following a failed hearing screening or confirmation of hearing loss. In Elpers et al.'s (2010) study, conducted in rural Kentucky in USA; caregivers reported poor communication of the hearing screening results. The hearing screening results were reportedly communicated to caregivers a few days or weeks after discharge from the hospital via telephone or posted mail. In Larsen et al.'s (2018) study, conducted in the Utah State in USA; only 48% of the caregivers reportedly received resources pertaining to childhood hearing loss and 33% were informed about available caregiver support organizations. Only one study's findings reported information provided to caregivers that was aligned with principles of FCEI. Results in Decker and Valloton's (2016) study conducted in Michigan in USA revealed that the information that caregivers received was partially in line with recommended practices. Caregivers were reportedly informed about the following, a) the importance of talking frequently throughout the day in everyday routines and activities; b) promoting listening skills and language by focusing on sound c) incorporating other communication channels; and d) the essential role of caregivers in EI.

In Jackson (2011) and Findlen et al.'s (2019) studies, caregivers across USA reported that they found the following resources most useful during information sharing a) written materials; b) verbal/visual demonstrations; c) hearing aid resources; d) discussion with other caregivers of children who are DHH; e) internet sources; f) explanations provided by professionals; g) parent-friendly books; h) discussion with adults who are DHH; i) Videos and DVDs; j) brochures and pamphlets and; k) detailed professional books.

The information provided to caregivers is essential in order to ensure caregivers' involvement in the intervention process. Information sharing dispels any misconceptions and emotional turmoil associated with a confirmed hearing loss. This information enables caregivers to make informed decisions jointly with professionals (Kuo et al., 2012; Malar et al., 2013). Therefore, EI professionals need to decide what information is essential to include in feedback sessions, as both the type and amount of information presented may impact caregiver recall (Watermeyer et al., 2012). The degree of accurate recall and understanding of information has significant implications for follow-up of treatment options, as well as commitment and adherence to treatment recommendations (Haskard-Zolnierek & DiMatteo, 2009; Watson & McKinstry, 2009). Thus, studies investigating caregivers' preferred mode of information sharing is vital, especially in low literacy populations such as South Africa where only 28% of a group of 20 and a group of 24-year-olds have a grade 12 qualification (Central Statistics, 1998).

3.4.2.3 Information Needs of Caregivers. Four of the 11 studies focused on caregiver coaching and/or information sharing, four investigated the information needs of caregivers. In Jackson et al. (2010), Jackson (2011), Decker and Valloton (2016) and Alyami et al.'s (2016) studies, caregivers reported the following information needs: a) general information about hearing loss; b) information relating to children's development and community services; c) available technology; d) specialized education for children who are DHH; e) accessing funding for services and support. Furthermore, the following support needs were also highlighted, support to use signs or Sign Language (Decker & Valloton, 2016); professionals to explain the diagnosis to siblings, other children, friends, etc. (Alyami et al., 2018); and connecting with caregivers of children who are DHH (Jackson et al., 2010; Jackson 2011), caregivers using a specific modality, other children who are DHH;

workshops; services provided in natural environments; service coordination (Jackson, 2011); as well as additional support for family life (Jackson et al., 2010).

Understanding caregiver information needs is essential to ensure that the information provided aligns with caregiver needs. The method and communicative style in which information is presented also influences caregiver recall and understanding (Schmidt von Wuhlisch & Pascoe, 2010). Consequently, information sharing should be a more reflective practice, characterized by flexibility and adaptability (Watermeyer et al., 2012); ensuring that information is presented effectively and appropriately.

The reported need for professionals to explain the hearing loss to siblings, other children and friends by caregivers in Saudi Arabia, in Alyami et al.'s (2016) study has significant implications in clinical practice for developing contexts. This finding illustrates poor levels of caregiver knowledge associated with hearing loss (Swanepoel & Almec, 2008). Thus, there is much scope for broadening the health education given to mothers during antenatal care, especially to include awareness of developmental milestones, infant hearing loss and its impact on speech and language developmental (Maluleke, Khoza-Shangase & Kanji, 2018).

3.4.3 Caregiver Satisfaction

Four articles that investigated caregiver satisfaction with FCEI programs were included in the review. Caregivers expressed general satisfaction with FCEI programs. In Ingber and Dromi's (2010) study, caregivers expressed satisfaction with professionals' attitude and practices towards family participation in the intervention program. The caregivers reported that professionals were willing to collaborate with them and encouraged them to participate in their child's intervention. Similarly, in Jackson et al.'s (2010) study, caregivers reported improved family interaction, parenting and support following FCEI.

However, caregivers reported decreased satisfaction with associated expenses of their child who is DHH and affordability thereof, inclusion within their community, support to relieve stress, and having time to pursue their interest.

In another study on caregiver satisfaction, Alyami et al.'s (2016) study reported that all the caregivers who participated in the study expressed satisfaction with the EI program, with 75% of the caregivers reporting that the FCEI program helped them learn auditory training and language activities to use with their child at home. In Findlen et al.'s (2019) study, 86% of the caregivers reported overall satisfaction with services provided during annual multidisciplinary assessment and monitoring appointments.

Caregivers' self-reported levels of satisfaction acknowledges their actual experience with FCEI programs and makes them the most suitable informants to improve accountability of actual screening, diagnosis, and intervention practice (Young & Tattersall, 2007). Accordingly, investigation of caregiver satisfaction with current EI initiatives in South Africa is warranted so as to identify gaps and incongruence in knowledge, beliefs, and practices that will ensure that FCEI programs that are implemented take into consideration the linguistic, cultural and socioeconomic diversity of the South Africa's population.

3.4.4 Challenges

The benefits of FCEI also include greater satisfaction of families with the service received (Dalmau et al., 2017). According to King et al. (2000), caregivers who experience services that are more family-centred have higher levels of satisfaction with care. However, various challenges have been reported as having been experienced with the process of FCEI in various contexts, by some of the studies reviewed.

Eleven studies addressing challenges associated with FCEI were included in this review. Further analysis led the authors of this paper to divide this theme according to the

following sub-themes: logistical challenges (n=5; 45%); professional related challenges (n=3; 27%); and caregiver related challenges (n=3; 27%).

3.4.4.1 Logistical challenges. Five studies focused on logistical challenges associated with the provision of FCEI. In Adedeji et al. (2015) and Merugamala et al.'s (2017) studies, the late identification, diagnosis and initiation of EI services for children who are DHH reported in these studies was attributed to a lack of attention to early hearing detection in Nigeria and India, respectively; thus, making early intervention elusive. Furthermore, in Merugamala et al.'s (2017) study delayed initiation of EI services were due to a lack of free public services and caregivers could not afford the costs at available private health care facilities.

Similar findings have been reported in the South African context as discussed in the introduction section above. The lack of attention to early hearing detection in semi-developed contexts such as South Africa, India and Nigeria raise implications for systematic planning and implementation of international level gold standard EHDI programs at various levels of service delivery. Comprehensive EHDI program implementation is characterized by three stages, firstly, hearing loss must be identified through hearing screening services. Secondly, the hearing loss must be confirmed, described and categorized. Lastly, intervention services must be provided (Storbeck & Pittman, 2008). Thus, urgent implementation of wide spread and accessible EI services would serve as a concrete step to equalize opportunities to optimize long term vocational and social outcomes for children who are DHH (Maluleke et al., 2019a).

In Elpers et al.'s (2010), Larsen et al. (2012) and Khoza-Shangase (2019) studies, caregivers reported challenges associated with a large number of appointments that their child had to attend. Furthermore, caregivers reported having to endure evaluations that required

two to three different appointments to be completed, in two or three locations. In addition, caregivers reported long waiting lists and delayed appointment availability as a challenge. Another significant challenge expressed by caregivers was difficulty with travelling to areas of healthcare and having to travel with extended family members, especially when there is no consistent mode of transport (Elpers et al., 2010; Merugumala et al. 2017; Khoza-Shangase, 2019).

Poor access to the necessary hearing health care services is not unique to the semi-developed context, as in Merugumala et al. (2017) and Khoza-Shangase's (2019) study. Penetration of hearing health care services and uptake of intervention remains low even in developed contexts (Swanepoel & Hall, 2010; Bernstein et al., 2018), as evidenced in Elpers et al (2010) and Larsen et al.'s (2012) studies. Thus, decentralization of access to hearing health care services and alternative models of service delivery must be explored. Telehealth provides significant promise in improving healthcare access, quality of service delivery, as well as the effectiveness and efficiency (Swanepoel & Hall, 2010). Especially in the South African context where 4.4 million children travel more than 30 minutes to reach a healthcare professional (Hal et al., 2013). However, further research in this area is warranted in order to ensure that such services are comparable to face-to-face service provision, offer greater affordability of audiologic services and improve the reach of audiological services to underserved communities (Swanepoel & Hall, 2010; Bernstein et al., 2018).

3.4.4.2 Challenges Related to Professionals. Of the ten studies that focused on challenges associated with FCEI, three studies highlighted challenges related to professionals. In Elpers et al.'s (2010) study, caregivers reported that paediatricians or healthcare providers did not expedite the hearing healthcare and ignored their concerns about their infant's hearing loss and that the paediatrician was unaware of EI programs offered which resulted in the child not receiving timely treatment. In Merugamala et al.'s (2017) study, caregivers

reported that they had been referred for a hearing evaluation from a general children's clinic, but had to "wander around looking for the right people". Moreover, in Khoza-Shangase's (2019) study, 48% of the caregivers reported that the professional did not seem to know or understand what was wrong with their child.

The authors of this paper argue that for FCEI initiatives to be effective and efficient, services must be easily accessible to the clients that it aims to serve. Heath care professionals' lack of knowledge pertaining to paediatric hearing loss highlights the need for EHDI programs to be mandated in South Africa and other semi-developed contexts. This will facilitate support and education of all health care professional involved in paediatric care (Petersen & Ramma, 2015). Thus, potential prospects for effective trans-disciplinary teamwork by ensuring sufficient awareness of childhood hearing loss by healthcare professionals involved in paediatric management exist (Maluleke et al., 2019b).

3.4.4.3 Challenges Associated with Caregivers. Two of the ten studies highlighted challenges associated with caregivers. In Elpers et al.'s (2010) study, 50% of the caregivers reported a lack of knowledge of treatment options for hearing loss. Similarly, in Khoza-Shangase's (2019), caregivers reported poor awareness and knowledge of hearing loss and the suitable services that were available. Authors of this paper argue that opinion that maternal awareness of infant and childhood hearing loss may prompt earlier suspicion of the hearing loss, and subsequent early intervention, especially in cases of delayed-onset hearing loss that cannot be detected via UNHS programs. This can be achieved by broadening the health education given to mothers during antenatal care and at immunization clinics, as discussed above (Maluleke et al., 2019b).

In Merugumala et al.'s (2017) study, 35% of the caregivers reported that traditional wisdom from elders played a crucial role in health-related decision-making in their families.

Consequently, the mother-in-law, who had the powerful role of decision making reportedly underestimated the seriousness of the hearing loss and dismissed caregiver concerns, resulting in delayed confirmation of the hearing loss and subsequent intervention. There are three social structures that reportedly influence access to health care in the South African context. These include economic inequalities, male partner control and social norms sentimental attachments around gender (Conroy et al., 2016).

These social structures render women limited power to acquire health information, make decisions regarding health, and take action to improve health (Conroy et al., 2016). Furthermore, reports from similar Sub-Saharan countries suggest that decisions regarding access to health services are often made by their spouse or a senior member of the family such as the mother-in-law, father-in-law, or grandmother (Ganle et al., 2015). These decision-making dynamics were reported in research pertaining to access to maternal health care and power imbalances within sexual relationships and healthy behaviour around HIV/AIDS. However, the authors of this paper argue that these principles apply to access to health care services for women and children irrespective of the ailment. Therefore, the authors of this paper maintain that healthcare professionals need to be cognizant of the complexity of contextual decision-making dynamics and explore ways of navigating this dynamic in clinical practice.

3.4.5 Telehealth

According to the World Health Organization (WHO), telehealth is the delivery of health care services by health care professionals through the use of information and communication technologies, where distance is a critical factor (WHO, 1998). Telehealth is viewed as a solution to the shortage of EI providers and challenges with providing services to geographically dispersed families (McCarthy et al., 2019). Three studies that investigated

telehealth were included in this review. Cole et al. (2019) conducted a survey to investigate service coordinators and EI provider' perceptions of telehealth and use of telehealth services within EI systems in Colorado, USA. Only 20% of EI providers reported that the children who are DHH on their case load received services via telehealth; while 97% of service coordinators reported that less than 25% of these children on their case load received services via telehealth. Participants also identified strengths and barriers of telehealth services. Participants identified flexibility, access to providers from rural areas, and heightened family engagement through use of coaching practices as strengths of telehealth. Whereas, use of internet technology and video conferencing platforms; as well as negative attitude towards the use of telehealth were identified as barriers.

Behl et al. (2017) compared the outcomes of telepractice to traditional in-person services for children, families and EI provides in Part C EI programs across USA. Results demonstrated a) statistically significant difference in favour of the telepractice group compared with the in-person group for norm-referenced, standardized language test scores; b) no statistically significant differences between groups with regards to family outcomes; however, in-person home visits resulted in higher scores for provider responsiveness and parents engagement ;and c) the number of visits and minutes of intervention were higher for telepractice with fewer cancellations due to weather or transportation.

Constantinescu (2012) investigated caregiver satisfaction for remote delivery of EI services via Computer-based videoconferencing (tele-health) in Brisbane, Australia. All the caregivers expressed satisfaction with the service with 89% reporting that receiving EI services via videoconferencing was a better alternative to travelling for regular face-to-face sessions. However, 61% of the caregivers reported experiencing technical difficulties that required trouble shooting during the session.

There has been an increase in internet access over the past decade, making the use of telehealth a more viable and cost-effective service delivery option for EI (Meadan & DacZewitz, 2015; Little et al, 2018). Furthermore, telehealth promotes and enhances caregiver involvement through family coaching (Stredler-Brown, 2017). However, it is crucial that its feasibility is investigated with regards to cost-effectiveness; installation, use and maintenance and of videoconferencing devices; as well as the associated technical support required. Moreover, access within the South African economically unequal society needs careful deliberation.

3.5 Conclusion

Various aspects of FCEI have been reported in the review. Findings of the review revealed that for quality FCEI services EI services should: a) take due consideration of the family's linguistic, religious, cultural background, and social context, as well as constructs of caregiver involvement and need for home visits; b) carefully explore aspects of FCEI programs such as caregiver involvement, information and support needs, caregiver satisfaction with current EI services; c) explore caregiver satisfaction with current EI to identify gaps and incongruence in knowledge, beliefs, and practices in order to ensure quality FCEI programs; d) mitigate contextual-specific challenges associated with EI services in order to ensure wide spread and accessible services; e) explore use of telehealth as an alternative and feasible service provision avenue that mitigates the reported barriers associated with access to health care – to ensure contextually relevant and contextually responsive care of children who are DHH. These considerations provide a springboard for the implementation and evaluation of FCEI programs, especially in the South African context. Current findings have significant value for the formulation of a framework for FCEI for children who are DHH in South Africa; as they identify and describe current practice models

and/or processes of FCEI for these children that the current authors can incorporate in this process.

In the next chapter, videoconferencing practices in healthcare are reviewed. Futhremore, suggestions of how these videoconferencing practices can be applied to FC-EHDI within the South African context are offered. Chapter 4 also outlines Moher et al.'s (2009) methodological framework, which was adopted in the scoping review.

Chapter 4

Embracing Videoconferencing Interview Applications beyond COVID-19: Review-guided Implications for Family-Centered[4] EHDI Services in South Africa

(Reprinted with permission, Appendix Q)

4.1 Abstract

Background: Preventative measures at the height of the COVID-19 pandemic rendered in-person interviews unfeasible and unsafe for both research and healthcare service provision. Thus, viable alternatives became imperative, and videoconferencing bridged the gap between service delivery, community need and community safety, and increased utilization and integration of telehealth into the healthcare environment.

Aim: The aim of this scoping review was to review practices of videoconferencing in healthcare and how these can be applied to family-centred EHDI within the South African context.

Methods: Electronic bibliographic databases including Sage, Science Direct, PubMed and Google Scholar were searched to identify peer-reviewed publications, published in English between April 2017 and April 2021; focusing on patients and healthcare professionals' perceptions, attitudes, and experience of videoconferencing use in healthcare.

Results: Findings from this review are discussed under five themes: videoconferencing use; need for videoconferencing training; videoconferencing benefits; videoconferencing challenges; and recommendations for successful videoconferencing. Generally, there is sufficient evidence of videoconferencing use across various disciplines in healthcare and

[4] Spelling variations in this chapter compared to the rest of the thesis are due to aligning the manuscript with the spelling used in *Discover Health Systems*, the journal where this chapter was published.

satisfaction with this service delivery mode and its benefits from both healthcare professionals and patients. However, patients and healthcare professionals require training on videoconferencing use to participate fully during videoconferencing consultations and mitigate some of the challenges associated with this service delivery mode.

Conclusions: These findings provided solid evidence-based guidance for the main study's methodology; and raised significant implications for effective and contextually relevant Family-centred-EHDI programs within the South African context.

Keywords: Videoconferencing, Telehealth, EHDI, Early Intervention, Family-centred

4.2 Introduction

Interviews are a viable and highly utilized data collection tool in qualitative research [1, 2][5] as well as in clinical practice [3]. In healthcare, patient interviews are used to obtain the relevant medical history information which assists in developing an appropriate clinical diagnosis and decision making [4]. Traditionally, these interviews have been conducted in-person in accordance with the consensus among scholars that this format is the 'gold-standard' for conducting interviews [1, 5, 6]. However, alternatives to in-person interviews became imperative when the Corona Virus Disease 2019 (COVID-19) was declared a pandemic by the World Health Organization (WHO) on 11 March 2020 [7, 8, 9]. In response to this declaration; nationwide lockdowns, as well as regulations around strict controls on movement and physical contact between people were implemented worldwide, with the aim of reducing transmission of the virus [3, 10, 11]; which rendered practices such as in-person interviews unfeasible and unsafe in some cases for either research purposes or for healthcare service provision [3, 10]. COVID-19 created a crisis in health, economy, education, sports, and global mobility, in ways that our human civilization has never seen before [11, 12]. Over and above the crisis it caused, the pandemic also created opportunities for re-imagining data collection for research, as well as healthcare provision remotely through information and communication technologies (ICT) where safety, access and distance are a barrier [3, 11].

Conducting videoconferencing interviews on ICT platforms such as Skype, Zoom Meetings and Google Meet are comparable to in-person interviews as communication is done in real-time and follows the same protocols as traditional in-person interviews [10, 13]; thus, providing a strong foundation for building rapport which is critical in family-centered early

[5] Vancouver referencing style is used in this chapter due to the manuscript that makes up this chapter having been published in *Discover Health Systems*. The number are reflected in the reference list next to the corresponding reference and highlighted in green.

hearing detection and intervention (FC-EHDI). Consequently, videoconferencing interviews, which are the focus of the current paper, are one of the fastest and reliable means of collecting qualitative data [10]. These interviews are attractive to qualitative researchers due to their convenience, cost-effectiveness and ability to reach participants over a large geographical spread when compared to in-person interviews. Furthermore, unlike teleconferencing interviews, videoconferencing interviews also afford the researcher the opportunity to transmit and respond to non-verbal cues [14], which are important in FC-EHDI, especially when a communication challenge in the form of a hearing impairment is a factor to consider.

Amidst the COVID-19 pandemic, transitioning from in-person to videoconferencing healthcare delivery through telehealth bridged the gap between service provision, community need and community safety [3, 15, 16]; and increased utilization and integration of telehealth into the health environment [17]. The COVID-19 pandemic also forced researchers, current researchers included, to transition from in-person interviews to videoconferencing interviews for data collection. It was during this process that the researchers realized that, like many other healthcare professionals (HCPs), audiologists do not have advanced preparation or training in this regard [13, 18, 19]. Lack of preparation for transitioning to telehealth as an alternative model for service delivery has resulted in limited use of telehealth, especially within the South African context, where it would be most beneficial due to limited HCPs compared to the population size requiring services [3, 20]. Thus, Khoza-Shangase [21] argues for careful deliberation around the use of alternative healthcare delivery models to increase access to early intervention.

South Africa has a high prevalence of congenital hearing impairment, with estimates indicating a prevalence of four to six in every 1000 live births in the public sector [22, 23]. Furthermore, the South African context is characterized by a quadruple burden of disease

where the HIV/AIDS epidemic coexists with a burden of tuberculosis, high maternal and child mortality, high levels of violence and injuries, as well as a growing burden of non-communicable diseases, which all contribute towards speech and language pathology prevalence [24]. Moreover, the South African context continues to experience resource-constraints which perpetuate the view that infant and childhood hearing impairment is less urgent when compared to other healthcare priorities and has consequently received lesser financial attention and minimal political will from the National Department of Health [9, 17, 25].

Consequently, implementation of EHDI services which encompass the earliest possible identification, diagnosis and provision of intervention for newborns and infants with hearing impairment in order to curb the communication disability associated with a late-identified hearing impairment through FC-EHDI, continues to be a challenge [24, 26, 27]. The original concept of telehealth was providing healthcare to underserved populations [18], such as infants and children with hearing impairment within the South African context. However, more studies are necessary to ensure that telehealth services are comparable to in-person service provision before these services can be implemented as a valid means of service delivery, as proposed by professional bodies in audiology [28]. Thus, the aim of this scoping review was to explore use of videoconferencing as a service delivery method in FC-EHDI programs in South Africa. Review of practices of videoconferencing consultations has implications for FC-EHDI service delivery, policy-making, and supports evidence-based decision making within the South African context.

This paper is part of a larger research project titled *"Family-Centered EHDI: Caregivers' experiences and evaluation of the process and practices in the South African context",* forming part of the first steps in formulating a framework for Family-Centered Early Intervention (FCEI) for children with hearing impairment in South Africa. This paper

was prompted by the researchers' transitioning from in-person interviews to videoconferencing interviews for data collection of the study at the height of the COVID-19 pandemic.

4.3 Methodology

This scoping review adopted Moher et al.'s [29] methodological framework, which comprised of the following stages: (1) identifying the research question; (2) searching for relevant studies; (3) selecting studies; (3) charting the data; and (4) collating, summarizing and reporting the results. Both researchers agreed on the research question; search terms, keywords and phrases; as well as on the relevant databases.

The aim of this scoping review was to explore the review question: "Can videoconferencing be used by audiologists as a service delivery method in FC-EHDI programs in South Africa?"

4.3.1 Data Sources and Search Strategy

A computer-aided search of four online journal databases, chosen on the basis of their content and accessibility to the researchers, was conducted. Electronic bibliographic databases including Sage, Science Direct, PubMed and Google Scholar were searched to identify peer-reviewed publications, published in English between April 2017 and April 2021, focusing on patients and HCPs' perceptions, attitudes, and experience of videoconferencing use in healthcare (Table 4.1). The following keywords were used: remote, videoconferencing, telehealth, telepractice, telemedicine, healthcare, service delivery. Boolean operators "AND" and "OR" were used between the phrases. The Boolean operator "NOT" was not used.

Table 4.1

Inclusion/Exclusion criteria for study inclusion

	Inclusion criteria	**Exclusion criteria**
Language	Publications in English	Publications in any other language besides English
Publications	Peer-reviewed original studies	Systematic review, scoping review, literature review, narrative review, feasibility study, editorial, commentary, letters to the editor, columns, opinions, viewpoints, or similar.
Date	Publications between April 2017 and April 2021	Publications before April 2019 and after April 2021.
Participants	Publications including patients and healthcare professionals	Studies not including patients and healthcare professionals
Context	Publications focusing on videoconferencing use in telehealth	Publications focusing on videoconferencing use outside of healthcare or health services.
Issue	Publications focusing on perceptions, attitudes, and experience of videoconferencing use.	Publications focusing on telehealth, telepractice or telemedicine without a specific focus on videoconferencing use.

A manual search of the reference lists of the articles included in the review was also conducted to identify additional articles. The researchers chose the period April 2017-April 2021 to ensure that current evidence was included when the review was conducted. This period was selected on the basis of evidence that demonstrated a growth in telehealth outpaced that of all other avenues of accessing healthcare from 2016 to 2017; thus, highlighting the need for increased efforts in exploring telehealth technology application in healthcare at this time [30, 31, 32]. Furthermore, a plethora of research on the use of ICT in healthcare was available at the height of the COVID-19 pandemic [33, 34], for inclusion in the scoping review. The time frame may have limited inclusion of seminal work in this field, which may have influenced current findings. Thus, this is acknowledged as a limitation in the interpretation of the findings in the current review. Another limitation of this review is that

since the completion of this scoping review, additional studies have since been published; however, a sample of these newly published studies has also been reviewed and the findings highlighted in this review.

4.3.2 Citation Management

All citations were imported into the web-based bibliographic manager Mendeley.

4.3.3 Eligibility Criteria

Eligibility of published studies was identified using a two-stage screening process; whereby, all the studies that contained the keywords and phrases were initially considered for the review, then studies that did not focus on the use of ICT in healthcare were excluded from the study.

4.3.4 Title and Abstract Relevance Screening

Title and abstract screening were conducted in accordance with Arksey and O'Malley's [35] recommendations to eliminate studies that did not meet the current review's inclusion criteria. The titles of the publications were examined as part of the first level review; then the abstracts were examined during the second level review; and lastly, during the third level review, the entire article was examined.

The first author identified all the articles for review. Both authors reviewed all articles that were included or excluded from the review to ensure the reliability and validity of the process of identifying the relevant articles. A high level of agreement was found on the kappa analysis (>.8). Following the data analysis, two independent reviewers (i.e., another PhD fellow and an academic member of staff in the department), reviewed the manuscript and the data to validate the researchers' conclusions.

4.3.5 Data Characterization

All relevant publications were recorded on a Microsoft Excel 2016 document [36], according to the following categories: author(s), publication year, title, context, study design, participants, and outcomes. Both researchers recorded the characteristics of each study.

4.3.6 Ethical Considerations

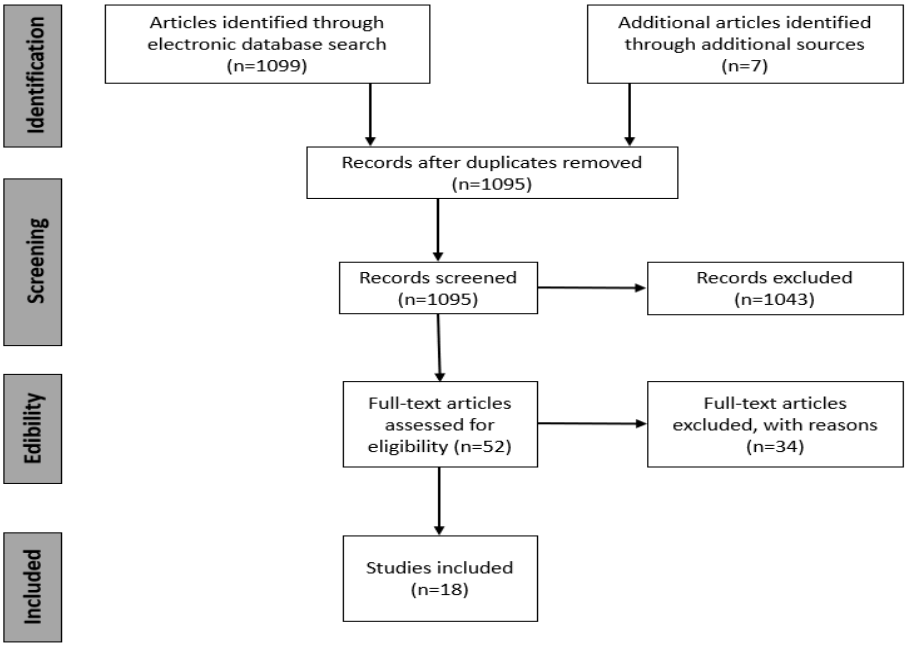
This scoping review adhered to the ethical standards for studies which do not include direct contact with human or animal subjects, including informed subjectivity and reflexivity, purposefully informed selective inclusivity, and audience transparency [37].

4.4 Results and Discussion

In total, 1095 articles that contained the search words were screened (Figure 4.1). Fifty-two of these were based on videoconferencing; whereas 1043 investigated systematic, scoping, narrative, and literature reviews; reviews and/or opinion pieces; history of telehealth and progress made; videoconferencing interviews for university and job interviews; knowledge management in telehealth; distance education support; and future directions of telehealth. Thirty-four of the 52 articles were excluded because they focused on telephone and or text-based communication during healthcare access and were comparing outcomes of in-person versus telehealth service delivery.

Figure 4.1

The PRISMA Flow Diagram Describing the Process of Study Selection



Note. Source: [29]

Eighteen peer-reviewed studies were included in this review (Table 4.2). These included 11 surveys, three ethnographic studies, three exploratory qualitative, and one cross-sectional study. All the articles were published in English. Gray literature was not included in this review. The synthesis included the research focus, context, participants, and outcomes. The studies included in this review were heterogeneous as they included quantitative, qualitative, and mixed-methods studies.

Table 4.2

Studies included in the current review

Author(s) & Year	Title	Context	Study design	Participants	Outcomes
McClellan et al. (2020)	Clinician telehealth attitudes in a rural community mental health center setting	Rural Kentucky	Ethnographic study	Clinical staff (Psychologists, Social Workers, Therapists, Mental Health Treatment Professionals)	**Videoconferencing use:** 56% provided services through telehealth. **Videoconferencing challenges:** establishing therapeutic alliance (39%), equipment-related concerns or technical challenges (15%).
Kraljević et al.'s (2020)	Telepractice as a reaction to the COVID-19 crisis: Insights from Croatian SLP settings	Croatia	Survey	SLPs	**Videoconferencing use:** 71% offered videoconferencing consultations to all their clients; 79% were satisfied, while 17% reported were completely satisfied with the services; 29% chose not to offer the service to some their clients due to the complexity of the client's clinical picture and the client's chronological age. **Videoconferencing challenges:** consultations that require physical examinations (e.g., auscultation) and diagnostics (e.g., imaging, cultures). **Videoconferencing challenges:** only 4.2% received additional education in telepractice via webinars or in-person training before the pandemic.

					Recommendations for videoconferencing: videoconferencing education is ‘absolutely necessary' (69%).
Cole et al.'s (2019)	Report on the use of telehealth in early intervention in Colorado: Strengths and challenges with telehealth as a service delivery method	Colorado, United States	Exploratory	Parents, Early intervention providers, Service Coordinators, Administrators	**Videoconferencing use:** only 25% of the caseload was receiving services via telehealth. **Videoconferencing benefits:** flexibility with scheduling appointments and conducting visits during a family's typical routines; access to families living in rural areas; heightening family engagement and use of coaching practices. **Videoconferencing challenges:** families did not participate due to challenges with the use of technology, limited access to internet connection, privacy and security challenges.
Powell et al.'s (2017)	Patient perceptions of telehealth primary care video visits	Thomas Jefferson University, United States	Survey	Patients	**Videoconferencing use:** 74% used videoconferencing calls for personal use with their smartphones but for chronic disease management, follow-up of a recent acute issue, a new acute issue, or to review lab results. **Videoconferencing challenges:** lag between video and audio, audio

					feedback, blurry images, and challenges with internet connection, privacy and security challenges.
Dean et al.'s (2019)	Improving value and access to speciality medical care for families: A paediatric surgery telehealth program	British Columbia Children's Hospital; Vancouver, Canada	Survey	Paediatric surgeons	**Videoconferencing use:** 84% were experiencing videoconferencing for the first time. 99% would use it again. **Videoconferencing benefits:** reduces stress, travel time, employment and school disruptions. **Recommendation for videoconferencing:** use of a digital whiteboard for illustrations.
Zalewski et al.'s (2021)	Lessons Learned Conducting Dialectical Behaviour Therapy via Telehealth in the Age of COVID-19	Eight countries including the United States, Australia, New Zealand, Canada, Ireland, Israel, Russia and the United Kingdom	Survey	Clinicians with Dialectical Behaviour Therapy training	**Videoconferencing use:** 88% switched from in-person to videoconferencing due to COVID-19; 74% had never used videoconferencing prior to the pandemic. **Videoconferencing benefits:** heightened family engagement, heightened use of coaching practices **Videoconferencing challenges:** limited visual and auditory cues, affects rapport, affects professionals'

					ability to observe the patient's emotions. **Recommendations for videoconferencing: d**iscuss limitations with clients so they express their emotions through words; administrative and technical support; use of a digital whiteboard to enhance patient education.
Imlach et al.'s (2020)	Telehealth consultations in general practice during a pandemic lockdown: Survey and interviews on patient experiences and preferences	New Zealand	Ethnographic study	Patients	**Videoconferencing use:** 5% had used videoconferencing to access general practices during the lockdown; only 17% had experienced videoconferencing prior the lockdown. **Videoconferencing benefits:** ease of having consultations fitted around their day, no hassle of wasting time, consultations were less rushed, more focused and personal, and provided space to talk more freely than usual. **Videoconferencing challenges:** need for a computer education component, need for support and assistance in preparing for video consultations, poor internet access, lack of data, patient and clinician lack of familiarity with online tools, insufficient broadband speeds, unstable internet connection, poor

					image resolution, poorly-angled cameras, poor sound quality, privacy and security challenges, concerns that they could not be physically examined, works well for non-urgent issues that do not require physical examination and complex health challenges **Recommendations for videoconferencing: t**echnological support must be provided in real time; use of 'workarounds' such as patients can send photos or emailing blood pressure readings as an adaptation to the telehealth environment, basic connectivity should be more robust with steady bandwidth.
Wu et al.'s (2020)	Smartphone-enabled, telehealth-based family conferences in palliative care during the COVID-19 pandemic: Pilot observational study	Taiwan	Survey	Patients with cancer, terminally ill or diagnosed with stroke, Family members	**Videoconferencing use:** 90% of the families were using videoconferencing for the first time; 71% were willing to use videoconferencing again for family meetings.
Dahl-Popolizio et al.'s (2020)	Telehealth for the provision of occupational therapy: Reflections on	United States	Exploratory study		**Videoconferencing use:** 70% used Zoom to deliver services, followed by Google meet (24.78%), Instant messaging (20.87%), Face Time

	experiences during the COVID-19 pandemic.			Occupational Therapists	(19.57%), Doxy (15.22%), Microsoft Teams (7.83%), Skype (6.52%) and Theraplatform (6.25%). **Videoconferencing benefits:** enabled access to families living in rural area; saves lives, money and time. **Videoconferencing challenges:** 83% experienced technical challenges such as the audio and/or video not working, computer requiring updates at the time of the session or internet lagging or dropping.
Taylor et al. (2021)	An evaluation of automated, internet-based psychiatric history taking.	Australia	Survey	Health Service Managers, Researchers, Nurses, Doctors, Allied Health Professionals	**Videoconferencing use:** use of videoconferencing to access healthcare became routine during the COVID-19 pandemic. **Videoconferencing challenges:** increased administration time to arrange appointments, and billing compliance. **Recommendations for videoconferencing:** conduct telehealth services in the office where there is better access to materials and privacy; HCPs must sit back so that the client can see gestures; technological support must be provided in real time; implement

					systems that are easy-to-use, private and secure, need for effective scheduling and excellent communication between all parties.
Saunders et al. (2020)	Audiology in the time of COVID-19 practices and opinions of audiologists in the UK.	UK (England, Wales, Scotland, Northern Ireland)	Survey	Audiologists	**Videoconferencing use: o**nly 32.5% used videoconferencing prior to COVID-19. Participants would use videoconferencing after the pandemic. **Videoconferencing benefits:** improve travel (95.0%), convenience (80.4%), improve flexibility (88.0%), scheduling (68.6%). **Videoconferencing challenges:** videoconferencing detrimental interpersonal interactions (58.8%).
Yang et al. (2020)	Family perspectives towards using telehealth in early intervention	Midwestern state, US	Survey	Parents of children who receive early intervention occupational therapy	**Videoconferencing use:** participants prefer in-person visits to videoconferencing, but prefer Videoconferencing over 'nothing'. Videoconferencing to be used as a supplement to in-person consultations i.e., as part of follow-up or to facilitate communication between parents and HCPs.

Cwikel & Friedmann (2020)	E-therapy and social work practice: Benefits, barriers, and training	Israel	Survey	Social Workers	**Videoconferencing use:** 96% had never used videoconferencing. **Videoconferencing challenges**: 96% had not been trained to use videoconferencing as a mode of service delivery. **Recommendations for videoconferencing:** need for quality training by an experienced practitioner, and technical support in real time, need for effective scheduling and excellent communication between all parties.
Kandola et al.'s (2018)	The Participant Recruitment Outcomes (PRO) study: Exploring contemporary perspectives of telehealth trial non-participation through insights from patients, clinicians, study investigators, and study staff.	British Columbia, Canada	Exploratory study	Patients, clinicians, study investigators, and study staff from 2 telehealth-based trials	**Videoconferencing challenges:** need for a computer education component to be provided for telehealth participants, support and assistance in preparing for video consultations, lack of confidence in computer use, and limited internet access.
Isautier et al (2020)	People's experiences and satisfaction with telehealth during the COVID-19 pandemic	Australia	Cross-sectional study	Patients with mental health	**Videoconferencing use:** videoconferencing experience is "just as good as" or "better than" traditional in-person medical visit.

	in Australia: Cross-sectional survey study			conditions and/or chronic health conditions	**Videoconferencing challenges:** participants could not access videoconferencing services because they did not have internet (10.5%), using these services felt too complicated (26.3%).
Myers et al. (2021)	Lessons Learned in Implementing VA Video Connect for Evidence-Based Psychotherapies for Anxiety and Depression in the Veterans Healthcare Administration.	United States	Ethnographic study	Mental Health Providers (Psychologists & Social Workers)	**Videoconferencing challenges:** 6% of videoconferencing sessions were flagged as having technical issues such as signal issues, internet being 'down' and user error, driving during the session.
Chrapah et al. (2021)	Patient and Provider Satisfaction with Paediatric Urology Telemedicine Clinic	Mid-western part of the United States	Survey	Paediatric Urologist, Dermatologist, Nurse	**Videoconferencing benefits:** access to expertise that save lives, saves money and traveling time. **Recommendations for videoconferencing:** need for operational support, need for effective scheduling and excellent communication between all parties,
Wallisch et al. (2019)	Parent perspectives of an occupational therapy telehealth intervention	United States	Survey	Occupational Therapists	**Videoconferencing benefits:** reduced stress, travel time, employment and school disruptions, heightened family engagement and use of coaching practices, was

					compatible with daily life and family structure.
Sample of studies conducted after current review					
Author(s) & Year	**Title**	**Context**	**Study design**	**Participants**	**Outcomes**
Cangi et al. (2021)	Preferences of Speech Language Therapists for telepractice in the COVID-19 pandemic and factors affecting their acceptance of the delivery model	Turkey	Survey	SLPs	**Videoconferencing use:** 49% had never had telepractice before COVID-19 **Videoconferencing challenges:** internet disconnections (67%), sound problems (52%), visual problems (63%), software-related problems (17%), computer-related problems (20%).
Wittmar et al. (2023)	Out-patient videoconferencing speech and language therapy via videoconferencing in Germany during the COVID-19 pandemic: Experiences of therapists	Germany	Cross-sectional survey	SLPs	**Videoconferencing use:** 87% used videoconferencing during the pandemic **Videoconferencing benefits:** expansion of therapy services (73%), no travel to see patients (62%), increased motivation for intervention (10%), prefer combination of telehealth and in-person consultations **Videoconferencing challenges:** not suitable for all conditions [dysphagia, speech disorders, high degree of hearing loss, damage to head and

					neck section], technical problems (52%), communication difficulties (30%). **Recommendations for videoconferencing:** Combination of telehealth and in-person consultation.
Cottrell et al. (2021)	Sustaining allied health telehealth services beyond the rapid response to COVID-19: Learning from patient and staff experiences at a large quaternary hospital	Brisbane, Australia	Sequential explanatory mixed methods	Patients, Allied Health Professionals (Nutrition & Dietetics, Occupational Therapists, Physiotherapists, Psychologists, Social Workers, SPLs, Administration staff)	**Videoconferencing use:** useful and effective. Participants prefer a blended model of telehealth and in-patient consultations. **Videoconferencing benefits:** time and cost saving. **Videoconferencing challenges:** not suitable for all allied health conditions, especially those that require physical examination; quality of internet connection; access to technical support, lack of confidence in trouble-shooting technical difficulties; suitability of patient's physical environment during telehealth consultations. **Recommendations for videoconferencing: p**articipants prefer a blended model of telehealth and in-person consultations.
Elbeltagy et al. (2022)	Teleaudiology practice in COVID-19	Egypt,	Cross-sectional survey	Audiologists	**Videoconferencing use:** practical approach during COVID-19 (42.8%).

	pandemic in Egypt and Saudi Arabia	Saudi Arabia			Only 25.4% used teleaudiology, with 40% using videoconferencing. **Videoconferencing benefits:** saves time (46.4%), saves effort (42.8%) **Videoconferencing challenges:** inability to provide full range of services (80.4%), patient's inability to use electronic communication (51.8%).
Campbell & Goldstein (2022)	Evolution of telehealth technology, evaluations, and therapy: Effects of the COVID-19 pandemic on paediatric Speech-Language Pathology services	38 US states, the District of Columbia, and Outside US	Survey	SLPs	**Videoconferencing benefits:** family involvement, convenience, scheduling flexibility **Videoconferencing challenges:** families' lack of comfort with videoconferencing (61%), internet connectivity (58%), difficult to assess some conditions [i.e., swallowing/feeding (74.6%), speech sound production (63.5%), augmentative and alternative communication (62.3%), hearing (60.6%), social aspects of communication (58.7%)]; access to services, lack of connectivity, appropriate environment to receive intervention, unsuitable substitute for in-patient care.
Almog & Gilboa (2022)	Remote delivery of service: A survey of	Israel	Survey	Occupational Therapists	**Videoconferencing benefits:** save time, money, access to patients who

	Occupational Therapists' perceptions				can't leave home, intervention is possible in times of emergency **Videoconferencing challenges:** inadequate home environment infrastructure, limited use of hands-on techniques, dependence on primary caregiver, inadequate for some populations. **Recommendations for videoconferencing:** ideal model is a combination of both telehealth and in-person consultations.

Findings of the current review revealed that although the concept of telehealth has existed since the early twentieth century and its benefits are widely reported, the overall uptake of telehealth outside emergency situations such as the COVID-19 pandemic was slow and fragmented [38, 39, 40]. This finding is not surprising as telehealth is viewed as a complex enterprise that raises multiple questions and challenges of multilevel sociopolitical, economical, organizational, professional, legal, technological and strategic factors [12, 41], with limited inclusion of this service delivery modality in curricula [3]. These elements are underscored in the five key themes that emerged from the current data synthesis namely; videoconferencing use, need for videoconferencing training, videoconferencing benefits, videoconferencing challenges, and recommendations for successful videoconferencing. Although conducted mostly in high-income countries (HICs) that vary from the South African context with regards to populations, resources, and health priorities, the studies included in the current review provide much needed direction for implementing videoconferencing FC-EHDI services within the South African context where there is limited research focus in this area. The articles will be reported and discussed under each of these identified themes.

4.4.1 Videoconferencing Use

Considering the COVID-19 pandemic, the landscape of telehealth markedly evolved, resulting in telehealth services being widely implemented within healthcare services to bridge the barriers that prevented people from accessing healthcare services in person [11, 16, 38]. This mode of service delivery has several key strengths that can enhance remote emergency response, assist with disease diagnosis, and provide ongoing healthcare delivery [38, 39].

In the current study, publications that focused on the use of videoconferencing in healthcare aimed to investigate attitudes, perceptions, experiences, and application of

telehealth, in various contexts. McClellan [42] examined rural clinical mental health staff members' attitudes towards telehealth in Kentucky, United States. Results of the study revealed that 56% of mental health staff members were providing services through videoconferencing. In Kraljevic et al.'s [43] study, which examined Speech-Language Pathologists' (SLP) perceptions and their application of telehealth in Croatia during the COVID-19 pandemic, 71% of the participants reported that they offered videoconferencing consultations to all their clients. Of these participants, 79% reported that they were satisfied, while 17% reported that they were completely satisfied with the services.

However, in Cole et al.'s [44] study, which aimed to understand perceptions of, and actual experiences with telehealth among caregivers and early intervention HCPs in Colorado, United States; participants reported that only 25% of the children on their caseload were receiving services via telehealth. Furthermore, in Powel et al.'s [45] study which described patient experiences with videoconferencing visits with their primary care physicians; 74% of the participants reported that they had used video calls on their smartphones for personal use, but not for accessing healthcare services.

Similarly, Dean et al.'s [46] study evaluated the paediatric surgical telehealth pilot program implemented in Canada from the family and HCPs' perspective. Eighty-four percent of the participants revealed that they were experiencing telehealth for the first time, and 99% of these participants further reported that they would use telehealth again. Furthermore, in Zalewski et al.'s [47] study, where they describe the challenges and lessons learned while applying dialectical behaviour therapy via telehealth across eight countries; results revealed that 88% of the participants had switched from in-person to telehealth using videoconferencing due to COVID-19; despite 74% of the participants never having used this platform prior to the pandemic.

In Imlach et al.'s [48] study, 5% of the participants reported that they had used videoconferencing to access general practices in New Zealand during the COVID-19 lockdown, while only 17% had experienced this modality prior the lockdown. Furthermore, in Wu et al.'s [49] study that established a smartphone-enabled telehealth model for palliative care family conferences; 90% of the families reported that they were using videoconferencing for the first time; and 71% of those families were willing to use videoconferencing again. Moreover, in Dahl-Popolizio et al.'s [50] study which explored how Occupational Therapists used telehealth during the COVID-19 pandemic; 77% of the participants supported telehealth as a substitute for in-person services, while 78% supported telehealth as a permanent option for service delivery. Encouragingly, in Taylor et al.'s [51] study which identified changes in telehealth use and the mechanisms that contributed to the changes, participants reported a 60% increase in video consultation use during the COVID-19 pandemic.

Similarly, in Saunders et al.'s [52] study which assessed Audiologists' opinions about teleaudiology, only 32.5% of the participants had used videoconferencing prior to COVID-19, nevertheless they reported that they would use it after the pandemic. However, in Yang et al.'s [53] study, which explored perspectives of families of children with disabilities, receiving occupational therapy services, regarding the use of telehealth in early intervention; participants reported that they preferred in-person visits, with the use of telehealth as a supplement to in-person consultations. Participants indicated a preference for use of telehealth as part of follow-up or to facilitate communication between caregivers and HCPs. Nevertheless, participants reported that they preferred telehealth over 'nothing' or 'no early intervention' services.

Similar findings of videoconferencing use from studies published since the completion of this review are reported; including limited use of videoconferencing prior to the COVID-19 pandemic, increased use of this service delivery mode during the pandemic

[54, 55], telehealth being viewed as an effective service delivery mode [56, 57], and participants' satisfaction with using videoconferencing during consultations [56].

With the advent of enhanced ICT and the COVID-19 pandemic, many services evolved to virtual service delivery, including in healthcare where adoption of technology-infused service delivery is increasingly prevalent [58, 59]. Telehealth has expanded to include all aspects of healthcare such as primary care, specialty medical care, and mental/behavioural health [58, 60], as evidenced by current findings. Thus, enabling patients living in remote areas to receive the same services as those who live in metropolitan centres with easy access to high quality healthcare [61]. These findings offer significant insights for videoconferencing FC-EHDI within the South African context. Through the inclusion of remote service delivery, audiologists can increase access to healthcare and support services for the child with hearing impairment and their families; for effective management of the child's daily hearing needs, ultimately increasing the family's engagement and overall satisfaction with EHDI services [60].

Videoconferencing would enable the audiologist to provide intervention to families in the comfort of their homes [62]; which has been shown to improve child development and is argued to be the best contextually-responsive approach for the African context [27, 62, 63]. Furthermore, these videoconferencing home visits may increase the family's sense of control and comfort; thus, allowing them to get the most benefit from the service. Furthermore, these home visits would allow HCPs to tailor their approach to service delivery, and increase caregiver participation [63, 64]. Without telehealth, home visits have been deemed to not be feasible within the South African context due a low per capita health budget and a shortage of professionals [65, 66, 67]. However, South Africa's contextual realities including a lack of resources, finances, poor infrastructure and technology necessitate careful consideration of parents, families and HCPs' attitudes and perceptions of telehealth and its application.

4.4.2 Need for Videoconferencing Training

In addition to being beneficial, telehealth is also viewed as disruptive, complex and requiring HCPs to learn new methods of consulting [38]. HCPs may not be knowledgeable and aware of telehealth, given the limited telehealth training that is offered in the curricula for medical and allied health professionals [3, 38]. Thus, it is imperative that educational programs for HCPs also focus on the understanding of telehealth and its applications to ensure that the healthcare workforce is telehealth-ready [3, 39, 68].

Cwikel and Friedmann [69] explored Social Workers' perceptions of the integration of e-therapy in social work practice in Israel. Results of their study revealed that 96% of the participants had never used e-therapy and had not been trained to use it as a mode of service delivery. In Kraljevic et al.'s [43] study, only 4.2% of the SLPs reported receiving education in telepractice via webinars or in-person training before the COVID-19 pandemic. Sixty-nine percent of these participants further reported that telehealth education was "absolutely necessary" for HCPs. Similarly, in Kandola et al.'s [70] and Imlach et al.'s [48] studies, participants reported a need for a computer education component to be provided for telehealth participants, in addition to some level of support and assistance in preparing for video consultations.

Embracing telehealth technology into all aspects of healthcare has created a growing role for HCPs to integrate and use telehealth technologies in practice. However, current findings reveal that there is a gap in the knowledge and training of HCPs for telehealth practice [68, 71]. According to Smith et al. [39], regular telehealth practice leads to more sustainable models of care and a telehealth-ready workforce. Thus, to ensure a telehealth-ready healthcare workforce, telehealth training and education should be included in the curriculum and post-graduate telehealth accreditation should be mandated [39, 71]. This

would send a clear message to current and future HCPs that telehealth is a legitimate part of usual and standard care. As well as increase telehealth use in everyday practice [3, 39].

Various suggestions exist regarding the knowledge and skills required to provide telehealth; however, a clear approach to educate HCPs is not yet mandated [3, 68, 71]. A multimodal telehealth education program is recommended in order to ensure didactic education and simulation experiences [71]. Khoza-Shangase et al. [3] argue for training programs to adopt a hybrid training model that includes telehealth as part of training and clinical service provision. This hybrid training model will provide a well-rounded educational experience that aligns with professional competencies for telehealth practice [68, 71]. Furthermore, ethical principles of patient care in telehealth must also be included as part of telehealth education [71]. For FC-EHDI videoconferencing services to be implemented in South Africa, due consideration of the content, format and timing of HCPs telehealth education is required; while being cognizant of the potential uses of videoconferencing in FC-EHDI, including screening, diagnostic testing, and FCEI [72].

4.4.3 Videoconferencing Benefits

The benefits of telehealth are widely recognized [16, 58]. Telehealth has been heralded for its potential to increase healthcare access and improve the efficiency of healthcare delivery [3,12, 73]. Perceived benefits that were reported by HCPs and patients in the current review include telehealth experiences being “just as good as” or “better than” traditional in-person medical visit experiences [74]; having access to expertise saves lives, money and time [48, 50, 75]; reducing stress, travel time, employment and school disruptions [46, 48, 52, 76]; ease of having consultations fitted around their day without the hassle of waiting time [48, 52]; telehealth consultations were less rushed, more focused and personal, and provided space to talk more freely than usual [48]; increased consultation volumes [51];

flexibility with scheduling appointments and conducting visits during a family's typical routines, such as dinnertime [44, 52]; access to families living in rural areas [44, 50, 53]; heightening family engagement and use of coaching practices [44, 47, 76]; facilitate parent training [53]; as well as compatibility with daily life and family structure [76].

Current findings are consistent with available literature on telehealth [60, 68, 77]; as well as studies published after the current review [56, 57, 78, 79]. There have been dramatic changes in healthcare in recent years, as evidenced by shortages of HCPs, mandates to decrease costs, and advances in technology, which necessitate adoption of telehealth as a mode of service delivery. Telehealth technologies present new and unique opportunities to increase patient access to healthcare, decreasing costs, and improve desired healthcare outcomes [68]. In audiology, especially within the South African context, telehealth seeks to provide an array of hearing care services to those who need them due to having to travel long distances to access services, and limited access to or lack of resources [3, 28, 72, 73]; thus, allowing remote and rural populations the same access to resources as is available to the patient in urban areas without the need to travel [80]. However, given South Africa's contextual challenges, the need for financial and resource allocation for telehealth within existing healthcare infrastructures and models; and due consideration of how best to implement effective FC-EHDI services through telehealth technology is warranted [3, 73]. Lack of such consideration will restrain South Africa from gaining benefits of telehealth including increased accessibility; cost-effective service delivery; enhanced family engagement; multidisciplinary collaboration; cultural and linguistic considerations; as well as opportunities to use this mode of service delivery for training and professional development.

4.4.4 Videoconferencing Challenges

The COVID-19 pandemic amplified the need for contact-free encounters, becoming a catalyst for the growth of these services [81, 82], that ensure patient and clinician health and safety, as well as uninterrupted service delivery [3]. Consequently, this mode of healthcare service delivery is receiving extensive research focus, including the challenges associated with its application [83]. Articles in this review, also investigated the challenges of videoconferencing use. The following challenges were identified: limited access to internet connection [44, 45, 48, 53, 70, 74, 84]; patient and HCPs' lack of familiarity with online tools [48, 70]; videoconferencing is detrimental to establishing rapport [52]; equipment-related or technical challenges [42, 44, 48, 50, 70, 84]; limited visual and auditory cues [42, 47]; lack of physical examinations [43, 48, 53]; privacy and security concerns [45,48]; lack of confidence in telehealth meeting family's needs [52]; and increased administration time for arranging appointments while ensuring that billing is compliant [51]. Similar challenges are reported in studies conducted by Cangi et al. [54], Wittmar et al. [55], Cottrell et al. [56], Elbeltagy et al [57], Campbell et al. [78], and Almog and Gilboa [79], which did not form part of this review as they were published outside of the review's stipulated period. Additional challenges reported in these studies include lack of an appropriate home environment for telehealth [55, 78, 79]; videoconferencing is an unsuitable substitution for in-person care for some populations and/or health conditions (including hearing impairment) [54, 55, 56, 78, 79]; dependence on the primary caregiver [79]; high preparation time [55]; and inability to provide the full range of services [55, 57].

In many countries, South Africa included, the quality of healthcare that is available to populations in rural contexts is lower than the quality of healthcare that is available in urban contexts [85]. The difference in the quality of healthcare between these two contexts is due to factors such as a lack of public transport to some healthcare facilities, and a lack of services

in rural contexts. Although this problem is a worldwide phenomenon, it is particularly acute in low-and-middle income countries such as South Africa [85]. South Africa has a poorly functioning health system, where systemic failures in the public sector persist. The public sector provides healthcare to 85% of the population ,while the private sector only provides healthcare to 15% of the population [83];consequently, the country is characterized by poor health outcomes [83]. Telehealth is recognized as the most cost-effective solution to South Africa's poor health outcomes and the difference in the quality of healthcare between rural and urban contexts [3, 80].

However, findings of the current review reveal that the notion that telehealth will allow the rural population the same healthcare access as the urban population is an exception rather than the norm [58, 80]. Thirty-three percent of the population in rural contexts in America reportedly lack the broadband internet access required for videoconferencing [38]. Furthermore, a report by the World Bank has shown that household internet access disaggregated by rural/urban location, with internet access rates being low for rural and poorer households in sub-Saharan Africa [85]. Thus, to implement FC-EHDI, issues of internet use as well as access require due consideration, especially within the rural context which is supposed to gain the most benefit from such remotely provided services.

Furthermore, patients' lack of digital health literacy, or the ability to access and evaluate health information using digital tools needs to be addressed, especially within the South African context. South Africa has low literacy levels with only 28% of a group of 20-to 24-year-olds having a grade 12 qualification [86]. In addition to low literacy levels, digital health literacy has been shown to be non-existent or rudimentary for patients, thus reducing attendance of telehealth visits; despite 50% of these patients owning a phone that can connect to the internet [87, 88]. Constantino et al. [88], maintains that the additive impact of health and digital health literacy barriers creates a seemingly insurmountable roadblock for already

vulnerable populations. Furthermore, the lack of information in the patient's language, and HCPs' lack of expertise in ICT have made it difficult to adopt telehealth [38, 80]. Although, English is the prominent language in South Africa, only 10% of the South African population uses English as their home language [89]. This has resulted in 11 million South Africans not receiving healthcare services in their home language, which results in poorer health outcomes [90]. Thus, these aspects require due consideration within the linguistically, culturally, and socioeconomically diverse South African context.

Humans rely on numerous social cues during their interactions with others [91]. These social cues include body language; facial expression; slight shifts in posture; variations of vocal pace, tone and loudness; use of gestures; modifying the physical distance; and initiating or withdrawing from conversations [83, 91]. However, with traditional videoconferencing approaches, there are substantial limits that affect the fluidity of these social experiences [91]. Thus, these social cues must be modified accordingly through making eye contact, i.e., the HCP looks at the camera and not the client's face on the screen; limiting facing down when taking notes, as this may appear as disinterest or distraction; conveying empathy through careful selection of the words used; leaning into the camera; and head nodding to encourage the client [68].

Another significant limitation of telehealth is the lack of a comprehensive physical examination [12]. According to Chowdhury et al. [92], some aspects of a physical examination are simply not feasible via telehealth. Thus, the true effectiveness of a telehealth physical examination, its impact on diagnosis, and healthcare outcomes is yet to be determined across various settings [12], health conditions, client populations, and across disciplines including audiology. Furthermore, clinician training must highlight the limitations associated with telehealth and inform on alternative methods that can be used in these situations [39].

In addition to the above-mentioned challenges associated with videoconferencing, patients' privacy and security concerns are not surprising due to frequent health data breaches and cyber-attacks [93]. Watzlaf et al. [94] reported that laptops, network servers, desktop computers, and other portable electronic devices constituted 51% of all healthcare data breaches between 2010 and 2015. As telehealth utilization increases in healthcare, it is imperative that HCPs and policy makers ensure that privacy policies are in place and easy-to-understand [38]. Furthermore, HCPs need to be familiar with the security features of their telehealth systems so that they can be able to mitigate security risks and protect their patient base [38, 93], while maintaining their confidentiality [72].

Both HCPs and patients should trust that the transmission of information during telehealth encounters remains private and secure [58]. Findings from the current review have significant implications for FC-EHDI videoconferencing consultations within the South African context, given the low digital literacy levels. Audiologists have an ethical and legal duty to protect their client's privacy and increasing data security while receiving, storing, and transferring data. If clients do not trust the telehealth platform, they will be reluctant to provide audiologists with the necessary information for efficient assessment, differential diagnosis and effective management [86]; and this will in turn negatively impact program outcomes and efficacy of telehealth services.

Lastly, administrative and clinical complexities are inherent with such an ambitious initiative as telehealth [95]. Hence, these authors recommended establishing an easy scheduling procedure to deliver more streamlined workflow. Thus, appropriate scheduling and administration aspects should be considered prior to implementation of videoconferencing consultations in any context. Furthermore, appropriate renumeration is needed for all telehealth services [39]. Payment rates should reflect the cost of the service without incentivizing the use of one service delivery mode over another. Thus, there is a

significant need of regulatory visibility governing payment parity across in-person and videoconferencing consultations [96]. It is essential that HCPs are educated about how the cost of telehealth is regulated, with clear regulations around billing for such services [68].

Prior to the COVID-19 pandemic, professional bodies had recommended the use of telehealth in various contexts; however, payment parity was not stipulated [96]. This all changed within the last year of the COVID-19 pandemic, when newer legislation supporting seamless integration of overcoming barriers surrounding the compensation structure were implemented across the US [38]. However, there is currently a lack of a position statement which offers a directive for audiologist in navigating through telehealth – including billing, within the South African context. The Health Professions Council of South Africa (HPCSA), which is the statutory body for HCPs, including audiologists, endorses advances in tele-audiology; however, there is a lack of practical support for post-COVID-19 use of telehealth and the conditions that are required to be met in order for appropriate reimbursement to be implemented [14]; hence the importance of the current findings on implementing effective FC-EHDI within this context.

4.4.5 Recommendations for Successful Videoconferencing

Telehealth offers a unique alternative to improve access, quality, continuity, and integration of health services for the benefit of the population [12, 41]. Thus, there is a need for HCPs to champion the use of telehealth in healthcare service delivery [20, 68]. For HCPs to address future healthcare needs, it is imperative that HCPs are knowledgeable about telehealth technologies and their application [3, 68].

Dean et al. [46], Zalewski et al. [47], Imlach et al. [48], Taylor et al. [51], Cwikel and Friedmann [69], and Chrapah et al. [75] provided the following recommendations for successful telehealth services: conduct telehealth services in the office where there is better

access to materials and privacy; discuss limitations with clients that they must express their emotions through words; HCPs must sit back so that the client can see gestures; technological support must be provided in real time; implement systems that are easy-to-use, private and secure; administrative and technical support; use of 'workarounds' such as patients can send photos or emailing blood pressure readings as an adaptation to the telehealth environment; use of a digital whiteboard to enhance patient education; need for effective scheduling and excellent communication between all parties; and basic connectivity should be more robust with steady bandwidth.

Similar recommendations for successful videoconferencing are reported by Smith et al. [39] and Constantino et al. [88]; including the establishment of telehealth policies; education and training for HCPs; and introduction of telehealth accreditation for HCPs. Furthermore, Smith et al. [39], Constantino et al. [88] and Reeves et al. [12] provided the following additional recommendations: supporting all stakeholders with an effective communication and change management strategy; establishing systems to manage telehealth services on a routine basis; provision of different modalities of telehealth (i.e. intermittent audio-only, video-enabled or in-person visits); provision of easily accessible, understandable educational materials in multiple languages on the use of videoconferencing; and provision of the services of a dedicated healthcare navigator to further assist with onboarding and boost digital health literacy where telehealth services are implemented. Moreover, Wittmar et al. [55], Cottrell et al. [56], and Almog and Gilboa [79] recommend a blended model of telehealth and in-person consultations as a mode of service delivery in order for patients to get optimal healthcare outcomes.

The recommendations provided in this review offer significant insight for successful videoconferencing, thus contribute towards increasing telehealth acceptance and use amongst HCP and families. According to Gajawarala et al. [58] and Khoza-Shangase et al. [97],

telehealth acceptance will likely increase as patients and HCPs become more adept at and comfortable with using telehealth instead of in-person interactions. However, a hybrid approach to service delivery in FC-EHDI within the South African context may be ideal when this telehealth is initially implemented in order to facilitate acceptance and uptake of telehealth as an independent, alternative service delivery mode. Given the limited telehealth training that HCPs have received, and use of telehealth within the South African context, the recommendations from the current review provide valuable insights. Thus, the findings in this review are significant for the implementation of effective FC-EHDI programs within the South African context; which will enable FC-EHDI professionals to improve healthcare access and outcomes to a heterogeneous population across diverse settings within the South African context.

4.5 Conclusion

In-person interviews are the gold standard for collecting rich data in qualitative research and relevant case history information in healthcare. However, the COVID-19 pandemic provided an incentive for a viable alternative to in-person interviews to curb the spread of the virus and subsequently highlighted the telehealth's immense capabilities to respond to global emergencies and increase access to healthcare services during the COVID-19 pandemic and beyond, especially within resource-constrained contexts such as South African.

Videoconferencing is crucial in providing telehealth services to vulnerable and underserved populations who stand to benefit the most. The flexibility and convenience; access to global talent pool; efficient screening process; enhanced collaboration; reduced environmental impact; cost savings; accessibility and inclusivity; as well as better work-life balance that videoconferencing provides needs embracing. However, telehealth is a complex

enterprise that raises multiple questions and challenges. Despite these challenges, evidence in support of the positive effects of telehealth through innovative use of ICT is mounting. Thus, to improve access to EHDI services and effective FC-EHDI programs to be implemented within the South African context, the necessary technological infrastructure, knowledge of digital technology applications, as well as a national policy and legal framework for telehealth are required with due cognizance of the socio-economic and political realities within the South African context. However, while telehealth in the form of videoconferencing can enhance accessibility and efficiency in FC-EHDI services, it should be considered as a complement to traditional in-person services rather than a complete replacement. A hybrid model that combines both approaches can provide the best of both worlds, ensuring that families receive comprehensive and person-centered care while taking advantage of the benefits offered by videoconferencing technologies.

Chapter 5 reports the findings of objectives 1 and 3 of this study. In this chapter, caregivers' expectations of EHDI services and their evaluation if the success and/or failure of these services in relation to their expectations is presented. The specific study design, participant recruitment strategy, data collection and analysis methods, as well as rigour are presented.

Chapter 5

EHDI Services Should Be Accessible! Caregivers' Expectations of EHDI Services in South Africa

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5.1 Abstract

Progress of Early Hearing Detection and Intervention (EHDI) services within the South African context lags behind that made by high-income countries internationally. Implementation of EHDI services in this context faces many challenges that underscore the need to ensure contextualised intervention approaches that meet the needs of South Africa's linguistically and culturally diverse population. The aim of the current study was to describe caregivers' expectations of EHDI services, and to evaluate the success and/or failure of the EHDI services in relation to these expectations. To achieve this aim, in-person, telephonic and videoconferencing narrative interviews were conducted with nine caregivers of children who are Deaf-or-Hard-of-Hearing (DHH), and analysed through reflexive thematic analysis. The following themes and sub-themes emerged from the narrative interviews: 1) expectations of the EHDI process ('early detection of hearing loss and 'EHDI should be accessible'), and 2) expectations for the outcomes of EHDI services ('age-appropriate acquisition of spoken language', 'mainstream education', and 'further education and independence'). These themes speak to concerns with the entire EHDI process from detection to intervention, including continuity of care. In order to ensure effective and sustainable EHDI services within the South African context; caregivers' expectations should be used to inform service provision and to guide best practice. Furthermore, these findings suggest a need to implement wide spread, integrated, and inter-disciplinary EHDI services that are linguistically and culturally

responsive and relevant; with caregivers and families forming a crucial part of the programs.

Keywords: caregiver, DHH, early intervention, EHDI, FCEI, hearing loss

5.2 Introduction

Children progress through multiple stages of speech and language development during their first year, from perceiving and vocalising speech sounds to producing the first word at 12 months of age (Gmmash & Faquih, 2022). However, for a child who is Deaf or Hard-of-Hearing (DHH) that is not always the case. The hearing loss results in incomplete access to spoken language, leading to negative effects on the understanding and development of spoken language (Wang & Engler, 2011; Maluleke et al., 2019a). Over the last decade, high-income countries (HICs) have demonstrated that through Early Hearing Detection and Intervention (EHDI) programs which include benchmark indicators of screening hearing before one month of age, diagnosing the hearing loss before three months of age, and enrolment in early intervention (EI) service before six months of age; children who are DHH can develop optimal spoken language abilities, thus minimising or reversing the negative effects of an unidentified hearing loss (DesJardin et al., 2014, Fulcher et al., 2012; JCIH, 2007; Moeller & Tomblin, 2015; Umat et al., 2018). Furthermore, great strides in hearing technologies have contributed towards language development trajectories that would have been unattainable in previous eras for these children (Szarkowski et al., 2020).

However, despite being classified as an upper-middle income country within the low-and-middle income country (LMIC) category, South Africa lags far behind HICs in terms of progress made in EHDI programs (Mustapha, 2023; Naidoo & Khan, 2022; World Bank, 2021). Universal implementation of EHDI and adherence to the Health Professions Council of South Africa's (HPCSA) (2018) guidelines of screening hearing no later than six weeks, diagnosing the hearing loss before four months and enrolment in EI services no longer than eight months of age; are not yet a lived reality in this context (Kanji & Opperman, 2015; Khoza-Shangase, 2019). This is due to documented challenges, including differences between the public and private healthcare sectors, inadequate human resources, lack of

political will, poor social determinants of health, high burden of disease, and lack of resource allocation for successful and national implementation of universal newborn hearing screening (UNHS) (Kanji & Khoza-Shangase, 2016; Khoza-Shangase & Kanji, 2021). These challenges are not unique to the South African context or to childhood hearing loss, and have been identified in various other LMICs and across numerous diseases and illnesses (Weiss & Pollack, 2017).

In EHDI, the challenges described above underscore the need to ensure that context-specific studies are conducted to guide best practice that is relevant to South Africa's contextual realities (Khoza-Shangase, 2021; Khoza-Shangase et al., 2017; Kanji & Khoza-Shangase, 2021). Contextualised intervention approaches would also facilitate family-centred early intervention (FCEI), which aligns with HPCSA's EHDI guidelines (HPCSA, 2018; Khoza-Shangase & Kanji, 2021; Maluleke et al., 2021a). FCEI is a family-professional partnership that places the needs of the child in the context of their family to optimise the child's developmental outcomes (Iversen et al., 2003; Maluleke et al., 2021a; McKean & Thurston, 2005). This approach recognises the role families and caregivers play in the implementation, integration and carry-over of care (Khoza-Shangase, 2022; Maluleke et al., 2021a; Moeller et al., 2013). Furthermore, FCEI recognises caregivers as important co-drivers of any intervention program, facilitates active caregiver engagement and involvement, and promotes self-efficacy in caregivers. Active caregiver engagement and involvement are essential in EI and result in higher rates of follow-through, greater participation in and adherence to EHDI, improved outcomes for children with hearing loss, and mitigation of the inequities associated with access to healthcare (HPCSA, 2018; Khoza-Shangase, 2022; Moeller et al., 2013; Yoshinaga-Itano, 2014).

It is through the family that children are born, socialised and cared for until they become independent (Department of Social Development, 2013). Caregivers and families

thus provide the most effective and economical system for fostering and sustaining the child's development (Bronfenbrenner, 1994; Maluleke et al., 2021a; Mantri Langeveldt et al., 2019). Caregivers and families also provide a linguistic and cultural environment in which children can develop (Balton et al., 2019; Schlebusch et al., 2016). Hence, provision of EHDI services in the family's home language would mitigate the language barriers experienced by caregivers when accessing EHDI services (Khoza-Shangase, 2019). Furthermore, linguistically and culturally congruent EHDI services would ensure that the child who is DHH is not distanced linguistically and culturally from the rest of their family or community (HPCSA, 2018; Khoza-Shangase & Mophosho, 2018).

South Africa is characterised by a linguistically and culturally diverse population (Statistics South Africa, 2016). However, EHDI services are offered predominantly in English, owing to a largely white, female, English- or Afrikaans-speaking staff complement (Khoza-Shangase, 2019; Pillay et al., 2020). This staff complement does not represent the linguistic and cultural diversity of the South African population (Pascoe & Norman, 2011). Global evidence on health indicators reveals that patients who do not belong to the dominant language and cultural group experience poorer health outcomes than patients who do (Flood & Rohlof, 2018; Steinberg et al., 2016). South Africa is no exception (Mtimkulu et al., 2023). Although English is spoken at home by only 10% of the population (Statistics South Africa, 2016), it is the dominant language in the country and is viewed as a language of power and prestige (Pascoe et al., 2018). As a result, 11 million South Africans do not access healthcare services in their home language (Statistics South Africa, 2016, Mophosho, 2018). This situation does not reflect the needs of South Africa, and the implementation of EHDI is thus not responsive or receptive to the needs of the population in this context.

In recent years, literature has demonstrated that for EHDI services to be effective, it is not enough to consider the availability, quality and equity of care provided, it is also

necessary to consider the adoption of the FCEI approach (Deng et al., 2018; Khoza-Shangase, 2019, 2022). Although there is an increasing awareness of caregivers' role in EI, limited attention is given to their opinions, their views, and their role in the EHDI process, by both the clinical and the research communities (Khoza-Shangase, 2019). Caregivers are the individuals within the child's family who play the most significant role in day-to-day child rearing and caregiving (Maluleke et al., 2021b; Masuku & Khoza-Shangase, 2018). Hence, understanding their expectations and providing EI that aligns with those expectations might ultimately contribute to positive patient outcomes (Gillian et al., 2013; Fitzpatrick et al., 2007; Fitzpatrick et al., 2016). The current study therefore aimed to describe caregivers' expectations of the EHDI process from detection to intervention, and to evaluate the success and/or failure of the EHDI process in relation to caregivers' expectations.

This paper forms part of a larger research project entitled "Family-Centred EHDI: Caregivers' experiences and evaluation of the process and practices in the South African context", describing the first steps in formulating a framework for FC-EHDI for children with hearing loss within the South African context.

5.3 Materials and Methods

5.3.1 Ethical Approval

Prior to the commencement of this study, ethical clearance was obtained from the university's Human Research Ethics Committee (Medical) (Protocol Number: H19/06/16). The work also adhered to the Helsinki Declaration of 1975, as revised in 2013 (World Medical Association, 2013).

5.3.2 Study Design

Results in the current paper are based on the narrative interviews that were conducted as part of the mixed methods convergent design employed in phase 1 of the main study.

5.3.3 Participants

In order to gain access to the participants, the first author obtained written permission from two EI preschool centres for children with developmental delay and disabilities, including hearing loss. The written permission allowed the first author access to the preschool records in order to identify potential participants for the current study. Subsequently, posters outlining the study, the recruitment strategy, participant inclusion and exclusion criteria, and data collection methods were placed in the reception area of each EI preschool centre.

The EI preschool centres also distributed flyers detailing the study to caregivers of former learners. Once a caregiver had indicated interest in being recruited to participate in the study, the first author was granted access to their child's preschool file.

A small number of participants is recommended for narrative interviews in order to ensure that the researchers obtain in-depth information about the research question, which is not achievable with a large sample size (Creswell & Plano Clark, 2018). Participants were recruited telephonically to participate in the study using non-probability sampling until data saturation was reached. Nine caregivers of children who are DHH participated in the current study. Caregivers met the following inclusion criteria:

- Caregiver of a child with hearing loss.
- Caregiver of a child diagnosed with a mild to profound, bilateral, or unilateral hearing loss.
- Caregiver of a child who was enrolled in an EI preschool centre in Gauteng, South Africa, between 2010 and 2020.

The participants' socio-demographic profile is summarised in Table 5.1. All the participants were female, with a mean age of 39 years at the time of the study. Five of the participants were Black (African), two were White, one participant was Coloured (Mixed

Race), and one participant was Indian, based on the race classification system used in South Africa. Two of the participants each had two children who had been diagnosed with hearing loss. This brought the total number of children the nine participants in the study to 11.

Table 5.1

Caregivers' socio-demographic profile

Heading	Sub-heading	Participants (N)
Gender	Male	0
	Female	9
Age	25-30	1
	31-36	3
	37-42	3
	43-48	2
Ethnicity	Black	5
	Coloured (Mixed race)	1
	Indian	1
	White	2
Marital status	Married	6
	Single	3
Highest qualification	Grade 11 or lower (Std 9)	2
	Grade 12 (Matric)	3
	Post-Matric Diploma	3
	Baccalaureate Degree(s)	0
	Post Graduate Degree(s)	1
Employment status	Employed	5
	Self-employed	2
	Student	0
	Unemployed	2
Number of children with hearing loss	One	7
	Two	2

The demographic and audiological profile of children who are DHH is summarised in Appendix S. Participants were caregivers of children with a mean age of 10.2 years and an age range of between six years and 15 years at the time of the study. Of the children, seven were male and four were female. The children had been diagnosed with hearing loss at a mean age of 12 months, with the age range of between zero and 30 months. All the children presented with an early onset bilateral hearing loss and had been fitted with hearing aids or cochlear implants, or both.

5.3.4 Data Collection

Data was collected using narrative interviews, with the interview schedule reflected in Box 1 below.

BOX 1: Interview script

- Tell me YOUR story.
- What were your expectations of the EHDI process?
- What were the successes and failures of this process based on your experience?
  - *What do you think worked well or did not work so well with the EHDI process based on your experience?*
- What are the facilitators and barriers to the EHDI process?
  - *What made the EHDI process work well and what made it not work so well?*

In-person, telephonic and videoconferencing interviews were conducted to collect the data. The study had aimed to conduct data collection through in-person interviews only; however, these plans had to be changed to accommodate COVID-19 restrictions

(National Department of Health, 2020). The in-person interviews were conducted during January and February 2020, prior to the World Health Organisation (WHO) declaring COVID-19 a pandemic (WHO, 2020). The telephonic and videoconferencing interviews were conducted between March 2020 and March 2021.

Five interviews were conducted in English, two interviews in Setswana, one interview in SeSotho, and one interview in IsiZulu, in accordance with the participants' preferences. The lead researcher conducted all the interviews and is proficient in all these South African languages, hence there was no need for an interpreter.

5.3.5 Data Analysis

The narrative interviews were audio-recorded and transcribed verbatim. Data collection and data analysis were conducted simultaneously in order to ensure that participant recruitment and data collection were discontinued once data saturation had been reached (Saunders et al., 2018). All the interviews were anonymised, with a participant number being allocated for participants and a pseudonym for the children. Reflexive thematic analysis was used to analyse the narrative interviews. For all interviews conducted in an African language, two bilingual translators translated the recordings into English and another bilingual translator back-translated the interview transcript into the source language. Plans to use transliteration were in place, in case no immediate meaning was found in English (Vaismoradi et al., 2016), but this did not occur.

Themes that were identified from the current data were analysed using the following guidelines recommended by Braun and Clarke (2013; 2020):a) familiarisation with the data, b) generating initial codes, c) generating themes, d) reviewing potential themes, e) defining and naming themes, and f) producing the report. Representative verbatim quotations were used in the write-up of the study to support the presented findings.

5.3.6 Rigour

Reliability and validity are two key aspects of all research (Cypress, 2017; Polit & Beck, 2012). Rigour in qualitative research equates to the concepts of reliability, validity and all the necessary components of quality (Cypress, 2017). In order to prevent bias and intersubjective understanding of the findings, all the researchers were involved in the analysis (Vaismoradi et al., 2016; Wertz et al., 2011). Reflexive thematic analysis is considered a reflection of the researcher's reflective and thoughtful engagement with the data and their reflexive and thoughtful engagement with the analytic process; thus, involvement of all the researchers during the analysis process allowed for exploration of multiple assumptions or interpretations of the data, and richer interpretation of the meaning of the data (Braun & Clarke, 2019; Byrne, 2022). Furthermore, a rich description of the participants and the children who are DHH is provided in order to increase transferability (Polit & Beck, 2012).

5.4 Results

Two key themes pertaining to caregivers' expectations of EHDI were identified from the reflexive thematic analysis namely; expectations of the EHDI process and expectations of the outcomes of EHDI services. Figure 5.1 provides a graphic illustration of these themes and their sub-themes.

Figure. 5.1

Themes and sub-themes that emerged from the narrative interviews

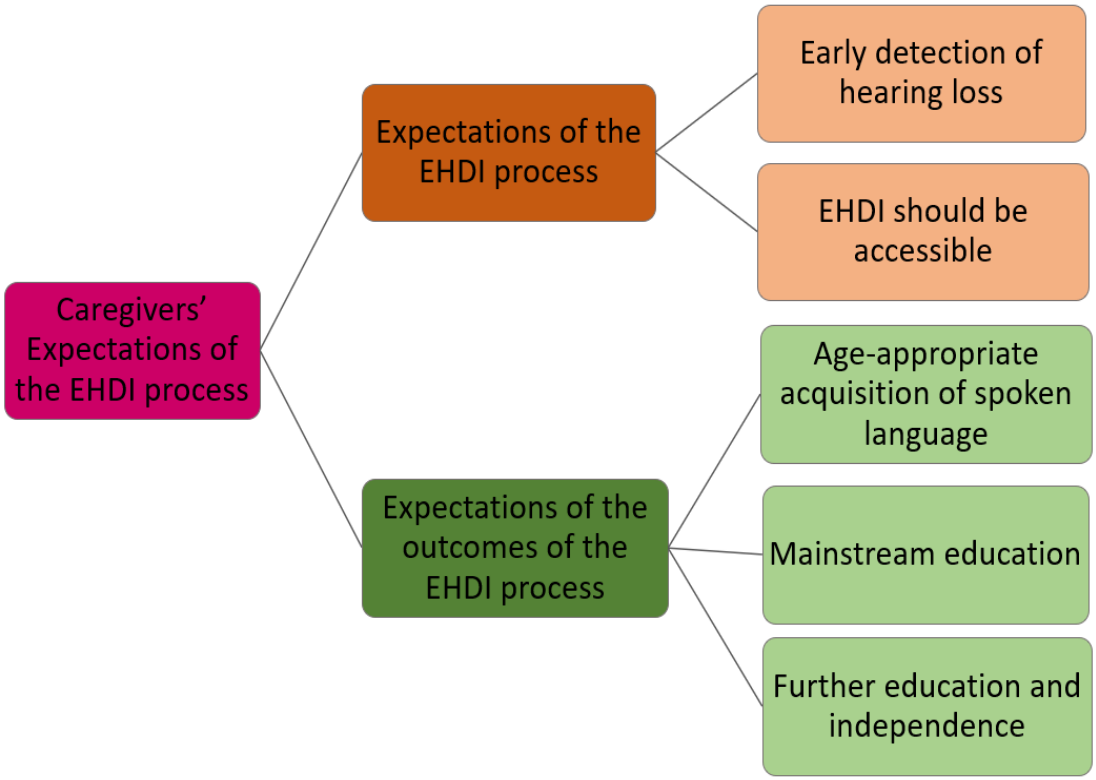


Table 5.3 reflects the themes, sub-themes and supporting quotations that were identified from the narrative interview data. All of these themes and sub-themes are presented below in relation to the success and/or failure of the EHDI services in meeting caregivers' expectations.

Table 5.2

Themes, Sub-themes and corresponding quotations

Themes	Sub-themes	Quotes
	Early detection of hearing loss	"…so, I think if we went for cochlear implant, for grommets implant twice. I mean he was not even a year and nobody picked that… nobody picked it up. Even the ENT, we see him for a whole year. He didn't pick it up." (CG 1)
		"If they had picked it up earlier, …He would have also been able to speak nicely." (CG 1)
		"Why was it not diagnosed at least in the first 6 months he was born?" (CG 1)
		"When I asked the 'sister'[nurse]…. this child is almost 2 years, why is she not talking…. She said I also don't know. I don't know what to say" (CG 2)
		"… [the second nurse] said…maybe after she turns 3 because the card shows that [the child must start talking] from 2 to 3 years. Maybe after she turns 3, we can see if there is a problem." (CG 2)
		"The clinics…they are the ones that are supposed to pick up that the child is deaf. They do tests, but they don't check ears." (CG 3)
		"We went to Hospital X, but they did not pick up the she was deaf." (CG 3)
		"I had taken him to the paediatrician with concerns [about delayed speech development] but she basically did a normal tympanogram and she said she did not have any concerns about his language development, because at that point, around 18 months his speech development was slower than what I had expected." (CG5)
		"It took at least 6-9 months for me to get an appointment at that point in time." (CG 8)
		"None of the doctors were like close by where we go. They always refer us further away." (CG 1)
		"Most of the services were here in Area P and Area Q… but now everything is basically in Area R right there by the school." (CG 6)

Expectations of the EHDI process	**EHDI services should be accessible**	"We had to go everyday through to Area R and I stay in Area T, so it was quite a road to travel. I would drive 350 km a day to get him to talk." (CG 8)
		"If we continue with speech therapy then, his speech would have been much better. He would have been able to speak, but because of financially and because nobody could refer us closer…" (CG 1)
		"In terms of affording a hearing aid and the fact that technology is changing every few years. For 2 [hearing] aids it's 55 000, *Sara*h's* is sitting at 30 (000), I think. Both of them have FM systems that's 30 000 each. So, hearing aids alone, and their devices alone exceed 100 000 rands. Then you also have to think about moulds, and with a growing child, you have to, especially from that like birth to 6 years, you have to change moulds every 6 months. Medical aids don't cover moulds at all. Even with us on comprehensive medical aid." (sic) (CG5)
		"It's not pocket change that we gonna throw in, and we are working one person's salary here because I don't work because of my son". (CG 6)
		I took her to private speech therapy with the medical aid from crèche, but the speech therapy was also a lot of money that they were claiming from the medical aid, so the medical aid got depleted. So, it was not working out for me as well." (CG 7)
		"Thank you, Jesus, that we were able to fund a lot of this ourselves. It cost us moving house and to pay for the first op, you know. So, a lot we had to do out of our own." (CG 8)
		"We wrote to medical aid because medical aid didn't want to pay and all that. But at last, they did do it with motivational letters and report from the audiologist." (CG 9)
		"At the time, they didn't have Black speech therapists at Hospital W, mostly it was White or Indians…so they should try to make sure that each hospital has 3-4 Black therapists…so they can help the person in their language." (CG 3)
		"And then the hearing aids are going to help her to hear…but sometimes when you talk to her…nothing. Even though she is wearing them." (CG 2)
		"He made it so easy to say, don't worry, he is gonna hear. He's gonna get a cochlear implant, but it wasn't easy. It was, oh a process that we went through." (CG 1)

	Age-appropriate acquisition of spoken language	"…he just can't speak, but he can hear us." (CG 4)
		"But the communication is, its ok. It's not 100% where we want it." (CG 1)
		"When I was at Hospital W, they showed me another child with the same problem as Lerato and se could talk. When I saw her, I realised that my child can also be helped… one day she can talk." (CG 2)
		"*Karabo** received the cochlear implant when he was still young so he developed speech normally." (CG 3)
		"Even now he [*Karabo**] always come home with new words. His English is progressing every day." (CG 3)
		"Because she [*Dimpho**] was fitted with the cochlear implant late, and has a lot of other difficulties, she did not develop speech as we had expected." (CG 3)
		"When she went to LSEN School 1, she adjusted so quickly to Sign Language." (CG 3)
		"She uses both Sign Language and speech, but her speech is low [poor]." (CG 3)
		"It's going well, but I think like LSEN School 6 they are encouraging him to sign and speak. But it seems like he prefers to sign." (CG 4)
		"Once he was in LSEN School 2 we put him there. Within 4 months, this child started like booming with talking." (CG 6)
		"He is still behind on his speech, there is still a big gap…" (CG 6)
		"She [*Paige**] hasn't had an issue in terms of language gaps, not as severe. We aided her very quickly, so she hasn't had any issues with language development or anything like that." (CG 5)
		"His [*Andrew**] pronunciation is still what he struggles with. He has a lateral 's'." (CG 5)
		"But we still have a lot of challenges. He [*Andrew**] has group-facilitated therapy sessions for social skills at school." (CG 5)

Expectations of the outcomes of EHDI services		"It's just those high sounds like 's' and 'f' that he can't pronounce very well." (CG 9)
	Mainstream education	"We also though that maybe after that process, the speech therapy…is gonna help… he will be able to go to normal things, mainstream school." (CG 1)
		"I used to wonder which school she was going to go to…. I would ask myself if she will be able to go to school. And I would lose hope that there is a school she can go to." (CG 2)
		"Even at the hospital they would say, you see how your child is, she doesn't need a normal school. She must get a special school." (CG 2)
		"They explained to me that with *Dimpho's** condition, she will not cope at a normal school, she needs to go to a deaf school. I was expecting that she will go to normal school, but the situation was the situation, I had to accept it." (CG 3)
		"From there we thought it was over, then we were suggested that we must move *Mandla** from like normal school where he was to special school so he can get more assistance." (CG 9)
		"Is he going to be able to be in a normal school? Because now… like the foundation classes, grade 1, grade 2 up to grade 4. I'm sure he is going to need a special school. So, I want to know in future maybe high school, will he still be able to go to normal school?" (CG 9)
		What we found was that there were extremes. There was the school for the Deaf and there were schools for remedial education that were either public or Model C. But there was nothing that accommodated for children ...somewhere on the spectrum." (CG 5)
		"*Paige** has managed to integrate into a mainstream school environment" (CG 5)
	Further education and independence	"We'll see how it goes with him,…try to pick up what he loves and see where we can push him." (CG 1)
		"…. what future is she going to have?" (CG 2)
		"I'm concerned about *Dimpho**…. so, I want to find out what I can do… to find something she can do with her hands [vocational work], like make-up or cooking." (CG 3)

		“The one thing that I pray and wish for. I would like to see my child go to university because she is very intelligent…. And it will be so sad to see such an intelligent child not be able to go to university because she can’t speak.” (CG 7)
		“Is he going to be able to provide for himself when he is old or what kind of job.” (CG 9)

5.4.1 Theme 1: Expectations of the EHDI Process

Participants' expectations of the EHDI process are presented in terms of the following sub-themes: a) early detection of hearing loss; and b) EHDI services should be accessible.

5.4.1.1 Early Detection of Hearing Loss. The first sub-theme that was identified for expectations of the EHDI process was caregivers' expectation that healthcare professionals (HCPs) detect their child's hearing loss early. EHDI services failed to meet caregivers' expectations in this regard. Four of the participants had discussed with various HCPs their concerns about to their child's not reacting to loud sounds or observed delayed speech and language milestones; however, the HCPs had dismissed caregiver s' concerns. Consequently, their child's hearing loss was only detected at a later stage.

Two of the participants reported that they had been referred to and had attended numerous appointments with various HCPs before a diagnosis of hearing loss was made. Furthermore, seven of the 11 children presented with risk factors for hearing loss, including; prematurity, neonatal intensive unit stay, Waardenburg syndrome, jaundice and chronic otitis media.

Only two of the eleven children had reportedly received timely EHDI services because their older sibling had also presented with a hearing loss and their caregivers had insisted on hearing screening and hearing evaluation when they were born.

5.4.1.2 EHDI Services Should Be Accessible. The second sub-theme that was identified for expectations of the EHDI process was caregivers' expectation that EHDI services would be accessible. However, EHDI services failed to meet caregivers' expectations. Nine participant caregivers expressed frustration with the distance from their home to the health facility where they received EHDI services, the high cost of services,

and/or the use of the English language throughout the EHDI process, which made access to EHDI services difficult.

For five of the nine participants EHDI services were situated far away from their homes. For three of these five participants, EHDI services were in areas that were hard-to-reach areas by public transport, which was the mode of transport available to them. Furthermore, for five of the participants, the high cost of EHDI services associated with audiology services, speech therapy services, amplification devices, and accessories such as FM systems made it difficult for them to access EHDI services. Only two participants received free EHDI services from state-owned hospitals in the public sector. The remaining seven participants received EHDI services from the private sector, and paid for these services directly (out-of-pocket) or through their medical aids. For one participant, the high cost of EHDI services resulted in their child not receiving EHDI services for a "few months" because they could no longer afford to pay directly for the services.

In addition to distance and cost challenges, participants also expressed concern with the use of the English language throughout the EHDI process. Appointments for all EHDI services were conducted in English, despite English not being the first language for six out of the nine participants. The reason provided for the use of the English language was that available schools that cater for the needs of learners who are DHH used only English as a medium of instruction.

5.4.1 Theme 2: Expectations of the Outcomes of the EHDI Process

Participants' expectations of the EHDI process will be presented according to the following sub-themes: a) age-appropriate acquisition of spoken language; b) mainstream education; and c) further education and independence.

5.4.2.1 Age-appropriate Acquisition of Spoken Language. The first sub-theme that was identified regarding expectations of the outcomes of the EHDI process was caregivers' expectation that their child would acquire age-appropriate spoken language when receiving EHDI services. EHDI services succeeded in meeting this expectation for only two of the 11 children, but failed to meet this expectation for the remaining nine children.

Only two of the 11 children received timely EHDI services and adequate acoustic input from their amplification devices to support the development of age-appropriate speech and language abilities. For four of the 11 children, despite receiving adequate acoustic input from their amplification devices to support speech and language development, late-enrolment in EHDI, among other factors which are beyond the scope of the current paper, resulted in delayed spoken language abilities; while for five of the children, limited audibility with their amplification devices and late-enrolment in EHDI, among other factors which are beyond the scope of the current paper, resulted in delayed spoken language abilities.. Of the latter five children, three had to switch to South African Sign Language (SASL) as their first language and spoken language as their second mode of communication.

5.4.2.2 **Mainstream Education.** The second sub-theme that was identified regarding expectations of the outcomes of the EHDI process was caregivers' expectation that their child would be enrolled in a mainstream school. EHDI services succeeded in meeting this expectation for only one of the 11 children (who was enrolled in a mainstream school) but failed to meet this expectation for the remaining 10 children, one of whom was enrolled in a remedial school, and eight of whom were enrolled in Schools for Learners with Education Needs (LSEN Schools), which provide support for learners who experience barriers to learning.

One participant did not express an expectation regarding her child's enrolment in a mainstream school. This participant reported that prior to receiving EHDI services for her child, she had not been aware that there were schools catering for children with hearing loss and as a result "would lose hope" that her child would ever go to school. This participant's child, at the time of the study, was enrolled in a remedial school where she was receiving instruction in English.

5.4.2.3 Further Education and Independence. The third sub-theme that was identified regarding expectations of the outcomes of the EHDI process was caregivers' expectations for their child's further education and independence. The failure or success of EHDI services in this regard is yet to be determined. For five of the nine participants, expectations regarding their child's further education and independence included an expectation that their child would go to university and be able to provide for themselves as adults. Participants who expressed expectations regarding their child's prospects also expressed concerns pertaining to their child's speech and language abilities and/or their academic performance at school. However, these concerns were not limited to caregivers of children who use Sign Language, but were also expressed by caregivers of children enrolled in a remedial school or an LSEN school.

5.5 Discussion

The aim of the current study was to describe caregivers' expectations of the EHDI process and to evaluate the success and/or failure of these programs in relation to caregivers' expectations. All nine participants in the current study were female. The fact that the sample for the current study was an all- female sample is consistent with the hierarchical and gendered role-assignment in various patriarchal contexts such as South Africa (Maluleke et al., 2021b; Merumagamala et al., 2017). Within these contexts, males are generally regarded

as the heads of the family, and females play the most significant role in day-to-day child rearing and caregiving (Masuku & Khoza-Shangase, 2018). Furthermore, reports from similar patriarchal contexts suggest that these hierarchical and gendered role-assignments accord women limited power to acquire health information, to make decisions regarding health, and to take action to improve health, and health access (Conroy et al., 2016; Merumagamala et al., 2017). Thus, HCPs need to be cognisant of the complexity of contextual decision-making dynamics and explore ways of navigating this dynamic in clinical practice (Maluleke et al., 2021b); in order to ensure best practice within this context.

The narrative interviews conducted in the current study revealed two key expectations, namely; expectations of the EHDI process and expectations of the outcomes of EHDI services. With regard to expectations of the EHDI process, the first sub-theme of the study revealed caregivers' expectations that HCPs would detect their child's hearing loss when they raised concerns about their child's failure to react to loud sounds or observed delayed speech and/or language milestones. However, EHDI services failed to meet this expectation. HCPs failed to detect the child's hearing loss and consequently refer the child for a hearing evaluation. Furthermore, participants were referred to and attended numerous appointments with various HCPs before their child was diagnosed with a hearing loss. Findings in the current study are concerning and suggest a lack of awareness on the part of HCPs of childhood hearing loss, its signs and symptoms, and the availability of EHDI services in the South African context.

The current study's findings that point to HCPs lack of awareness of these aspects are supported by Naidoo and Khan (2022), whose study showed that there is a general lack of awareness and knowledge about EHDI services among some HCPs in the South African context. In a study by Khan and Joseph (2020) , 42% of primary healthcare nurses reported that they were not knowledgeable about the risk factors for hearing loss. Similar findings of

HCPs lack of awareness of EHDI, childhood hearing loss, its signs and symptoms, and the availability of EHDI services have been reported in India, another LMIC. In a study by Yerraguntla et al.'s (2018), only 3.33% of doctors reported that they would refer a child to an audiologist for a hearing evaluation, while 23.33% reported that they would refer to a paediatrician and 76.67% reported that they would refer the child to an Ear-Nose-and-Throat specialist. Furthermore, the doctors were able to list the signs and symptoms of hearing loss including hyperbilirubinemia, low birth weight and family history; however, none of them included lack of or inconsistent responses to sounds or loud noises and delayed spoken language abilities on the list of signs and symptoms.

Nurses and doctors are the first point of contact within the healthcare system (Kieft et al., 2014; Khan et al., 2018). This is especially the case for the 85% (at least) of the South African population that accesses healthcare in the public sector (Khan et al.,2018; Khoza-Shangase & Kanji, 2021). The authors of the current paper thus maintain that HCPs' failure to identify signs and symptoms of childhood hearing loss compromises the EHDI process. Until UNHS is realised within this context, audiologists need to advocate for and promote EHDI and NHS amongst HCPs (Khoza-Shangase & Kanji, 2021). Communication and collaboration between HCPs, in an interdisciplinary approach, are a crucial aspect of effective EHDI services (HPCSA, 2018; Naidoo & Khan, 2022) and would facilitate information sharing amongst HCPs and improved awareness of infant hearing loss, helping to develop referral pathways that would assist in earlier identification of infant and childhood hearing loss (Naidoo & Khan, 2022). Furthermore, an interdisciplinary approach of shared knowledge and skills for a common goal, will advance hearing health and developmental outcomes for children who are DHH, while pooling the necessary resources into an efficiently run healthcare system, as advocated by the World Health Organization (WHO, 2010, 2020).

The second sub-theme for caregivers' expectations of the EHDI process was their expectation that the EHDI process would be accessible. However, EHDI services failed to meet this expectation, because caregivers had to travel long distances, often using public transport, to access EHDI services. Similarly, in a study by McLaren et al. (2014), distance from facilities posed a barrier for South Africans wishing to access healthcare. With specific reference to audiology in this context, Kanji and Khoza-Shangase (2018) found that distance from healthcare services negatively influenced follow-up return rates in NHS programs, while in Naidoo and Khan's (2022) study, caregivers identified the cost of transport as a barrier to EHDI.

Furthermore, the current study found that the high cost of EHDI services, amplification devices, and their accessories contributed to the failure of EHDI process to meet caregivers' expectation of accessible EHDI. Similarly, Naidoo and Khan (2022) found that, caregivers also identified the cost of the hearing evaluation in the private sector as a barrier to EHDI. According to Burger and Christian (2020), affordability of healthcare remains a constraint within the South African context. Even when healthcare services are provided free of charge, the monetary and time costs of travel to healthcare facilities represent the cost of access to healthcare (Chimbidi et al., 2015).

EHDI services' failure to meet caregivers' expectations of accessible services with regard to distance and cost is not limited to EHDI services within the South African context. The South African Constitution provides for the right to healthcare services; however, being afforded the right to something does not necessarily translate into getting the service or the quality of care (Chiwire, 2016). South Africa is characterised by persistent inequitable quality of health services provision (de Villiers, 2021). Furthermore, the healthcare system faces a range of systemic and structural challenges, which include widespread inefficiencies, staff

shortages, variability in skills sets between rural and urban areas, and suboptimal care levels of patient management (Khoza-Shangase, 2019).

In an effort to address these challenges, South Africa is introducing the National Health Insurance (NHI) system, with the goal of fostering healthcare reform to improve service provision and healthcare delivery for all socioeconomic groups, while also partnering with providers and organisations within the private sector in the delivery of healthcare (de Villiers, 2021). Though the NHI offers hope to the disadvantaged, it will not be ready soon, leaving the current healthcare arrangements, with their own vulnerabilities, needing an urgent revamp (Chiwire, 2016). Thus, current findings raise implications for improving access to healthcare services, such as EHDI, through improving affordability of healthcare and proximity to healthcare facilities.

One of the proposed models for improving healthcare access in resource-constrained contexts like South Africa is through tele-audiology (Swanepoel & Hall, 2010; Sebothoma et al., 2021). Tele-audiology, a subset of telehealth, is the utilisation of telecommunication technologies to reach patients, reduce barriers to the best healthcare, enhance patient access to healthcare practitioners, and spare patients from having to travel long distances to obtain high-quality care (Krupinski, 2015; Khoza-Shangase & Sebothoma, 2022). Increased efforts by the South African government towards information and communication technologies and the fourth industrial revolution, coupled with telehealth's immense capabilities to increase access to healthcare services as demonstrated during the COVID-19 pandemic, make tele-audiology a viable option to improve access to EHDI within the South African context (Khoza-Shangase & Sebothoma, 2022; Maluleke & Khoza-Shangase, 2023; State of the Nation Address [SONA], 2020). However, South Africa is experiencing challenges with meeting the country's electrical demands, resulting the implementation of various stages of power outages referred to as 'load shedding' (Laher et al., 2019; Wood, 2023). The current

load shedding challenges pose a challenge to telehealth within this context. Thus, further deliberations on internet access and use, especially within the remote contexts which are supposed to gain the most benefit from these services, are essential.

In addition to distance and the high cost of services, use of the English language throughout the EHDI process resulted in EHDI services' failure to meet caregivers' expectation that EHDI services would be accessible. English was used as a 'preferred' language even though it was not the first language for six of the nine participants. South Africa has a richly diverse population in culture and language; clinical interactions should therefore be conducted using a mode or language of communication which patients and families can understand, especially where the core scope of function is in communication pathology (HPCSA, 2018; Khoza-Shangase, 2019; Khoza-Shangase & Mophosho, 2018). Using the language that the family can understand improves the degree of accurate recall and has significant implications for follow-up of treatment options, commitment and adherence to treatment recommendations, and improved health outcomes (Flood & Rohloff, 2018; Watermeyer et al., 2017; Watson & McKinstry, 2009). Thus, robust efforts to embrace linguistically- and culturally-congruent EHDI services are warranted in the South African context.

The second key theme that was identified from this study was caregivers' expectations of outcomes of the EHDI process. The first sub-theme of caregivers' expectation of the outcomes of the EHDI process was their expectation that their child would acquire age-appropriate spoken language once fitted with amplification devices. EHDI services failed to meet this expectation as only two of the 11 children developed age-appropriate spoken language abilities. Similar results are reported in studies conducted by Fitzpatrick et al (2007), and by Young and Tattersall (2007), where caregivers showed high expectations of EHDI services in enabling their child to achieve what a child with normal hearing would

achieve. Furthermore, in a study by Gilliver et al. (2013), caregivers expected that their child's hearing loss would be easily and effectively managed by early fitting of amplification devices.

Early access to EHDI services is critical for children who are DHH to develop optimal speech and language development (Barr et al., 2019; McCreery et al.,2015). However, providing amplification at an early age is not sufficient to support positive developmental outcomes for children who are DHH, given the complexity of childhood hearing loss (Findlen et al., 2019; McCreery et al., 2015). There are multiple factors that influence development outcomes for children who are DHH, such as co-morbid medical, social and developmental factors. Thus, the effect of the timing of intervention is small compared to the aforementioned factors (Barr et al., 2019; Gilliver et al., 2013; Khoza-Shangase, 2021).

Caregivers' expectation that their child would be able to hear once fitted with amplification devices and would subsequently develop age-appropriate spoken language abilities thus highlight the need for adequate informational counselling for caregivers. Caregivers' expectations that amplification devices will result in their child achieving like a child with normal hearing may be misguided when considering the various factors that influence developmental outcomes for children who are DHH (Gilliver et al., 2013). Caregivers' expectations must be realistic in relation to their child's characteristics (Gilliver et al., 2013). Furthermore, perpetration of the belief that EI equates to normal development may place unnecessary guilt or pressure on those families where EI did not occur or fails to provide such outcomes. Thus, providing families with evidence-based information needs to be balanced in such a way as to provide information about the benefits of EI and its outcomes within a realistic framework (Gilliver et al., 2013).

The second sub-theme of caregivers' expectations of outcomes of the EHDI process was their expectation that their child would be enrolled in a mainstream school. EHDI services failed to meet this expectation, as only one of the 11 children was enrolled in a mainstream school, two children were enrolled in a remedial school, and the remaining eight children were enrolled in LSEN schools. This finding confirms the notion that children who are DHH are primarily placed in the country's limited number of special schools for the deaf, which contradicts the South African ethos of inclusive education (Human Sciences Resource Council, 2018; Khoza-Shangase, 2021).

The South African government has increased efforts to attain educational goals through initiatives such as Early Childhood Development (ECD) programs and continuity of care for children who are DHH, from the health sector to the education sector, through access to therapeutic services that mitigate barriers to learning for these children. Furthermore, White Paper 6 (Department of Education, 2001) asserts that in order to make inclusive education a reality, a conceptual shift regarding the provision of support for learners who experience barriers to learning is required. However, we know far less about educating the child who is DHH than is commonly believed (Shaver et al., 2013). The current authors therefore agree with the assertion by Shaver et al. (2013) that a better understanding of the effectiveness of various practices in regular and separate settings and how they are affected by complexities in child characteristics, is essential if we are to ensure that children who are DHH are placed in settings that are most enabling rather than administratively expedient.

The third sub-theme of caregivers' expectations of outcomes of the EHDI process was their expectations for their child's further education and independence. The success or failure of EHDI services' in meeting this expectation remains to be seen. However, the findings of the current study relating to caregivers' expectations for their child's future prospects are warranted, given that early detection is key to initiating EI services and delayed provision of

rehabilitation services can hinder a child's overall development leading to long-term negative consequences (Gmmash & Faquih, 2022). These negative consequences pose a threat to quality of life with regard to education, employment, and integration in society for the child who is DHH (Khoza-Shangase, 2021; Yoshinaga-Itano, 2014).

Furthermore, reports from the South African context show that up to 70% of children with disabilities, which includes children who are DHH, are out of school, despite being of school-going age (Donohue & Bornman, 2014), while an estimated 93% of adults who are DHH are unemployed (Parliamentary Monitoring Committee, 2013). Current findings highlight an urgent need for the Departments of Health, Social Development and Basic Education to invest in initiatives that are aimed at properly resourcing, coordinating and managing the child with hearing loss from EHDI, ECD centres, and school through an integrated and collaborative approach that involves the child who is DHH, their family and EI professionals.

5.6 Limitations

The results are based on reports of events that occurred prior to the narrative interviews being conducted; thus, time might have influenced caregivers' recall of their experiences. Furthermore, use of purposive sampling and inclusion of caregivers of children from EI preschools in Gauteng only is not representative of the general population of caregivers of children who are DHH in South Africa. It can therefore cannot be assumed that the findings of this study are representative of all caregivers and children who are DHH within the South African context. The results of the current study cannot be interpreted beyond the sampled population; however, they provide a firm foundation for further research. An investigation of caregivers' expectations of EHDI services from different geographical locations and healthcare facilities is warranted.

5.7 Conclusion

Findings from this study revealed that EHDI services failed to meet caregivers' expectations of a) early detection of hearing loss; b) accessible EHDI services; c) age-appropriate acquisition of spoken language; and d) enrolment in a mainstream school for the child who is DHH. These findings emphasise the need for context-specific solutions and strategies that will ensure that EHDI services are effective, sustainable, and evidence-based, and that they recognise caregivers as significant co-drivers of successful EHDI services. Furthermore, these findings highlight the need for implementation of wide-spread, integrated, and inter-disciplinary EHDI services that meets the needs of South Africa's linguistically and culturally diverse population.

In chapter 6, the findings of objectives 2 and 5 are presented; namely, describing caregivers' experience of the EHDI process from detection to intervention and describing caregivers' level of satisfaction with current EHDI programs. The specific study design, participant recruitment strategy, data collection and analysis methods employed to obtain these findings are also presented.

Chapter 6

Caregivers' Experiences of the Early Hearing Detection and Intervention (EHDI) Process from Detection to Intervention in South Africa[6]

(In Review, Appendix T)

6.1 Abstract

Background: As the implementation of early hearing detection and intervention services (EHDI) in many countries gathers pace, attention is shifting from arguments for universal newborn hearing screening and subsequent early intervention to closely focus on the evaluation of the practice and process of EHDI programs. However, there are very few studies within the South African context that have focused on caregivers' own accounts of how they experience the EHDI process for their child with hearing impairment.

Methods: The study aimed to describe caregivers' experience of the EHDI process from detection to intervention, within the South African context. Narrative interviews were conducted in-person, telephonically or via videoconferencing with nine caregivers of children with hearing impairment. The interview data was analysed using inductive thematic analysis.

Results: Three key themes emerged from the interview data: a) caregivers experienced denied timely access through healthcare workers' dismissal of their concerns; not being referred to audiologists timeously; receiving fragmented services; receiving services far from where they live; the cost of EHDI services; and through the use of English as a medium of communication for all EHDI services; b) participants' experience of support services was

[6] Spelling variations in this chapter compared to the rest of the thesis are due to aligning the manuscript with the spelling used in *BMC Health Services Research*, the journal where this chapter was submitted.

deemed not to be sufficient due to lack of awareness of hearing impairment and EHDI; limited family counselling; lack of available Sign Language training; and constrained financial support; and c) caregivers expressed appreciation of EHDI services due to observed language development of their child; their child's academic performance; and their interaction with EHDI team members.

Conclusion: Current findings revealed limited availability, affordability and accessibility of EHDI services in the South African context and raise significant implications for clinical practice, policy implementation and advocacy within the departments of health, social development, and basic education in this country. These findings also highlight the need for economic evaluation of EHDI programs, where EHDI is placed on the political advocacy and resource allocation agenda; and widespread implementation of FC-EHDI, within this context.

Keywords: caregiver experiences, early intervention, early hearing detection and intervention, family-centered, newborn hearing screening, hearing impairment

6.2 Background

Global evidence demonstrates that quality early intervention (EI) programs, such as Early Hearing Detection and Intervention (EHDI), provide both immediate and long-term benefits for children, families and communities as they promote the realization of young children's full potential [1, 2][7]. EHDI programs are recommended to identify, diagnose and treat newborns and infants with disabling hearing impairment as early as possible in order to ensure that optimum, cost-effective solutions, that enable children to communicate effectively and develop to their maximum potential, are realized [3, 4].

Consequently, the Health Professions Council of South Africa (HPCSA) [3] recommends that EI services following diagnosis of hearing impairment must be family-centered within a community-based model of service delivery that is culturally congruent for them to be efficacious. Through linguistic and culturally appropriate family-centered EHDI (FC-EHDI) services, caregivers and families can be empowered with knowledge to optimize their child's developmental outcomes and ensure that EHDI services do not distance the child linguistically and culturally from their families and communities [5, 6].

Without family involvement, EI has been shown to be unsuccessful, and what few effects are achieved are likely to disappear once the intervention is discontinued [6,7, 8]. Thus, as implementation of EHDI services in many countries gathers pace, attention is shifting from arguments for universal newborn hearing screening (UNHS) and subsequent EI to closely focus on the evaluation of the practice and process of EHDI programs [6, 8]. However, within low-and-middle income countries (LMICs), such as South Africa, limited research focus has been placed on evaluating the service provided in terms of aspects such as

[7] Vancouver referencing style is used in this chapter due to the manuscript that makes up this chapter having been published in *BMC Health Services Research*. The number are reflected in the reference list next to the corresponding reference and highlighted in yellow.

efficacy of interventions, outcomes, and making caregivers key co-drivers of the programs [9].

This article therefore aims to describe caregivers' experience of the EHDI process from detection to intervention, within the South African context. Investigating caregivers' own accounts of how they experience the EHDI process from detection to intervention within this context builds on the scanty 'indigenous' knowledge base for children and families, with disabilities [10], and establishes evidence that is contextually relevant and responsive to South Africa and its unique challenges. This paper forms part of a larger research project titled *"Family-Centered EHDI: Caregivers' experiences and evaluation of the process and practices in the South African context",* with it describing our first steps in formulating a framework for FC-EHDI for children with hearing impairment within the South African context.

6.3 Methods

6.3.1 Study Design

Results of this article are only based on the narrative interviews that were conducted as part of the mixed methods convergent design employed in phase 1 of the main study.

In order to gain access to the participants, the researchers obtained written permission from two early intervention (EI) preschool centres in South Africa, allowing the researchers access to the preschool files/records in order to identify potential participants for the current study. Subsequently, the researchers compiled a list of all possible participants' contact details using purposive non-probability sampling. Participants were recruited telephonically to participate in the study until data saturation was reached.

6.3.2 Study Sample

Nine caregivers of children with hearing impairment participated in the current study according to the following inclusion criteria:

- Caregivers were the primary caregiver of the child with hearing impairment.
- Caregivers of children diagnosed with a mild to profound, bilateral or unilateral hearing impairment, from EI preschools in Gauteng, South Africa.
- Caregivers of children who were enrolled in EI preschool centres from 2008 to date.

All participants were female, with a mean age of 39 years. Five of the participants were Black (African), two were White, one participant was Coloured (Mixed race), and one participant was Indian. Two of the participants had two children each, who were both diagnosed with hearing impairment.

The mean age of the children in the study was 10.2 years, with the age range of between six years and 15 years. There were seven males and four females. The majority of the children were diagnosed with hearing impairment at a mean age of 12 months, with the age range of between zero months and 30 months. All the children presented with an early onset bilateral hearing impairment. All the children had amplification devices in the form of hearing aids and/or cochlear implants.

6.3.3 Data Collection

Data collection was conducted using narrative interviews, with the interview schedule reflected in Box 1 below. The narrative interviews were conducted in-person, telephonically and via video-conferencing. The study had aimed to conduct data collection through face-to-face interviews only, however, these plans had to be changed to accommodate COVID-19

restrictions [11].

BOX 1: Interview script

- Tell me YOUR story.
- What were your expectations of the EHDI process?
- What were the successes and failures of this process based on your experience?
  - *What do you think worked well or did not work so well with the EHDI process based on your experience?*
- What are the facilitators and barriers to the EHDI process?
  - *What made the EHDI process work well and what made it not work so well?*

Five interviews were conducted in English, two interviews were conducted in Setswana, one interview was conducted in SeSotho and one interview was conducted in IsiZulu, based on the participant's preference. The lead researcher conducted all the interviews and is proficient in all these South African languages, and so there was no need for an interpreter.

6.3.4 Data Analysis

The narrative interviews were audio-recorded and transcribed verbatim. All the interviews were anonymized, allocating a participants' number for participants. Inductive thematic analysis was used to analyse the narrative interviews. For all interviews conducted in an African language, two bilingual translators translated the recordings into the target language and another bilingual person back-translated it into the source language. If no immediate

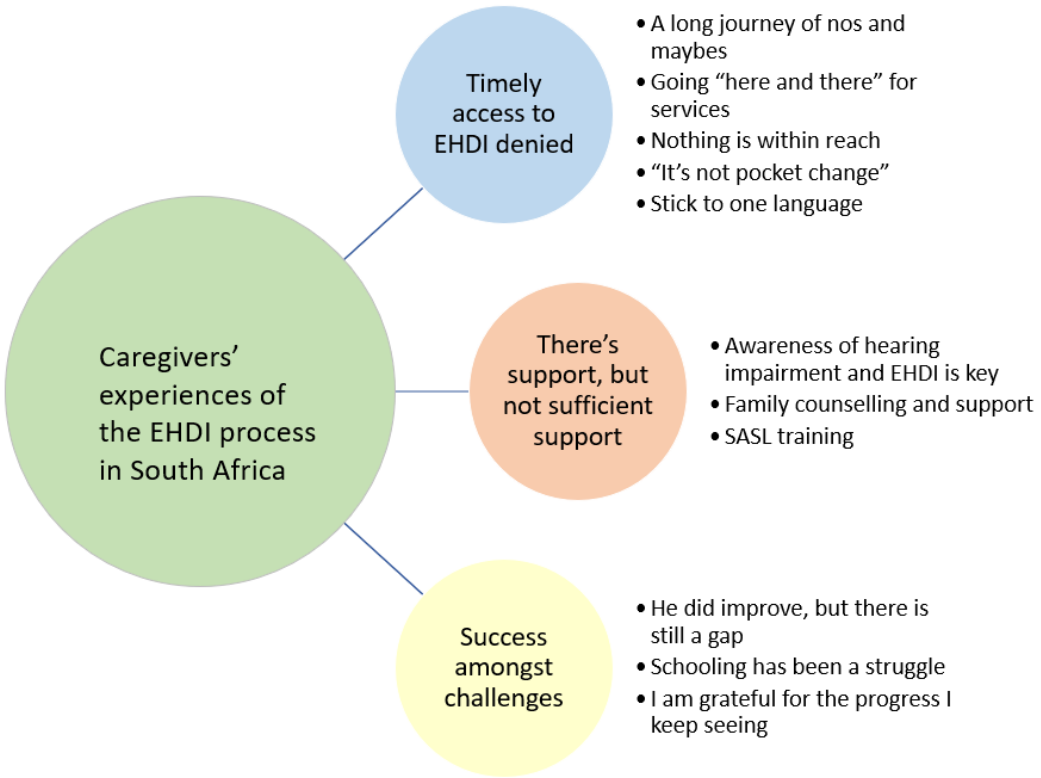
meaning was found in the target language, plans to use transliteration were in place [12], however this did not occur.

Themes that emerged from the current data were analysed through the steps recommended by Braun and Clarke [13], namely; a) familiarization with the data, b) generating initial codes, c) searching for themes, d) reviewing themes, e) defining themes, and f) write-up. Representative verbatim quotations were then used in the write up of the study to support the presented findings.

6.4 Results

Figure 6.1 provides a graphic illustration of the key themes and sub-themes that emerged from the narrative interviews.

Figure 6.1
Themes and sub-themes emerging from the narrative interviews



The inductive thematic analysis revealed three key themes: 1) timely access to EHDI denied; 2) there's support, but not sufficient support; and 3) success amongst the challenges. Each of these themes is presented and discussed in detail below. Appendix T reflects the themes, sub-themes and supporting quotations.

6.4.1 Theme 1: Timely Access to EHDI Denied

Participants' experience of denial of timely access will be presented according to the following sub-themes: a) a long journey of nos and maybes; b) going "here and there" for services; c) nothing is within reach; d) it's not pocket change; and) stick to one language.

6.4.1.1 A Long Journey of Nos and Maybes. For six of the participants, their initial experiences of *denial of timely access to EHDI* were through healthcare workers' (HCWs) dismissal of their concerns pertaining to their child not reacting to loud sounds or observed delayed speech and language milestones.

6.4.1.2 Going "here and there" for Services. Participants reported having to go to various HCWs and appointments before their child was eventually diagnosed with hearing impairment; and receiving intervention services to address the impact of their child's hearing impairment and co-morbidities from three different HCWs, in different locations.

6.4.2.3 Nothing is Within Reach. Available intervention and support services for the children within this sample were reportedly in areas that were far away and often in hard-to-reach areas when using public transport, with three of the participants relying on public transport to navigate around.

Participants reported similar experiences regarding their child's schooling. Schools were reportedly far from where participants live and requiring special transport arrangements at times, with significant cost implications. The schools that participants provided information on include preschools, primary and high schools, therefore the entire basic education experience.

6.4.1.3 It's Not Pocket Change. Participants in this study reported high cost of the clinical and support services, amplification devices, as well as schooling for their child with hearing impairment. Only two participants reported that their children received amplification devices and therapy sessions for free at public clinics and hospitals. However, seven of the participants expressed frustration with the cost of services, amplification devices and accessories. Furthermore, medical aids (medical insurance or funding) do not always pay for the full costs of the amplification device and/or accessories. This resulted in one participant changing membership from one medical aid to another in an effort to find a medical aid that would be better suited to her son's healthcare needs.

In addition to cost of services and amplification devices, participants experienced high costs associated with access to appropriate schools that would cater for their child's educational needs, as not all schools in South Africa cater for children with additional educational needs, such as children with hearing impairment. Participants in the study reported moving their child from one preschool to another midway through the academic year because he no longer had a sponsor to continue paying for the school fees; and opting to enrol their child at a "normal" preschool because they could not afford the recommended preschools. "Normal" in this context refers to mainstream preschool without any special needs support.

6.4.1.4 Stick to One Language. Only three of the participants were from households that spoke English as their first language; however, all participants were required to use the English language as a medium of communication throughout the EHDI process. The six participants who did not speak English as their first language reported that they had been advised by speech therapists and/or audiologists to only use one language, English, at home in order to avoid confusing their child.

Reasons provided for the use of English included that the child would be receiving speech therapy in English and that available schools that cater for the needs of learners with hearing impairment used English as a medium of instruction. Use of English resulted in participants and their families having to change the language used at home, a challenge since this also made assumptions that the child will only engage with their immediate family and not with extended family members and the community where they lived.

All the participants reported that they use English at home with their child, with the exception of two participants who reported that their children also use South African Sign Language (SASL), which they learnt at their child's school. For families with children that used SASL as well, families had to then learn two additional languages; different to their home language, in order to communicate with their children.

6.4.2 Theme 2: There's Support, but not Sufficient Support

The second theme that emerged from the narrative interviews data was participants' experiences of the presence of support services throughout the EHDI process; however, these support services were deemed not to be sufficient. Participants' experiences of support services will be discussed according to the following sub-themes: a) awareness of hearing impairment and EHDI is key; b) family counselling and support; c) SASL training; and d) financial assistance.

6.4.2.1 Awareness of Hearing Impairment and EHDI is Key. Two participants reported that they were able to understand their child's hearing impairment only after the doctor explained the hearing impairment to them. However, participants' experiences also revealed that information (knowledge) is typically shared with the mother of the child and not the father because of their usual absence during appointments, and this affected decision-making during the EHDI process. Furthermore, participants' experience revealed that awareness and knowledge of infant and childhood hearing impairment gained during the

EHDI process resulted in earlier diagnosis of hearing impairment for younger siblings as well as that of friends' or employees' children.

One of the challenges pertaining to awareness that participants experienced was on how and where to access support once the child was older than the ages encompassed within EHDI, as well as establishing and maximizing their child's potential future prospects.

6.4.2.2 Family Counselling and Support. Only two participants reported receiving family counselling and support services from the EI partner for families of hearing-impaired children, HI HOPES. These participants reported that HI HOPES assisted with accepting and adjusting to their child's hearing impairment.

6.4.2.3 Sign Language Training. Only two participants whose children used SASL reported receiving training from their child's school on Saturdays, which enabled them to communicate with their child.

6.4.2.4 Financial Assistance. All the participants reported frustrations based on the costs associated with the EHDI process from detection to intervention, as well as schooling. A need for financial assistance was expressly raised by three participants. These participants reportedly received financial assistance through three avenues: free healthcare services a public hospitals and clinics, the government issued Care Dependency Grant (CDG), as well as independent donations.

6.4.3 Theme 3: Successes Amongst the Challenges

The third theme to emerge from the narrative interview data was participants' fair satisfaction with the EHDI process; despite the earlier reported challenges. All participants expressed satisfaction with the EHDI process, notwithstanding the "long and challenging" journey that it was. Participants' satisfaction with the EHDI process will be discussed

according to the following sub-themes: a) he did improve, but there is still a gap; b) schooling has been a struggle; and c) I am grateful for the progress I keep seeing.

6.4.3.1 He Did Improve, But There is Still a Gap. All participants expressed satisfaction with the observed speech and/or language development of their child once they started receiving EHDI services, while being cognizant of the persistent lag in their communication and scholastic abilities for some of the children based on the time of diagnosis of their child's hearing impairment.

6.4.3.2 Schooling has Been a Struggle. Despite experiencing frustration initially with regards to enrolling their children in appropriate schools, participants expressed satisfaction with the schools their children were enrolled in from preschool to high school, while acknowledging some of the challenges pertaining to their children's academic performance. Participants reported that the most common challenges that their children experienced at school were reading and languages. Only three participants reported that their children were currently performing well at school and had not experienced any challenges.

6.4.3.3 I Am Grateful for the Progress I Keep Seeing. All the participants expressed satisfaction with one or more aspects of the EHDI process. Aspects of the EHDI process that participants expressed satisfaction with included interaction with EHDI team members, satisfaction with the school that their child had been enrolled in due to their child being happy at the school, and the progress that their child had made.

6.5 Discussion

This study provides an in-depth qualitative analysis of caregivers' narrative interviews and is the first study to fully explore caregivers' experience of the EHDI process from the point where their child's hearing impairment is detected to intervention.

The first major finding of the current study indicates that caregivers experienced denial of timely access to EHDI services. Inequity in accessing healthcare is a global challenge and affects the performance of any healthcare system [14], South Africa's healthcare system included [9, 15]. Consequently, the South African government has over the years introduced various initiatives and programs aimed at improving healthcare, efficiency, and quality of delivery and access for all users [16]. However, despite the country's progressive constitution and the rights of all citizens to access quality healthcare delivery, healthcare outcomes remain polarized and unequal [17], as is evident in the findings of the current study.

Caregivers' denial of timely access to EHDI services through HCW's dismissal of caregivers' concerns and failure to refer caregivers to the audiologist for a hearing evaluation indicates HCW's lack of awareness of infant hearing impairment, and its signs and symptoms. This finding is consistent with Birdsey and Joseph's [18] contention that doctors in LMICs are often the reason for delays in identification and initiation of EI in infant and childhood hearing impairment. In Maluleke, Khoza-Shangase and Kanji's [19] study, children were only diagnosed with hearing impairment following caregiver concerns despite presenting with risk factors for infant hearing impairment. Furthermore, in Khan and Joseph's [20] study, 42% of primary healthcare nurses reported that they were not knowledgeable about the risk factors for hearing impairment. Moreover, in Casoojee's [21] study, a general lack of compliance with referral protocols according to EHDI principles was also reported.

Within the South African context, nurses and doctors are the first point of contact within the healthcare system for at least 85% of the population [22]. Thus, the authors of the current paper maintain that failure of HCWs to identify risk factors for infant hearing impairment followed by prompt referral to audiologists significantly compromises the EHDI process. Until UNHS is realized within this context, improved HCWs awareness of infant

hearing impairment is vital towards earlier identification of infant and childhood hearing impairment. Furthermore, aligning newborn hearing screening (NHS) with immunization visits has been shown to be a viable option due good immunization coverage rates and availability of audiologists during official working hours [22, 23].

Moreover, HCWs' dismissal of caregiver concerns reflects a view of caregivers as passive consumers of healthcare services and not as active participants in a family-professional partnership. Findings of the current study raise implications for a need for a paradigm shift from viewing the caregiver as a peripheral player in child-focused interventions to a care paradigm where caregivers have the opportunity to share their opinions, expertise, needs and preferences with HCWs [6, 24, 25]. Families provide a rich cultural context in which children learn and develop; thus, intervention approaches that can be easily incorporated into their daily lives and are congruent with their beliefs and practices, such a FC-EHDI, are efficacious [7, 26].

Caregivers also experienced denial of timely access to EHDI by having to go "here and there" for services. Caregivers were referred to various HCWs and were required to attend numerous appointments before a diagnosis of their child's hearing impairment was made. Healthcare in the private sector is reported to be highly fragmented, with little co-ordination of care between HCWs [27], as is evident in the current study. This finding highlights the need for centralized, non-fragmented, interdisciplinary FC-EHDI services. According to Khan et al. [22], the effectiveness and success of EHDI services is contingent upon EHDI team members being involved in an interdisciplinary team. This interdisciplinary approach of shared knowledge and skill for a common goal, will advance hearing health and developmental outcomes of hearing-impaired children, while pooling the necessary resources into an efficiently run healthcare system – as advocated by the World Health Organization [28].

Moreover, caregivers had to travel long distances, often using public transport, in order to be able to access clinical, therapeutic, and schooling services for their children. Similarly, in a study by McLaren, Ardington and Leibbrandt [30], distance to facilities posed a barrier for South Africans wishing to access healthcare. Specific to audiology within this context, Kanji and Khoza-Shangase [23] found distance from healthcare services negatively influenced follow-up return rates in NHS programs. Notably, the three participants that experienced the most transport challenges in the current study; 1) changed employment in an attempt to mitigate transport challenges; 2) changed the school where the child was enrolled in; or 3) enrolled the child in a school environment that was not able to cater to their child's educational needs.

Caregivers also experienced denial of timely access through the high costs of services, amplification devices and accessories linked to the management of their hearing-impaired children. Post-apartheid, the South African government aimed to improve access to healthcare for the poorest and most marginalized sub-groups by abolishing user fees for primary healthcare [17], and this is the goal of the National Health Insurance [NHI] [30]. However, prior to the implementation of the NHI, affordability remains a constraint, vulnerable subgroups such as black South Africans, the less educated, the unemployed and the poor tend to be less likely to have adequate access to healthcare [17], as evidenced by the demographic profile of the current study's participants. Furthermore, out-of-pocket costs for 16% of the population that are covered by medical aid are tangible barriers that tend to be correlated with race, socio-economic status and rural– urban differentials [31].

Even when health services are provided free of charge, as is the regulation for healthcare service provision for children under the age of six years in public hospitals, monetary and time costs of travel to healthcare facilities represent the price of access to healthcare [32]. These costs may pose a significant barrier for vulnerable segments of the

population, leading to overall poorer health outcomes [30]. Travel costs in South Africa are reportedly high relative to other LMICs, which means that small differences in distance can translate into large differences in access [30]. Our results are consistent with previous findings which indicate that travel costs are but one of many barriers to accessing care [32]. These findings raise implications for improving the quality of healthcare, such as EHDI, through improving affordability of healthcare and proximity to healthcare facilities. Furthermore, these results highlight the need for economic evaluation of EHDI programs within the South African context, where EHDI is placed on the political advocacy and resource allocation agenda [33].

Lastly, caregivers experienced denial of access through the use of English as a 'preferred' language in order for them to access EHDI services and schooling for their child. This is despite the fact that English is spoken by 10% of the population as their home language [6]. This effect creates a cycle of exclusion of the patient and family from receiving effective treatment or care for 11 million Black South Africans [5, 34]. South Africa is characterized as a multicultural, multilingual country, making it important for professionals to provide services that are culturally and linguistically appropriate [3, 5, 22].

The second significant finding of the current study was caregivers' experiences of the available support services that were deemed to be insufficient. Notably, caregivers reported an understanding of their child's hearing once HCWs had explained it to them as well as through the family counselling and support services obtained through programs such as HI HOPES. Furthermore, caregivers reported earlier diagnosis of hearing impairment of other children as a result of their increased knowledge of infant hearing impairment gained from such counselling and support services. Ninety percent of children with hearing impairment are born to hearing parents who often have little to no knowledge of childhood hearing impairment [18, 35]. Thus, this finding highlights the importance of informational

counselling for caregivers, over and above emotional counselling. Informational counselling is vital within the EHDI process and has significant implications for follow-up of treatment options, as well as commitment and adherence to treatment recommendations [6, 36]. According to Davids et al. [35], caregivers need diverse information about hearing impairment including; their child's development, the needs for family-centered service provision, and their child's education and future opportunities [35]. This information should be provided in a responsive and sensitive manner for them to be amenable to accessing follow-up services [22, 35].

Unsurprisingly, findings of the current study also revealed a lack of informational counselling for fathers due to their absence during consultations. Literature has highlighted limited participation of fathers during EI [37]. Reasons provided in literature for fathers' limited participation include work schedules; traditional role perception, with fathers as breadwinners and mothers as caregivers; and having most EHDI team members being female, thus resulting in fathers feeling uncomfortable with receiving instructions from a female or having to discuss their reactions to their child's disability [6, 8, 37].

This finding has significant implications for the South African context where social structures may render women limited power to acquire health information, make decisions regarding health, and take action to improve their health [38, 39]. Paternal participation in childcare has been associated with improved language and cognitive development during childhood, fewer behavioural problems at school, more positive peer relationships during childhood, better development of self-regulatory and pro-social skills; and better positive psychological adjustment [37, 40]. However, research in FC-EHDI is heavily reflective of mothers [40]. Thus, authors of the current paper argue that involvement of fathers in the EHDI process within the South African context requires serious deliberation, if better health outcomes have been linked to it.

Only three of the nine participants reported an above-average socio-economic status, thus the need for financial assistance for some of the participants to access the services was inevitable. Financial assistance for the high costs associated with EHDI services, as discussed above, afforded caregivers the opportunity to access EHDI services which they would otherwise not have been able to access for their children. Free healthcare services as a means to promote equitable access, in the form of NHI, is discussed above. In addition to free healthcare services, caregivers reported using the CDG to pay for some of the costs associated with accessing schooling for their child with hearing impairment.

The CDG grant is a social protection mechanism directed at children with disabilities, such as hearing impairment; mostly within poor households [17, 41]; in order to address structural inequity and poverty [41]. However, literature suggests that the CDG is not enough to compensate for the disability-related costs faced by households with disabled members [42]. Evidently, the CDG was utilized in accordance with its intended purpose by somewhat sheltering caregivers and their families from the costs incurred as a result of the hearing impairment. However, the authors of the current paper argue that the Department of Social Development needs a re-structuring of the current CDG in order to ensure comprehensive support for children with disabilities, including hearing impairment.

The last major finding of the current study was caregivers' satisfaction with the EHDI process, in spite of the challenges raised. Without EHDI, children presenting with a congenital or early-onset hearing impairment will present with delayed speech and language milestones [25, 43]. This study's findings of delayed speech and language abilities following late-identified hearing impairment are consistent with studies by Fulcher et al. [44] and Maluleke et al. [19]. This finding highlights the need for widespread, timely, and comprehensive FC-EHDI services which will afford children with hearing impairment the

earliest possible identification and intervention [45]; in order to achieve age-appropriate speech and language outcomes [44].

Caregivers also expressed satisfaction with their child's academic performance. Findings of the current study support the established clear link between early identification and intervention of hearing impairment, speech and language development, as well as academic performance [19, 46]. As a group, children with hearing impairment show long-term academic difficulties than peers with typical hearing [47]. These academic difficulties particularly include reading and literacy [47, 48]. However, in Tomblin et al.'s [47] study, resilience by performing at a level comparable to peers with typical hearing was observed. Both findings, are reported in the current study. The resilience that was observed in Tomblin et al.'s [47] study was attributed to aided hearing and EI, with similar findings in the current study. These findings, therefore, demonstrate that when children with hearing impairment are identified early and receive intervention services timeously, they are likely to experience academic success [49] on par with their peers. These findings further highlight the need for widespread, timely, and comprehensive FC-EHDI services which will afford children with hearing impairment the earliest possible hearing loss identification and intervention.

Lastly, caregivers expressed satisfaction based on their child's general progress. Caregivers' self-reported levels of satisfaction acknowledge their actual experience with family-centered EI programs and make them the most suitable informants to improve accountability of the actual process from detection to intervention [50]. Similar findings of caregiver satisfaction have been reported in high-income countries by Jackson et al. [51], Alyami et al. [52] (2016), and Findlen et al. [53]. This account of caregiver satisfaction with current EHDI services within the South Africa context contribute to identify the gaps and incongruence in knowledge, beliefs, and practices that can ensure that the EHDI process

takes into consideration the linguistic, cultural, and socioeconomic diversity of South Africa's population [6].

Current findings should be interpreted bearing in mind the limitations of the study. These results are based on reports of events that occurred prior to the narrative interviews being conducted, thus time might have influenced caregivers' recall of their experience. Furthermore, inclusion of caregivers of children from EI preschools in Gauteng is not representative of the general population of caregivers of children with hearing impairment in South Africa. Moreover, caregivers were from an urban context and better-resourced province, thus their experiences may underrate the challenges and experiences of caregivers from rural contexts and under-resourced provinces. Therefore, it cannot be assumed that the findings of this study are representative of all caregivers and children with hearing impairment within the South African context.

6.6 Conclusion

Findings from the current study reveal limited availability, affordability, and accessibility of EHDI services within the South African context. Furthermore, EHDI services are not linguistically- and culturally-responsive to the diverse South African population. These findings highlight the lack of government support and funding for EHDI, along with fragmented implementation of EHDI services which render the current EHDI process ineffective. Thus, a need exists for economic evaluation of EHDI programs and widespread implementation of FC-EHDI within the South African context in order to ensure optimal developmental outcomes for children with hearing impairment within the documented contextual constraints. Furthermore, there is a need for re-structuring current EHDI processes in order to achieve multi-dimensional support that is required by children with hearing impairment and their families from the departments of health, social development, basic education and higher education.

Chapter 7 identifies the barriers and facilitators to the EHDI process from caregivers' perspectives (Objective 4). Furthermore, this chapter presents the specific study design, participant recruitment strategy, data collection and analysis methods employed to obtain the findings.

Chapter 7

Barriers and Facilitators to Early Hearing Detection and Intervention in South Africa: A Narrative Inquiry of Caregivers' Experiences[8]

(In Review, Appendix V)

7.1 Abstract

Background: South Africa, like other low-and-middle-income countries has a prevalence of paediatric hearing impairment. However, significant delays in the ages of identification, diagnosis, and intervention for children who are deaf or hard-of-hearing exist, due to numerous contextual barriers. The contextual barriers to early hearing detection and intervention have received a lot of research focus, yet the facilitators to these services have received limited research focus.

Methods: The aim of this study was to identify barriers and facilitators to these services, based on caregivers' experiences. This study adopted a narrative inquiry with nine, purposely selected caregivers of children who are DHH. The interview data were analysed using reflexive thematic analysis.

Results: Findings of the current study identified three barriers to early hearing detection and intervention services within the South African context, namely; professional-related, logistical factors, and caregiver-related factors. In addition to the barriers, the narrative interview data identified three facilitators, namely; caregiver knowledge, support services, and efficient service provision.

[8] Spelling variations in this chapter compared to the rest of the thesis are due to aligning the manuscript with the spelling used in *BMC Pediatrics*, the journal where this chapter was submitted.

Conclusion: Findings of the study suggest the need for context-specific solutions in order to ensure evidence-based best practice within this context. Furthermore, the context-specific facilitators identified in this study; provide an exceptional view of strategies that can be used to continuously strengthen EHDI service delivery within this context.

KEYWORDS: caregivers; early hearing detection and intervention, family-centered early intervention, early intervention, paediatric hearing impairment

7.2 Background[9]

Hearing impairment is the fourth leading cause of disability worldwide, but data on its prevalence and epidemiology in low-and-middle income countries (LMIC), including South Africa, is scarce[1,2,3,4] . The estimated incidence of congenital or early-onset hearing impairment in South Africa is about 6 in every 1000 live births or 20 babies born daily[5,6]. With such a high prevalence of paediatric hearing impairment within this context, early hearing detection and intervention (EHDI) has become an important goal for the audiology community; in order to curb the widely reported communication, cognitive and academic challenges that are consequences of a late-identified hearing impairment[4,5,6].

Universal Newborn Hearing Screening (UNHS) is the initial stage in any EHDI program and has become standard practice in high-income countries; however, such is not the case within the South African context[7]. Evidence within this context indicates significant delays in the ages of identification, diagnosis, and intervention for children who are deaf or hard-of-hearing (DHH)[8,9,10]. These delays have been linked to contextual barriers such as scarcity of financial, human and physical resources; locations of audiologists mainly in the private sector; burden of disease challenges; as well as transport, logistical, organizational and cultural challenges[2,5,6,11,12]. As a result of these barriers, paediatric hearing impairment is viewed as less urgent and has consequently received lesser financial attention and political will from the Department of Health[13,14] .

Facilitators to access to healthcare services, including EHDI, are not as evidently recorded in the literature[15]. Identified facilitators include legislative support for EHDI, financial support, friendly audiologists, awareness of hearing impairment, and availability of

[9] Vancouver referencing style is used in this chapter due to the manuscript that makes up this chapter having been submitted to *BMC Pediatrics*. The number are reflected in the reference list next to the corresponding reference and highlighted in grey.

support services[8,15,16]. The scarcity of reported facilitators, compared to barriers, may be due to limited research focus in this area and the lack of EHDI services in LMICs[15,17]. However, it is essential that the strengths and achievements of EHDI services be identified in order to ensure best practice and develop a standard of care, especially within the South African context[18].

Adherence to EHDI principles is the goal of any efficacious intervention program[2]. Within the South African context, these goals include identifying the hearing impairment no later than four months of age, and commencement of early intervention services no later than eight months of age[7,19]. In order to achieve these established goals, it is vital to develop and implement EHDI services that are contextually-responsive; and include input from caregivers and families of children who are DHH, as co-drivers of any intervention program. Exploring caregiver views would lead to EHDI services that are contextually-relevant and responsive; evidence-based; and are cognizant of child, caregiver and family needs[2]. Thus, the current study aimed to identify barriers and facilitators to the EHDI process based on caregivers' experiences.

This paper forms part of a larger research project titled *"Family-Centered EHDI: Caregivers' experiences and evaluation of the process and practices in the South African context",* forming part of the first steps in formulating a framework for FCEI for children who are DHH in South Africa.

7.3 Methods

7.3.1 Design

The current study employed a narrative inquiry which forms part of the mixed methods convergent design adopted for phase 1 of the larger research study.

7.3.2 Participants

Purposive, convenience sampling was used for this narrative inquiry, which enabled the lead researcher to recruit participants whose children were enrolled in early intervention preschools in Gauteng.

A small number of participants is recommended for narrative interviews in order to ensure that the researchers obtain in-depth information about the research question, which is not achievable with a large sample size[20]. Participants were recruited telephonically until data saturation was reached, and no new information was being obtained. Fifteen caregivers were recruited to participate in the study. Nine caregivers participated in the study thus, the recruitment rate was 60%.

The inclusion criteria for participants included:

- Caregiver of a child who is DHH
- Caregiver of a child diagnosed with a unilateral or bilateral, mild to profound
- Caregiver of a child who is DHH who was enrolled in an early intervention preschool in Gauteng from 2010-2018

7.3.3 Data Collection

The narrative interviews were conducted utilizing the interview schedule reflected in Box 1, below.

BOX 1: Interview script

- Tell me YOUR story.
- What were your expectations of the EHDI process?
- What do you think worked well or did not work so well with the EHDI process based on your experience?
- What made the EHDI process work well and what made it not work so well?
- How satisfied were you with the services that you received?

The narrative interview script was developed within a constructivism framework and guided by previous literature and the aims of the larger research study. A pilot study was conducted with two caregivers whose children were enrolled in the early intervention preschools, who were not part of the main study, to determine the suitability of the interview script. Results of the pilot study revealed that the interview script was appropriate. Two questions were rephrased for clarity.

The study had aimed to conduct data collection through face-to-face interviews only, however, these plans had to be changed to accommodate COVID-19 restrictions[21]. Three in-person interviews were conducted from January to February 2020, prior to the World Health Organisation (WHO) declaring COVID-19 a pandemic[22]; while telephonic (2) and videoconferencing (4) interviews were conducted from March to June 2020. All the interviews were audio-recorded. The interviews were conducted in English (5), Setswana (2), one in SeSotho (1), and IsiZulu (1), according to the participant's preference. The lead researcher, who conducted the interviews, was proficient in all these South African

languages, thus, there was no need for an interpreter. The interviews lasted an average of one hour, 10 minutes each.

In addition to the narrative interview, participants completed a socio-demographic questionnaire which included population group (race), home language, age, marital status, educational level, economic status, etc. (Appendix E). Three participants completed the informed consent letter and socio-demographic questionnaire in person. For six participants, who conducted telephonic and videoconferencing interviews, the informed consent letter and socio-demographic questionnaires were emailed to them.

7.3.4 Data Analysis

The audio-recorded interviews were transcribed verbatim and anonymized by allocating a participant number for participants and pseudonyms for the children. Data were analysed using reflexive thematic analysis according to the guidelines recommended by Braun and Clarke[23,24] , namely, a) familiarization with the data, b) generating initial codes, c) generating themes, d) reviewing potential themes, e) defining and naming themes, and f) producing the report.

Two bilingual translators translated five of the interviews conducted in an African language into the target language. A third bilingual person back translated the transcription into the source language[25].

In order to prevent bias and develop an intersubjective understanding of the findings, all the researchers were involved during the analysis process[25]. Reflexive thematic analysis is considered a reflection of the researcher's reflective and thoughtful engagement with the data and their reflexive and thoughtful engagement with the analytic process; thus, involvement of all the researchers during the analysis process allowed for exploration of multiple assumptions or interpretations of the data, as well as richer interpretations of the meaning of the data[26,27].

The results from the socio-demographic questionnaire were analysed using descriptive statistics.

7.4 Results

7.4.1 Description of Participants

Participants' socio-demographic profile is summarised in Table 7.1. All nine participants were female, with a mean age of 39 years. Of the nine participants, five were black, two were White, one was Coloured (Mixed race), and one was Indian. One participant had a post-graduate degree, three participants had a post matric diploma, 3 participants had matric, and 2 participants had a Grade 11 or lower as their highest qualification attained. Of the nine participants, five were employed, 2 were self-employed and another two participants were unemployed. Two of the participants each had two children who were diagnosed with hearing loss. This brought the total of children between the nine participants in the study to 11.

Table 7.1

Participants' socio-demographic profile

Heading	Sub-heading	Participants (N)
Gender	Male	0
	Female	9
Age	25-30	1
	31-36	3
	37-42	3
	43-48	2
Ethnicity	Black	5
	Coloured (Mixed race)	1
	Indian	1
	White	2

Heading	Sub-heading	Participants (N)
Marital status	Married	6
	Single	3
Highest qualification	Grade 11 or lower (Std 9)	2
	Grade 12 (Matric)	3
	Post-Matric Diploma	3
	Baccalaureate Degree(s)	0
	Post Graduate Degree(s)	1
Employment status	Employed	5
	Self-employed	2
	Student	0
	Unemployed	2
Number of children with hearing loss	One	7
	Two	2

Participants were caregivers of seven male and four female children who were DHH. The age range for these children at the time of the study was between six and 15 years, with a mean age of 10.2 years. The children's age of diagnosis ranged between zero and 30 months, with a mean age of 12 months. All eleven children presented with a congenital or early onset bilateral hearing impairment and were fitted with hearing aids and/or cochlear implants, bilaterally. The demographic and audiological profile of the children whose caregivers participated in the narrative interviews is summarised in Appendix S.

The results are presented according to the main themes. The themes that were generated from the data in the current study are presented in Table 7.2.

Table 7.2

Main themes and sub-themes identified from the narrative interviews

Barriers	
Themes	**Sub-themes**
Professional-related factors	• Lack of knowledge • Consulting "many people" before diagnosis • Mandatory use of the English language
Logistical factors	• Going "here and there" • Too many appointments • Nothing is within reach • It's not pocket change
Caregiver-related factors	• Lack of awareness • Lack of fathers' involvement
Facilitators	
Themes	**Sub-themes**
Caregiver knowledge	
Support services	• Family counselling and support • SASL training • Financial assistance
Efficient service provision	• "Nice" teachers • Caring audiologists • "Good" schools

7.4.2 Barriers to the EHDI process in South Africa

Three major themes were identified as barriers to the EHDI process from the narrative interviews; namely, professional-related factors, logistical factors, and caregiver-related factors.

7.4.2.1 Professional-related Factors. Six of the participants experienced delayed access to EHDI programs due to healthcare workers' (HCWs) dismissal of their concerns pertaining to their child not reacting to loud sounds or due to observed delayed speech and language milestone, resulting in late-diagnosis of the hearing impairment. These participants reported that their child had not received newborn hearing screening services.

"When I asked the 'sister'[nurse]… this child is almost 2 years, why is she not talking…She said I also don't know. I don't know what to say" (CG 2)

“She [Paediatrician] basically did a normal tympanogram and she said that she did not have any concerns about his language development, because at that point, around d18 months his speech development was slower than what I had expected.” (CG 5)

Furthermore, two participants reported having to go to various HCWs and appointments before their child was diagnosed with hearing impairment. Moreover, one participant reported being referred to three different HCWs before a referral to an audiologist was made.

"We had to go to doctor, to doctor, there were so many people" (CG 1)

Six out of nine participants reported mandatory use of the English language throughout the EHDI process, despite the fact that only three of the participants were from an English-speaking household. The six non-English speaking participants reported having to change the language used at home because they had been advised to only speak English with their child so as to avoid confusing them. Reasons given for mandatory use of the English language was that HCWs only provided speech therapy in English; and that schools that cater for the needs of learners who are DHH used English as a medium of instruction.

“She speaks English because she was receiving speech therapy in English at the clinic and the hospital.” (CG 2)

“Speech therapy was in English because at the time there were no Black speech therapists, it was only White and Indian.” (CG 3)

7.4.2.2 Logistical Factors. One participant reported receiving fragmented EHDI services from three different HCWs, in three different locations, which resulted in challenges with scheduling and attending the appointments.

"She receives speech therapy from Speech Therapist D. She gets audiology at Hospital C and the (cochlear) mapping is done at School G." (CG 7)

Furthermore, all the participants expressed frustration with having to attend "too many appointments" during the EHDI process. One participant reportedly changed to permanent night shift so that she would be able to keep up with her son's appointments and minimize absenteeism from work.

"I had to change to work night shift. We have permanent night shift….so you work one week in and one week off. So, I make appointments for the week I am off." (CG 3)

For five of the participants the number of appointments their child had to attend was exacerbated by co-occurring comorbidities such as attention deficit hyperactivity disorder (ADHD), visual impairment, migraines, and epilepsy which warranted intervention from different HCWs and in some cases, different locations.

"Dimpho attends neuro [neurology appointments], speech [therapy] and she is asthmatic. She is also receiving medication for epilepsy…So I used to be absent sometimes 3 to 4 days not going to work." (CG 3)

Five of the participants reported that EHDI services were far away and often in hard-to-reach areas when using public transport, which was the mode of transportation for three of the participants.

"None of the doctors were like close-by we go." (CG 1)

"It was quite a road to travel. I would drive 350 km a day to get him to talk." (CG 8)

Seven participants expressed frustration with the cost of services, amplification devices and accessories. Participants also reported that medical aids did not always pay for the full cost of the amplification device and/or accessories.

"It really comes down to, are you financially able to give your child the support they need?" (CG5)

"The things are so expensive." (CG 7)

7.4.2.3 Caregiver-related Factors. Two participants reported a lack of awareness of paediatric hearing impairment as well as speech and language developmental milestones which resulted in late-identification of their child's hearing impairment. These participants also reported that their child did not receive newborn hearing screening services.

"If the crèche didn't pick it up, we wouldn't have known that there is something wrong." (CG 1)

"I thought maybe she will talk because children are different" (CG 2)

Two participants also reported that fathers' absence during appointments affected decision-making during the EHDI process. The one participant reported making the decision to allow her daughter to undergo cochlear implantation surgery despite her husband's reluctance, which goes against her tradition.

"Her father was reluctant about having the cochlear implant fitted. I had received counselling when I went to Hospital B." (CG 2)

Another participant reported that the fathers' absence during appointments resulted in her daughter sometimes missing therapy because her father did not understand why she required weekly therapy or the urgency to replace hearing aid batteries when they ran out.

"At that time, he really did not understand because he didn't receive counselling." (CG 7)

7.4.3 Facilitators of the EHDI Process

Three major themes were identified as facilitators of the EHDI process from the narrative interviews; namely, caregiver knowledge, support services, efficient service provision.

7.4.3.1 Caregiver Knowledge. Three participants reported that the knowledge they gained during the EHDI process resulted in timely diagnosis of hearing impairment for younger siblings as well as that of friends' or employees' children.

> *"So, when Karabo was born I asked them to do the tests immediately so that if he also has a hearing loss, it will be best if he can be fitted with the cochlear implant while he is still young." (CG3)*

> *"She [domestic worker] had a little kid and the kid was like 6 months old and was not saying 'boo' or 'baa' or whatever.... I took her there and it was determined that she was deaf." (CG 8)*

7.4.3.2 Support Services. Two participants reported receiving family counselling and support services from the early intervention partner for families of hearing-impaired children, HI HOPES; which assisted with accepting and adjusting to their child's hearing impairment.

> *"Hi-Hopes came and visit us and speak about a child who is deaf and how to accept it. Which is good, I think." (CG 1)*

Two of the participants whose children used South African Sign Language (SASL) reported receiving training from their child's school on Saturdays, which enabled them to communicate with their child and assist them with their schoolwork.

"The first year, we did go to School B for Sign Language classes." (CG1)

"I know Sign Language, but I am not 100%, … I learnt it at the school…" (CG3)

Only three participants, who reported that their socio-economic status as average and below-average, received financial assistance in the form of free healthcare, donations, sponsors, subsidies and the care dependency grant (CDG). The financial assistance enabled these participants to access EHDI programs, ensured that their children had access to amplification devices and accessories, as well as ensure that caregivers could afford their child's school fees.

"All devices and therapies were free at the hospital" (CG 3)

"When she was at the pre-school, the speech therapists at Hospital B managed to get donations to pay for the rest of her fees." (CG 2)

"Audiologist B went through Hot FM and got a sponsor to pay for Karabo's [preschool] fees." (CG 3)

"I then went to Speech Therapist D, who said she would give me a subsidy (discount) … So, Speech Therapist D is the one who actually helped me out in terms of getting a [pre]school for my child." (CG 7)

"I use the grant money to help pay for their school fees." (CG 3)

7.4.3.3 Effective Service Provision. Five of the participants expressed appreciation for the EHDI team members and the quality of the service they received from their child's school; which encouraged them to adhere to the intervention process and intervention recommendations.

"I don't see her as an audiologist. I see her as my sister or mother because she was always there for me." (CG 3)

"At first I was not very keen on the school, but when my son was in there, he was a different child." (CG 6)

7.5 Discussion

The first barrier identified in the current study related to professional-related factors. Findings of the current study suggest HCWs' lack of knowledge of paediatric hearing impairment, risk factors, and its impact on speech and language development; as well as when to refer to an audiologist, which is concerning. Similar findings of HCWs' lack of knowledge and subsequent late identification of hearing impairment are reported in various countries, including South Africa[8,28,29]. Within the South African context, HCWs such as nurses and doctors are the first point of contact within the healthcare system for at least 85% of the population[11]. Thus, successful implementation of any healthcare program relies on the appropriate knowledge of these professionals[29]. Failure of HCWs to rightly refer children and caregivers to the audiologist compromises the EHDI process. Thus, until UNHS is realized, improved HCWs knowledge of paediatric hearing impairment will aid in earlier identification for children who were not screened at birth or who present with late-onset hearing impairment.

HCWs' dismissal of caregiver concerns also suggests a view of caregivers as passive consumers of healthcare services and not as experts of their own child, in accordance with family-centered early intervention (FCEI) principles, and as recommended by the HPCSA for services of children with hearing impairment[19,30,31]. This finding implies a need for a paradigm shift by HCWs from viewing the caregiver as a peripheral role player in child-focused interventions, to a care paradigm where caregivers have the opportunity to share their

opinions, expertise, needs and preferences with HCWs through FCEI[30,31,32]. Active caregiver involvement and engagement in EHDI is in line with HPCSA's EHDI guidelines and has been shown to optimize the child's developmental outcomes[19,31,33].

Furthermore, the current finding of all the participants receiving EHDI services does not align with the South Africa Government[34], which gives all 11 official languages equal esteem and treatment. English is the prominent language in political, educational, and social settings, within the South African context[35]. However, it is only spoken by 10% of the population as their home language[34]. Thus, provision of EHDI services in English does not respond to the needs of more than 11 million South Africans[36,37]. Due to South Africa's multicultural and multilingual population it is imperative that EHDI services are culturally and linguistically congruent[11,19].

The second barrier identified in this study was related to logistical factors. Ideally, an EHDI program should provide a continuum of care, with a multidisciplinary team of HCWs working together to implement a comprehensive program that includes, newborn hearing screening, diagnosis, and FCEI[38]. A lack of cohesion has been shown to hamper effective implementation of EHDI services[39]. Similar findings of caregivers attending numerous appointments before a diagnosis of their child's hearing impairment was made are reported in Khan and Joseph's[39] study. This finding of a lack of timeous and appropriate referral to the audiologist is especially significant in the South African context given the aforementioned burden of disease challenges[13,31]. However, through collaborative and interdisciplinary EHDI services, the child who is DHH and their family can benefit from timely and comprehensive intervention, while pooling the necessary resources to advance hearing health outcomes[11,39].

The finding of participants having to travel vast distances, often using public transport in order to ensure that their child received EHDI services confirms the distance challenges with access to healthcare reported in other studies[39,40,41,42]. Post-apartheid, the South African

government aimed to improve access to the poorest and marginalized, by expanding the physical availability of public healthcare, thus reducing distance challenges[40]. However, there is a limited number of audiologists employed in the public health sector when compared to those in the private health sector, resulting in a low audiologist-to-patient-ratio as well as a heavy clinical service load in the public sector[13]. Thus, reducing distance challenges within this context, did not translate to improving access to hearing healthcare services, specifically EHDI.

Implications of this finding are two-fold. Firstly, more audiologists are needed, especially within the public healthcare sector for more equitable capacity distribution and to curb the capacity-demand challenges that exist[6,12] . Secondly, de-specification of newborn hearing screening services and task shifting of these services to personnel such as nurses has been recommended as a viable alternative. This option is especially attractive within the South African context, not only due to the reported immunization coverage rates at public health clinics and community health centres which stand at 83%; but also considering that approximately 60% of births occur at the facilities[11,43,44].

Participants also experienced high costs of services, amplification devices and accessories, which were only partially covered by medical aids. Out-of-pocket costs for 16% of the population that are covered by medical aid are tangible barriers within the South African context[45]. The intended implementation of the national health insurance creates an opportunity to ensure that access to needed healthcare services does not place undue financial hardships on families[46,47]. However, the national health insurance will not be ready anytime soon, leaving the current healthcare arrangements with their own vulnerabilities, needing an urgent revamp[48]. Thus, current findings raise implications for further deliberations on ways to improving access to healthcare services, such as EHDI, through improving affordability of healthcare services.

Furthermore, despite available free primary healthcare in South Africa, affordability of healthcare remains a constraint; as monetary and time costs of travel to healthcare facilities also represent the price of access to healthcare[40]. Increased efforts by the South African government towards information and communication technologies and the fourth industrial revolution; coupled by telehealth's immense capabilities to increase access to healthcare services, as demonstrated during the COVID-19 pandemic make tele-audiology an attractive alternative to improving access to EHDI[49,50,51]. However, literature indicates that disparities in healthcare service delivery exist within this mode of service delivery due to low internet access rates a lack of digital health literacy in poorer households[52,53]. Furthermore, South Africa is experiencing challenges with meeting the country's electrical demands, resulting the implementation of various stages of power outages referred to as 'load shedding'[54,55]. The current load shedding challenges pose yet another challenge to telehealth within this context. Thus, further deliberations on internet access and use, especially within the remote contexts which are supposed to gain the most benefit from these services, are essential.

The third barrier identified in this study was caregiver-related factors. Caregivers' lack of awareness of paediatric hearing impairment delayed help-seeking for their child who is DHH. The current finding is not unique to this study[7,8,10] . The finding from the current study suggests a need to expand the health education provided to caregivers during antenatal care to include developmental milestones, paediatric hearing impairment and its impact on speech and language development[8], as well as available EHDI programs. Furthermore, it is important that the information is presented in the caregivers' home language as this can facilitate understanding[56], and influence caregiver recall and understanding[57]; which may affect the uptake of recommended services[11,57].

Caregiver-related factors also included lack of fathers' involvement in EHDI which affected decision-making. This finding of a lack of fathers' involvement in early intervention

is consistent with an all-female-participant sample in the current study. Furthermore, a lack of father's involvement in early intervention and research is highlighted by Hintermair and Sarimski[58], and Pedersen and Olthoff[59]. Positive associations between fathers' involvement and child outcomes such as cognitive and language skills are reported in literature[56,58,60]. Thus, this finding suggests a need for deliberations pertaining to fathers' involvement in EHDI within the South African context; with sensitivity towards cultural gender roles and caregiving responsibility. Furthermore, inclusion of "dad-focused" activities that are designed to be a father-son or father-daughter even may improve father's involvement in the intervention process[56,60,61].

In addition to the barriers, from the narrative interview data , themes pertaining to facilitators for EHDI services were generated. The first facilitator that was identified was caregivers' knowledge of paediatric hearing impairment and EHDI, resulting in earlier diagnosis for younger siblings as well as friends' and employees' children. This finding confirms the authors' earlier assertion of a need to expand the health education provided to caregivers during antenatal care. Increased maternal awareness of paediatric hearing impairment prompts earlier suspicion of hearing impairment, thus decreasing ages of identification of hearing impairment[8].

The second facilitator that was identified was related to support services. Availability of support services that reduce the burdens and stressors families experience, following diagnosis of their child's hearing impairment, are believed to make it easier for caregivers to focus on the needs and care of their child[62]. Communication mode notwithstanding, a child with hearing impairment presents unique communication challenges for hearing parents[56]. Audiologists are uniquely poised to support healthy family functioning from the start of the child's life by supporting all members of the family, as well as eliminate ineffective communication and strained caregiver-child interactions[58]. Furthermore, provision of

intervention in the family's home has been linked to improved child development and parenting[60]; and allows families to get the most benefit from tailored service delivery[62]. Thus, wide implementation of these services through FCEI is recommended in order to improve hearing healthcare access and outcomes[31].

Through free primary healthcare services, subsidy, donations, sponsorship, and the CDG; three participants were able to access EHDI services and pay for school fees that they would otherwise not have been able to afford. The World Health Organization[63] has encouraged countries to move towards achieving universal coverage, equity in access and guaranteed financial risk protection; hence the national health insurance, as outlined above. South Africa has one of the highest income inequalities in the world, such that the poorest 10% share about R1.1 billion compared with R381 billion shared by 10% of the richest population[64]. This alarming maldistribution of income means that more than 84% of the population may not be able to access health services due to high costs[65]. Thus, the current finding highlights a need to protect the poor from the high costs of healthcare, while guaranteeing them access to the care they need without needing to rely on the generosity of individual donors, sponsors, and subsidies- which stands at the heart of the proposed national health insurance[66]. Furthermore, this finding suggests a need for re-structuring the policies of addressing healthcare access need to be strengthened in order to ensure that they are all-inclusive in addressing the needs of all children with disabilities including children who are DHH.

The last facilitator that was identified from the narrative interviews was efficient service provision. Service quality is defined as the balance of expectation and satisfaction in the mutual relationships between customers and organizations addressing their needs[67]. The current findings of caregivers' appreciation of the services that they received are positive; however, the fact that this was not the experience for all the participants is concerning.

Amidst South Africa's aim to improve delivery of quality healthcare[68], regulatory bodies such as the HPCSA have developed guidelines with recommendations for best practice with regard to EHDI[19]; these guidelines align with the international consensus statement which articulates the tenets of the philosophy and promote wider implementation of FCEI[32,69]. Thus, the finding of the current study highlights a need for adherence to evidence-based principles and guidelines in EHDI programs; as well as evidence to support best practice within the South African context. Contextual best practice guidelines would improve access to EHDI, the quality of EHDI programs and outcomes for children who are DHH within this context.

The current findings should be interpreted bearing in mind the limitations of the study. These results are based on reports of events that occurred prior to the narrative interviews being conducted, thus time might have influenced caregivers' recall of their experience. Furthermore, inclusion of caregivers of children from early intervention preschools in Gauteng is not representative of the general population of caregivers of children who are DHH in South Africa. Moreover, due to use of reflexive thematic analysis, findings in this study do not provide a single or 'correct' answer, therefore, it cannot be assumed that the findings of this study are representative of all caregivers and children who are DHH within the South African context.

7.6 Conclusion

EHDI has become an important goal within the South African context, due to the high prevalence of hearing impairment. However, the contextual barriers identified in the current study including; professional -related factors, logistical factors, and caregiver-related factors suggest the need for context-specific solutions in order to ensure evidence-based best practice within this context. Furthermore, the context-specific facilitators identified in this study;

including caregiver knowledge, support services and efficient service provision, provide an exceptional view of strategies that can be used to continuously strengthen EHDI service delivery within this context.

7.7 Implications for Practice

Implementation of contextually-relevant and responsive EHDI services is crucial in ensuring that these services are both accessible and efficacious within the South African context, and other LMICs. This study sets a strong foundation upon which barriers and facilitators to EHDI in LMICs can be investigated in future research. Furthermore, findings of this study suggest a need for improved HCWs knowledge of paediatric hearing impairment; recognition of caregivers as co-drivers of EHDI services through FCEI; and expansion of the health education provided to mothers during antenatal care to include developmental milestones paediatric hearing impairment and its impact on speech and language development; and deliberations on strategies to improve fathers' involvement in the intervention process. Moreover, these findings suggest a need for improved access to EHDI services through de-specification of newborn hearing screening service and task shifting to nurses at public clinics and community health centres; as well as deliberations on of telehealth's potential and applicability in enabling audiologists to provide services that are culturally and linguistically appropriate.

7.8 Ethics Approval and Consent to Participate

The current study adhered to the Helsinki Declaration of 1975, as revised in 2013[70]. To this end, before data collection for the study could be conducted, ethical clearance was secured from the University of the Witwatersrand's Human Research Ethics Committee (Medical) (Protocol Number: H19/06/16).

To gain access to participants, written permission was obtained from two early intervention preschool centres which cater for children who are DHH in Gauteng, South

Africa, allowing the researchers access to the preschool records in order to identify potential participants for the current study. Researchers placed posters at reception areas of the preschools delineating the study, recruitment strategy, participant inclusion and exclusion criteria, as well as methods that were involved in data collection. Written informed consent was obtained from the participants prior to data collection.

In the next chapter, caregivers' perceptions of the extent to which the EHDI service they received were family-centred (Objective 6), and the association between caregivers' demographics and their perceptions of family-centredness they received (Objective 7) are presented. This chapter also presents the specific study design, participant recruitment strategy, data collection and analysis methods employed to obtain these findings.

Chapter 8

Family-Centeredness of Early Hearing Detection and Intervention Programs in South Africa[10]

(In Review, Appendix W)

8.1 Abstract

Objective: Early hearing detection and intervention continues to be a challenge in South Africa due to numerous contextual challenges. However, implementing family-centered early intervention services within this context could mitigate some of the access to healthcare challenges for children who are deaf or hard-of-hearing, as well as facilitate significant benefit from these services for both children who are deaf and hard-of-hearing and their families. Thus, this study aimed to determine caregivers' perceptions of the extent to which the EHDI services they received were family-centered, as well as to explore the association between caregivers' demographics and their perceptions of family-centeredness of the services they received.

Methods: A mixed methods convergent design was employed for the current study. Narrative interviews were conducted with nine participants, and sixteen participants completed the modified Measurement of Processes of Care-56, as part of the survey research.

Results: Results revealed that caregivers were satisfied with the family-centeredness of the EHDI services that they received; however, caregivers' experiences provide a unique opportunity for improvement of family-centered early intervention services within the South African context.

[10] Spelling variations in this chapter compared to the rest of the thesis are due to aligning the manuscript with the spelling used in the *Brazilian Journal of Otorhinolaryngology*, the journal where this chapter was submitted.

Conclusion: Findings from the current study reveal that early hearing detection and intervention services within the South African context are family-centered. However, for these services to be effective, linguistically and culturally-congruent; various considerations and deliberations of the contextual realities are required.

Keywords: EHDI, EI, FCEI, hearing impairment

Level of evidence: 3

8.2 Introduction[11]

Early hearing detection and intervention (EHDI) continues to be a challenge in low-and-middle income countries (LMICs), including South Africa[1,2,3]. Challenges associated with implementation of EHDI in this context have been attributed to capacity versus demand challenges, shortage of equipment, and a lack of newborn hearing screening (NHS) programs, burden of disease challenges, social determinants of health, as well as physical and economic aspects related to access to healthcare[1,4,5,6,7]. Furthermore, access to EHDI programs is significantly affected by linguistic and cultural differences that are not responsive to the population's needs[6,8,9].

The Health Professions Council of South Africa [HPCSA][10], recommends that early intervention (EI) services for children who are deaf or hard-of-hearing (DHH) must be family-centered within a community-based model of service delivery that is culturally congruent. Maluleke et al.[11], argue that the HPCSA's[10] recommendation can be achieved through establishing Family-Centered Early Intervention (FCEI) services. FCEI services could mitigate the access to healthcare challenges experienced by these and their families. Evidence from high-income countries (HIC) has demonstrated the benefits of FCEI including; developmental gains for the child; as well as better psychological well-being, increased self-efficacy, and a sense of control for caregivers[12,13,14,15]. However, despite these documented benefits, there is a lack of research focus on FCEI within the South African context.

[11] Vancouver referencing style is used in this chapter due to the manuscript that makes up this chapter having been submitted to the *Brazilian Journal of Otorhinolaryngology*. The number are reflected in the reference list next to the corresponding reference and highlighted in pink.

Thus, the current study aimed to determine caregivers' perceptions of the extent to which the EHDI services they received were family-centered; and explore the association between caregivers' perceptions of the family-centeredness of the EHDI services they received and socio-demographic factors. This study forms part of a larger research project titled "Family-Centred EHDI: Caregivers' experiences and evaluation of the process and practices in the South African context".

8.3 Methods

A mixed methods convergent design was employed in this study. Narrative interviews and survey research were conducted for the qualitative and quantitative strands, respectively.

8.3.1 Ethical Considerations

This study adhered to the Helsinki Declaration of 1975, as revised in 2008[16]. Prior to conducting the study, ethical clearance was secured from the University's Human Research Ethics Committee (Medical) (Protocol Number: H19/06/16), and permission was obtained from all relevant authorities. Informed consent was also obtained from all the participants.

8.3.2 Participants

Non-probability purposive sampling was used in this study. Different sample sizes were used for the qualitative and quantitative strands of the convergent design. Caregivers who participated in the study met the following inclusion criteria:

- Caregiver of a child diagnosed with a mild to profound, bilateral, or unilateral hearing impairment.
- Caregiver of a child who was enrolled in an EI preschool centre in Gauteng, South Africa, between 2010 and 2020.

8.3.2.1 Qualitative Strand (Narrative Interviews). A small number of participants was used during the narrative interviews in order to ensure that the researchers obtain in-depth information about the research question, which would not achievable with a large sample size[17]. Participants were recruited telephonically until data saturation was reached.

Nine (n=9) caregivers participated in the narrative interviews; their socio-demographic profile is summarised in Table 8.1.

Table 8.1.

Participants caregivers' socio-demographic profile

Heading	Sub-heading	Participants (N)
Gender	Male	0
	Female	9
Age	25-30	1
	31-36	3
	37-42	3
	43-48	2
Ethnicity	Black	5
	Coloured (Mixed race)	1
	Indian	1
	White	2
Marital status	Married	6
	Single	3
Highest qualification	Grade 11 or lower (Std 9)	2
	Grade 12 (Matric)	3
	Post-Matric Diploma	3
	Baccalaureate Degree(s)	0
	Post Graduate Degree(s)	1

Heading	Sub-heading	Participants (N)
Employment status	Employed	5
	Self-employed	2
	Student	0
	Unemployed	2
Number of children with hearing loss	One	7
	Two	2

The demographic and audiological profile of the children whose caregivers participated in the narrative interviews is summarised in Appendix S.

8.3.2.2 Quantitative Strand (Survey Research). Twenty-one (*n*=21) participants, including the nine caregivers who participated in the narrative interviews, participated in the survey. Sixteen participants completed the modified Measurement of the Processes of Care-56 (MPOC-56) (57% response rate) and 21 participants completed the demographic questionnaire (75% response rate). The different sample size in the was factored in all statistical analysis[18]. Thus, the sample size used for all statistical analysis was 16. Participants' socio-demographic profile is summarised in Table 3.

8.3.3 Data Collection

Data collection was conducted using narrative interviews (Appendix D) and the modified MPOC-56 (Appendix F).

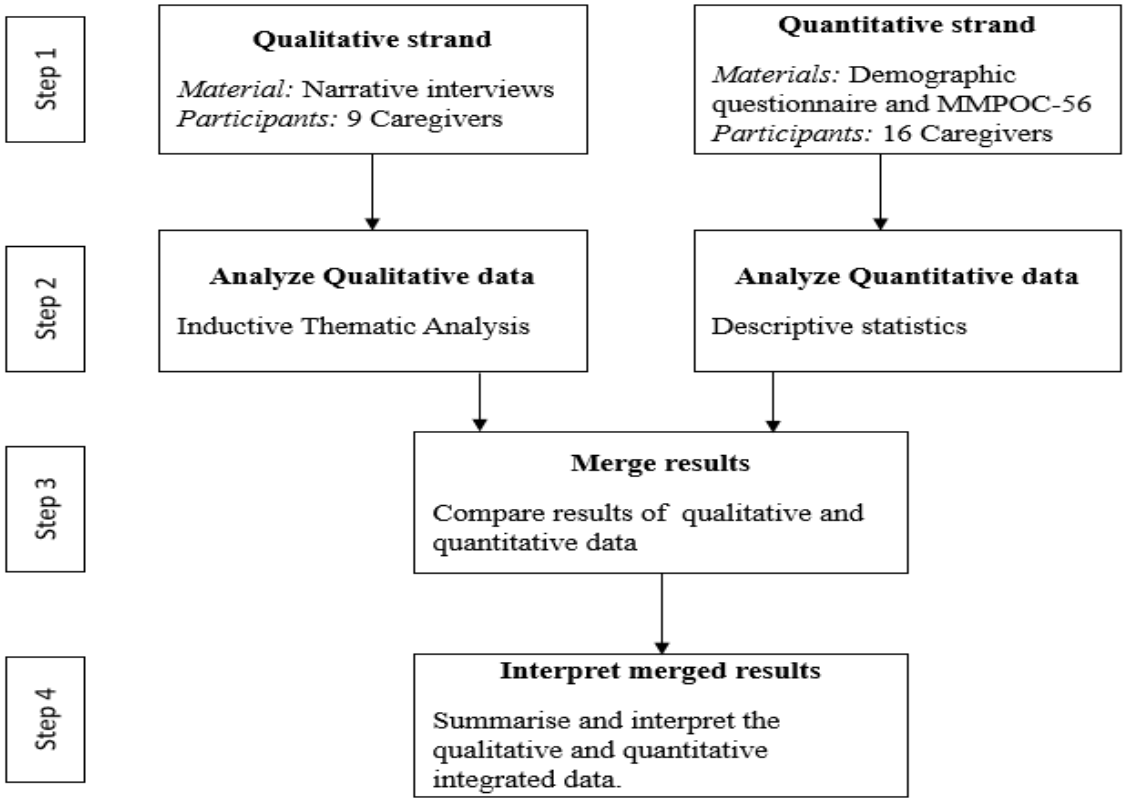
8.3.3.1 Narrative Interviews. In-person, telephonic and videoconferencing interviews were conducted. Two interviews were conducted in English, two in Setswana, one in SeSotho, and one in IsiZulu; according to participants' preferences. The lead researcher conducted all the interviews and is proficient in all these South African languages, thus an interpreter was not needed.

8.3.3.2 Survey Research. The family-centeredness of paediatric habilitation services was measured using the modified MPOC-56; a 56-item, standardized tool that measures the family-centeredness of the behaviours of healthcare service providers (HCPs)[13,19,20]. The MPOC-56 uses closed-ended questions and comprises of five factorially determined domains. Responses are made using a 7-point Likert scale which ranges from 0 (never) to 7 (to a great extent)[13].

8.3.4 Data Analysis

Initially, the qualitative and quantitative data were analysed independently and separately. Then findings from both data sets were compared, interpreted and discussed[17] (see Figure 8.1).

Figure 8.1
Mixed-methods convergent design



8.3.4.1 Narrative Interviews. Data collection and data analysis were conducted simultaneously in order to ensure that participant recruitment and data collection are discontinued once data saturation is reached[21]. All the interviews were audio-recorded, transcribed verbatim, and anonymized by allocating a participant number for participants and pseudonyms for the children.

Reflexive thematic analysis was used to analyse the narrative interviews. For all interviews conducted in an African language, two bilingual translators translated the recordings into English and another bilingual translator back-translated the interview transcript into the source language. Themes that were identified from the current data were analysed using the guidelines recommended by Braun and Clarke[22,23]. To prevent bias and intersubjective understanding of the findings, all the researchers were involved in the analysis[24,25]. Furthermore, a rich description of the participants and the children who are DHH, as well as representative verbatim quotations are provided.

8.3.4.2 Modified MPOC-56. The survey results were analysed using descriptive statistics. Furthermore, the association between personal, family and socio-demographic factors and caregivers' perceptions of family-centeredness of the EHDI services they received was established using the Kruskal-Wallis test. All statistical analysis was conducted using the Stata software.

8.4 Results

Table 8.2 reflects the sub-scale scores for all the five domains of the modified MPOC-56.

Table 8.2
Modified Measure of Process of Care (MMPOC-56) domain scores

Domain	N	Mean	Std. Dev	Min	Median	Max
Enabling and partnership	16	5.8	1.3	2.4	6.5	7.0
Providing general information	16	6.0	0.9	4.1	7.0	7.0
Providing specific information	16	6.3	1.3	4.2	7.0	7.0
Coordinated and comprehensive care	16	6.2	0.8	4.6	6.0	7.0
Respectful and supportive care	16	5.5	1.4	3.2	6.0	7.0

0= not applicable, 2= not at all, 3= to a very small extent, 4= to a moderate extent, 5= to a fairly great extent, 6= to a great extent, 7= to a very great extent

The *respectful and supportive care* domain received the lowest sub-scale score, which demonstrates that HCPs did not consistently demonstrate due regard to participants' knowledge and insight into their child as illustrated by participants' reports of HCPs dismissing their concerns pertaining to their child not reacting to loud sounds or observed delayed speech and language milestones, which resulted in late identification of the hearing impairment, as evidenced by the following statement:

> *" She [paediatrician] said that she did not have any concerns with his language development because at that point, at 18 months his speech development was slower than what I had expected"* (CG 5)

The *enabling and partnership* domain received the second-lowest sub-scale score. Six of the nine participants do not speak English as their home language; however, all EHDI services were conducted in English. Reasons provided for the recommended use of English were that EHDI services are provided in English and that available schools that cater for the needs of learners who are DHH used English as a medium of instruction. Two of the participants stated the following:

"Maybe they should try to have 3-4 black therapists at each hospital so they can be able to speak the same language as the patient." (CG 3)

"I was trying to tell the kids and everyone else in the house to try and speak English so she can make progress with her speech. So, that thing was so hard for them so I left it." (CG 7)

The *providing general information* domain received the third lowest sub-scale score. Participants were satisfied with the general information that they received during EHDI services as illustrated by the following quotes:

" Hi-Hopes came and visit us and speak about a child who is deaf and how to accept it... Which is good, I think." (CG 1)

"They gave me an indication that if they had to start a Boeing 747 next to his head, he would hear it as a pin drop. That was pretty much deaf, deaf." (CG 8)

The *coordinated and comprehensive care* domain received the second-highest sub-scale score. Participants were satisfied with the manner which the care they received was coordinate and all-inclusive of the services that their child needs, as illustrated by the following quote:

"Everything so far has been working out quite well. It's all positive, everything is just working out to what he needs." (CG 6)

However, some participants reported dissatisfaction with this aspect, as evident in the following quotes:

"...refer us to the right people at the right time, not for us to go here and there…. " (CG 1)

"Each child had their own appointment date. So, I used to be absent sometimes 3 to 4 days not going to work." (CG 3)

The *providing specific information* domain received the highest sub-scale score. Participants were satisfied with the information that was provided to them, that was specific to their child and their family during EHDI services. This information allowed them to make informed decisions for their child and allowed them to learn South African Sign Language (SASL). Three participants stated the following:

" I received genetic counselling... So, when Tshwarelo was born I asked them to do the tests immediately…" (CG3)*

"Her father was reluctant about having the cochlear implant fitted. I had received counselling when I went to Hospital B." (CG 2)

"I know Sign Language, but I am not 100%, that much. But I can communicate with them." (CG3)

As part of the second aim of the study, no statistically significant difference was identified between personal, family and socio-demographic factors and caregivers' perceptions of family-centeredness of the EHDI services they received, across all domains. Notably, the p-values for the statistical association between gender and enabling partnership ($p=0.15$), employment status and general information ($p=0.09$), employment status and specific information ($p =0.10$), language used for EI and enabling and partnership ($p=0.12$), language used for EI and general information ($p=0.11$), language used for EI and specific information ($p=0.06$), and language used for EI and coordinated care ($p=0.09$) all approximated $p \leq 0.05$. Thus, with a larger sample size a statistical association may be observed across these domains and participants' personal and socio-demographic profiles, specifically, and as well as all domains' socio-demographic profiles in general.

8.5 Discussion

Current evidence supports the implementation of intervention that is family-centered, however, in practice, implementation of FCEI is in very early stages in most countries[19], including South Africa. To the best of our knowledge, this is the first study using the MPOC-56 to evaluate EHDI services within the South African context. Thus, responding to the call for healthcare services evaluations not to only focus on outcomes, but also the quality of services provided from the end-user's perspectives[20].

Findings of the current study suggest that EHDI services within the South African context are embracing the values of FCEI, to various degrees across the five domains. HCPs' embrace of FCEI demonstrates the recognition that the child and family must be viewed in context[26,27], which is very much linked to the African spirit of *ubuntu,* that places significant value on family and community rather than the individual.

The current study's sub-scale scores are between 5.5 and 6.3 across the five domains is consistent with studies conducted by McManus et al.[12], Antunes and Vas[19], and Shevell et al[20] with sub-scale scores between 4.1 and 6.7 across the five domains. Furthermore, relating the current study's MPOC-56 findings to participants' narrative interviews provided unique insights for quality improvement of FC-EHDI services.

The *respectful and supportive care* domain obtained the lowest domain sub-scale score, followed by the *enabling and partnership* domain. Provision of care that is respectful and responsive to the child and their family's needs, preferences, and values is an integral principle in FCEI[28,29] . If HCPs do not demonstrate the necessary skills associated with respectful and supportive care, negative outcomes are to be expected[30]. Thus, the current study's findings of HCPs' dismissal of caregiver concerns suggests a view, by HCPs, of caregivers as passive consumers of healthcare services and not as active participants and key

co-drivers in a family-professional partnership. Furthermore, the use of English with six non-English speaking participants throughout the EHDI process does not align with the *enabling and partnership* domain and creates a paradox which does not respond to the population's needs[6,8,31].

Implications for this finding are three-fold. Firstly, there is still a need for HCPs to embrace the notion of caregivers as partners in the intervention process; and provide them with the opportunity to share their opinions and expertise through FC-EHDI[11,32,33]. Secondly, HCPs lack of prompt action based on caregiver concerns significantly compromises the EHDI process. Until universal newborn hearing screening (UNHS) is realized within this context, improved HCPs regard for caregiver concerns is vital towards earlier identification of paediatric hearing impairment[29,34]. Thirdly, clinical interactions must be conducted in a language which the child, caregiver and family can understand, especially where the core scope of function is in communication pathology[10,26,35]. Using the language that the caregiver can understand has significant implications for follow-up of treatment options, commitment and adherence to treatment recommendations, as well as improved health outcomes[36,37,38] .

Inherently, EHDI programs support the philosophy that families must have the information they need to make the best decisions throughout their journey of raising a child who is DHH[39]. Thus, caregivers require HCPs to provide general and specific information pertaining to the child's hearing impairment. Findings pertaining to the *providing general information* domain and the *providing specific information* domains, are encouraging. Ninety percent of children who are DHH are born to hearing caregivers, who often have limited knowledge of paediatric hearing impairment[40]. Thus, informational counselling is vital for these caregivers within the EHDI process[11,37]. According to Davids et al.[41], caregivers need diverse information about hearing impairment including; developmental outcomes, the needs for family-centered service provision, education, and future opportunities. Provision of

relevant and necessary information can empower families to make decision about their children and alleviate the stress that arises from uncertainty[19,42]. Thus, the current authors agree with David et al.'s[41] contention that the informational counselling provided to caregivers should be provided in a responsive and sensitive manner for them to be amenable to accessing follow-up services – for sustainability of the intervention.

Findings of the current study also revealed a lack of informational counselling for fathers due to their absence during consultations. Similar findings of limited participation of fathers during EI are reported in Hintermair and Sarimski's[43] study. Reasons for fathers' limited participation include work schedules; and traditional role perceptions of fathers as breadwinners and mothers as caregivers. Paternal participation in childcare has been associated with improved language and cognitive development, fewer behavioural problems at school, better development of self-regulatory and pro-social skills, and better positive psychological adjustment[43,44]. Thus, authors of the current paper argue that paternal involvement in EHDI services within the South African context requires serious deliberation, if better health outcomes have been linked to it.

Ideally, EHDI services should provide a continuum of care, with a multidisciplinary team of HCPs working together to implement a comprehensive program that includes, UNHS, diagnosis, and FCEI[45]. A lack of cohesion has been shown to hamper effective implementation of EHDI services[46,47]. While encouraging, findings from the current study pertaining to the *coordinated and comprehensive care* domain, demonstrate that EHDI services are highly fragmented. This finding is characteristic of the South African healthcare system[48] and suggests an urgent need for centralized, interdisciplinary FC-EHDI services. According to Khan et al.[29], the effectiveness and success of EHDI services is contingent upon EHDI team members being involved in an interdisciplinary team. This interdisciplinary approach of shared knowledge and skill for a common goal, will advance hearing health and

developmental outcomes of children who are DHH, while pooling the necessary resources into an efficiently run healthcare system – as advocated by the World Health Organization[49].

Notably, no association was established between personal, family and socio-demographic factors and caregivers' perceptions of family-centeredness of the EHDI services they received. In Shevell et al.'s[20] study, higher socio-economic status was significantly associated with a lower median score on the *providing general information* and *providing specific information* domains, respectively. This finding was attributed to higher socio-economic status being associated with greater caregiver expectations for information from HCPs. The difference between the current findings and Shevell et al.'s[20] findings may be attributed to the different contexts in which the studies were conducted, as well as populations included in the two studies.

The current study's findings must be interpreted paying cognizance to the study's identified limitations. The results reported in this paper are based on reports of events that occurred prior to the narrative interviews being conducted and completion of the modified MPOC-56, thus time might have influenced caregivers' recall of their experience. Furthermore, inclusion of caregivers of children from EI preschools in Gauteng only is not representative of the general population of caregivers of children who are DHH in South Africa. Therefore, it cannot be assumed that the findings of this study are representative of all caregivers and children who are DHH within the South African context. An investigation of caregivers' expectations of EHDI services from different geographical locations and healthcare facilities is warranted, particularly where rurality and low socio-economic status may have influence.

8.6 Conclusion

Findings from the current study reveal that EHDI services within the South African context are family-centered. Caregivers were satisfied with the family-centeredness of the

EHDI services they received. Caregivers' experiences provide a unique opportunity for improvement of FC-EHDI services within the South African context. For effective FC-EHDI services that are linguistically and culturally-congruent, due regard of caregivers as partners in the intervention process is vital. Caregivers must be enabled to participate fully in EHDI services through ensuring that these services are conducted in a language that the caregivers can understand. Furthermore, HCPs should provide informational counselling that is responsive to the child, caregiver and family's needs. Moreover, paternal involvement in EHDI within the south African context requires serious deliberation.

Chapter 9 explores caregivers' preferences for characteristics associated with EHDI services (Objective 8); including the specific study design, data collection materials, data collection procedures, and data analysis methods employed to obtain the findings.

Chapter 9

Caregivers' Preferences for EHDI Services in South Africa: Evidence from a conjoint analysis

(Submitted, Appendix X)

9.1 Abstract

Background: Early Hearing Detection and Intervention (EHDI) is recognised as the standard of care for newborns and infants presenting with a hearing loss, to ensure that these children communicate effectively and develop to their maximum potential. Some progress has been made towards implementation of these programs within the South African context. However, there is a dearth of research of caregivers' preferences for EHDI programs. Caregivers play a significant role in the well-being and development of children with hearing loss, and their preferences can greatly influence the outcomes of intervention efforts.

Objective: This study explored the caregivers' preferences for EHDI programs for children with hearing loss. A conjoint analysis was conducted with thirty-one caregivers of children with hearing loss. Data were analysed using conditional logit model.

Design: Findings in this study provide valuable insight for the development of context-specific and context-responsive EHDI programs for children with hearing loss and their families. Results from this study indicated that caregivers preferred that EHDI services be (1) conducted in their home language, (2) diagnostic evaluations be conducted at their nearest healthcare facility (HCF), (3) early intervention services be provided at their home, (4) support service be provided as a regular part of early intervention services, and that (5) the cost of EHDI services be decreased in order to ensure affordability of these services.

Conclusion: Understanding caregivers' preferences is essential for effective evidence-based practice for EHDI programs, especially within the South African context where such programs are limited. Findings from this conjoint analysis allow for quantification of the trade-offs caregivers are willing to make between the different attributes and attribute levels, providing valuable insights into treatment preferences within EHDI programs. These findings can help in optimising early intervention strategies, improving patient satisfaction, and enhancing treatment outcomes in this population, in this context.

Keywords: early intervention, EHDI, conjoint analysis, discrete choice experiment, hearing loss

9.2 Introduction

Early Hearing Detection and Intervention (EHDI) is recognised as the standard of care for newborns and infants presenting with hearing loss, and encompasses the earliest possible identification, diagnosis, and provision of intervention for these newborns and infants, to ensure that they can communicate effectively and develop to their maximum potential (HPCSA, 2018; Naidoo & Khan, 2022). A review of published literature on EHDI within the South African context highlights the country's considerable efforts towards implementation of these programs (Hussein et al., 2018; Kanji, 2016; Khan et al., 2018; Naidoo & Khan, 2022). Despite the documented progress, EHDI programs within this context are still limited, resulting in late diagnosis and intervention for children with hearing loss (Ehlert & Coetzer, 2020; Hussein et al., 2018; Khoza-Shangase, 2019; Storbeck & Young, 2016; Swanepoel & Clark, 2019). Furthermore, despite a waiver of user fees being implemented at public healthcare facilities (HCFs), EHDI services are not affordable to the general public due to the high costs associated with these services, costs of amplification devices and accessories within the private healthcare sector, as well transport costs to public HCFs (Gordon et al., 2020; Khoza-Shangase, 2019; Maluleke et al., 2023).

Additionally, challenges with accessing EHDI services due to capacity versus demand challenges; differences between the care in public and private healthcare sectors; as well as language and cultural incongruence between the general public and the largely white, female, English- or Afrikaans-speaking staff complement, have also been reported (Hussein et al., 2018; Khan et al., 2018; Khoza-Shangase, 2019; Khoza-Shangase & Kanji, 2021; Pillay et al., 2020). These challenges underscore the need for context-specific research within the South African context to guide best practice that is relevant and responsive to these contextual realities (Khoza-Shangase, 2021; Khoza-Shangase et al., 2017; Kanji & Khoza-Shangase, 2021). Feasibility of, approach to, barriers and facilitators of, as well as the models

of care of EHDI programs have been investigated and documented within this context; however, investigations of caregivers' preferences for EHDI programs are lacking within this context.

Preference in healthcare refers to the specific activity, treatment and provider conditions that patients desire for their healthcare experience (Swift et al., 2021); while attribute refers to the characteristics, features, of healthcare services (Ryan & Farrar, 2000). Considering patient preference when making healthcare decisions is increasingly considered an essential element of evidence-based practice (Dirksen et al., 2013; Smith et al., 2020). When intervention has taken patients'' preferences into account, interventions become more tailored and customised; engagement between the patients and healthcare providers become enhanced; cultural and linguistic considerations are addressed; patient satisfaction and compliance with adherence to treatment recommendations are increased; and program development and policy are informed (Sekhon et al., 2017; Khoza-Shangase, 2022; Mtimkulu et al., 2023). These factors may impact on the overall effectiveness of the intervention and improved outcomes for patients (Sekhon et al., 2017, Mtimkulu et al., 2023).

Thus, the current study aimed to explore caregivers' preferences for EHDI services for caregivers of children with hearing loss. This study focuses on caregivers as important co-drivers of any early intervention program; and forms part of a larger research project entitled "Family-Centred EHDI: Caregivers' experiences and evaluation of the process and practices in the South African context", describing the first steps in formulating a framework for FC-EHDI for children with hearing loss within the South African context.

9.3 Methods

9.3.1 Study Design

This study employed a conjoint analysis design. A conjoint analysis (or discrete choice experiment) is a survey approach that uses survey methods to elicit trade-offs among attributes and attribute levels to determine participants' preferences for goods and services with a series of hypothetical scenarios (Eggers et al., 2021; Larsen et al., 2021). This approach provides an estimation of the relative importance people attribute to various components of care, measures how individuals are willing to trade between these attributes (characteristics or features) and estimates the overall satisfaction they gain from various forms of health service provision (Ali & Ronaldson, 2012; de la Cuesta et al., 2022; Eggers et al., 2021). A conjoint analysis adopts a Lancastrian framework which assumes that every individual has a preference over the set of alternatives available to them based on the perceived benefit of using the good or service (Lancaster, 1966; Mangham et al., 2009; Ryan et al., 2001). Conjoint analysis can be used to assess the relative importance of different factors or attributes related to treatment options. In EHDI, this information can be valuable in determining the preferences of caregivers and designing effective early intervention strategies.

9.3.2 Participants

Non-probability purposive sampling was used in this study. Thirty-one of the forty (77.5%) caregivers recruited to participate in the study completed the conjoint analysis questionnaire. Caregivers who participated in the study met the following inclusion criteria:

- Caregiver of a child diagnosed with a mild to profound, bilateral, or unilateral hearing loss.

- Caregiver of a child who was enrolled in an EI preschool centre in Gauteng, South Africa, between 2010 and 2020.

Table 9.1 summarises caregivers' socio-demographic information.

Table 9.1

Participants' socio-demographic profile

Heading	Sub-heading	Participants N (%)
Gender	Male	4 (12.9%)
	Female	27 (87.1%)
	Prefer not to answer	0
Age	35 years or younger	6 (19.4%)
	36-45 years	22 (71%)
	46-55 years	3 (9.7%)
	56 years and older	0
	Prefer not to answer	0
Ethnicity	Black	12 (38.7%)
	White	11 (35.5%)
	Coloured (Mixed race)	5 (16%)
	Indian	2 (6.5%)
	Prefer not to answer	1 (3.2%)
Marital status	Single	6 (19.4%)
	Married	24 (77.4%)
	Divorced	1 (3.2%)
	Separated	0
	Widow	0
	Prefer not to answer	0

Heading	Sub-heading	Participants N (%)
Highest qualification	Grade 11 or lower (Std 9)	2 (6.5%)
	Grade 12 (Matric)	11 (35.5%)
	Post-Matric Diploma	8 (25.8%)
	Baccalaureate Degree(s)	3 (9.7%)
	Post Graduate Degree(s)	6 (19.4%
	Prefer not to answer	1 (3.2%)
Employment status	Student	0
	Employed	22 (71%)
	Self-employed	8 (25.8%
	Prefer not to answer	0
	Unemployed	1 (3.2%)

Most of the caregivers were female (87.1%), between the ages of 36 and 45 years (71%), married (77.4%), with a Grade 12 (35.5%) highest level of qualification, and employed (71%). Of the caregivers, 38.7% were Black, 35.5% were white, 16.1% were Coloured and 6.5% were Indian, when using the race classification system used in South Africa.

9.3.3 Ethical Considerations

Prior to the commencement of this study, ethical clearance was obtained from the university's Human Research Ethics Committee (Medical) (Protocol Number: H19/06/16). Furthermore, the work adhered to the Helsinki Declaration of 1975, as revised in 2013 (World Medical Association, 2013).

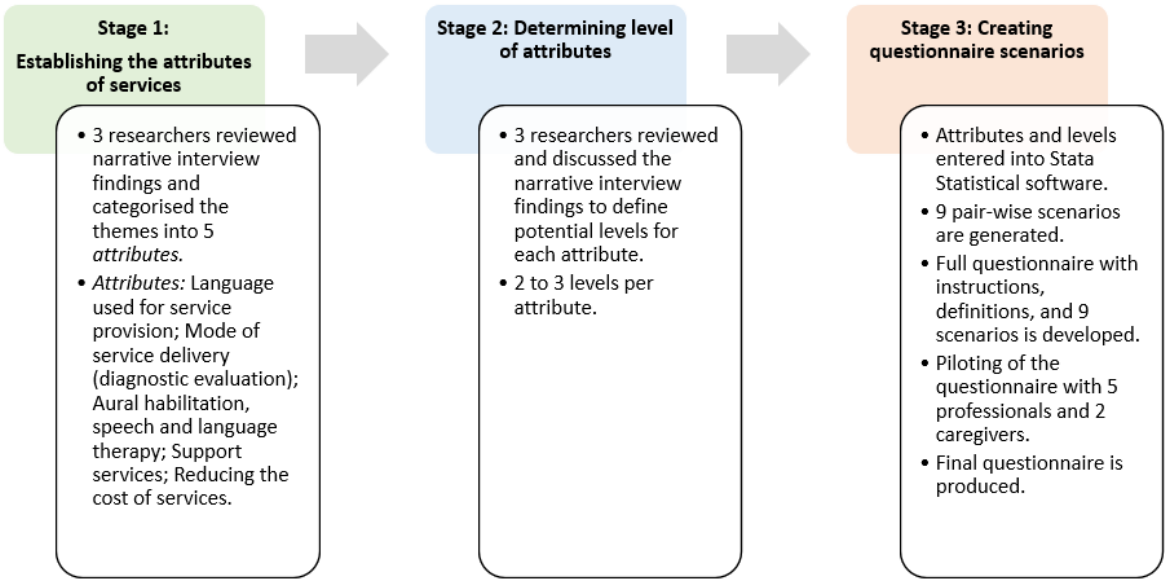
9.3.4 Materials

Data were collected using a Google Forms conjoint analysis questionnaire. The questionnaire was in English and comprised of two sections, a demographic questionnaire section and a conjoint analysis section.

The conjoint analysis questionnaire formed part of phase 2 of the main study. Following the definition of the research question where the specific objectives of the study were determined, the conjoint analysis questionnaire was developed according to the steps as outlined in Reed et al. (2013). The development of a conjoint analysis questionnaire is made up of three stages, namely, establishing the attributes of services, determining level of attributes, and creating questionnaire scenarios, as depicted in Figure 9.1 below.

Figure 9.1

Description of conjoint analysis questionnaire development



Stage 1: Establishing the attributes of services. This stage involved identifying the principal attributes and attribute levels of the services. For this study, the narrative interview findings previously reported in Maluleke et al. (2023) informed the content of the

questionnaire. A literature review was also conducted to supplement the identified attributes and levels. Five main attributes were included to ensure that the conjoint analysis survey instrument was manageable, and these were: 1) language used for service provision, 2) diagnostic evaluation, 3) aural habilitation, speech and language therapy, 4) support services, and 5) reducing the cost of services.

Stage 2: Determining level of attributes. In this stage, the levels (options) of care were defined for each attribute. The level represents a choice that describes an attribute, and each attribute was defined by three levels, resulting in the creation of scenarios.

The final list of attributes and levels is provided in Table 9.2.

Table 9.2

Attributes and attribute levels

Attributes	Attribute levels		
Language used for service provision	English	Home language	Any one of the South African languages.
Diagnostic evaluation	Child receives EHDI services and is referred to other HCWs (i.e., pediatrician, social worker, psychologist) of the caregiver's choice for all the other services that the child/and or caregiver need.	Child receives EHDI services at the nearest healthcare facility that offers all services (i.e., ENT, psychology) that the child/and or caregiver need.	Child receives all EHDI services (i.e., audiology, speech therapy, ENT, psychology) via telehealth. Child and caregiver might be required to go to the healthcare facility for some tests/procedures.

Attributes		Attribute levels	
Aural habilitation, speech and language therapy	Regular direct therapy sessions (i.e., once a week) at the nearest healthcare facility.	Regular sessions (i.e., once a week) at home with the child, caregiver and HCW.	Regular sessions (i.e., once a week) at home with the child, and caregiver via telehealth. Direct therapy is then offered if there is a speech and/or language delay or no progress.
Support services	Caregivers information sessions.	Regular part of services according to the child, caregiver, and family's needs.	Caregivers seek information independently.
Reducing the cost of services	Decrease transport cost to healthcare facility.	Decrease cost of services i.e., screening, evaluation, aural habilitation, speech and language therapy, etc.	Decrease cost of amplification devices, FM systems, etc.

Stage 3: Creating scenarios. Once the attributes and levels were determined, these were combined into pairwise choices, for each scenario. All the possible pairwise choices would render the questionnaire unmanageable, thus the scenarios were developed using a fractional factorial design in STATA 17. Nine scenarios with pairwise choices identified as "Service A" and "Service B", with the carrier phrase "Which service do you prefer?" were included in the study.

Before distribution, the questionnaire was reviewed by the researchers for appropriateness and clarity. Subsequently, a final step of revisions and pilot testing of the questionnaire for clarity and ease of completion was conducted with five audiologists working with children with hearing loss, and two caregivers of children with hearing loss.

The caregivers that formed part of the pilot study were not included in the main study. Following pilot testing, minor revisions were conducted as follows:

- The similarity of the services in each scenario was emphasized in the instructions for completing the questionnaire, as well as the need for caregivers to read all the attribute levels in each service carefully before making a selection.
- A description of the terms and abbreviations used in the questionnaire was visible with each scenario on the Google Form as to reduce the "cognitive resources" caregivers would require to complete the questionnaire.
- A third attribute level for "language used for service provision" (any one of the South African languages) was included to minimize the perceived similarity and repetition of services for caregivers.
- The attribute name "mode of service delivery" was changed to "diagnostic evaluation".
- The font type for the Google Form was changed from Times New Roman to Lucida Sans as it is one of the fonts that are easier to read and understand when displayed on mobile devices (Joshi et al., 2014; Richardson, 2022).

9.3.5 Data Collection Procedures

To gain access to the participants, the first author obtained written permission from two early intervention preschool centres for children with developmental delays and disabilities, including hearing loss. Subsequently, posters outlining the study, the recruitment strategy, participant inclusion and exclusion criteria, and data collection methods were placed in the reception area of each early intervention preschool centre. The preschool centres also distributed flyers detailing the study to caregivers of former learners. Once a caregiver had

indicated interest in being recruited to participate in the study, the preschool centres compiled a list of the caregivers and their contact details which were then sent to the first author.

Caregivers were recruited to participate in this study telephonically. Once caregivers indicated an interest in participating in the study, an information letter and consent form were sent to them via email. Once informed consent was obtained, the questionnaire was sent to participants via email or WhatsApp. The questionnaire was sent out as a Google Form to ensure anonymity of caregivers' responses; thus, the main researcher sent reminders to all caregivers who had not confirmed completion of the questionnaire. Three reminders were sent to participants if they had not responded by the set date. A reminder was sent at the end of week one, and another one at the end of week three. A third reminder was sent at the end of week 5.

9.3.6 Data Analysis

The conjoint analysis results were analysed using the conditional logit model, using STATA 17. The conditional logit model is the method mostly used in conjoint analysis and analyses preference data (Wang et al., 2019; Soekhai et al., 2019). The conditional logit model represents participants' choices as a function of the choice's characteristics; thus, enabling the researcher to predict caregivers' preferences of attributes on condition of the attribute levels (Shi et al., 2018; Soekhai et al., 2019).

For this study, aggregate data of caregivers' responses for each attribute were used during data analysis.

9.4 Results

Tables 9.3 details the results from the conditional logit. Negative coefficients indicate that the attribute level is less preferred (reluctance) than the base level. The results will be discussed in accordance with the attributes reflected.

Table 9.3

Results of the conditional logit

Attributes	Levels	Correlation coefficient (r)	*p*-value	95% Confidence Interval
Language used for service provision	*Any language*	Base level		
	English	1,466	0,011*	0,37 - 2,85
	Home language	1,609	0,022*	0,21 - 2,721
Mode of service delivery (diagnostic evaluation)	*Child receives EHDI services and is referred to other HCWs of the caregiver's choice*	Base level		
	Child receives EHDI services at the nearest healthcare facility	0,262	0,288	-0,577 - 1,152
	Child receives all EHDI services via telehealth	-0,223	0,105	-0,795 - 1,006
Aural habilitation, speech and language therapy	*Regular sessions at home with the child, caregiver and HCW*	Base level		
	Regular direct therapy sessions at the nearest healthcare facility.	-0,693	0,134	-1,600 - 0,214
	Regular sessions via telehealth	-0,336	0,416	-1,148 - 0,475
Support services	*Caregivers seek information independently*	Base level		
	Caregivers information sessions.	-1,52e-16	1.000	-0,877 - 0,877
	Regular part of services	0,095	0,827	-0,761 - 0,951
Reducing the cost of services	*Decrease cost of amplification devices*	Base level		
	Decrease cost of services	0,262	0,533	-0,562 - 1,087
	Decrease transport cost to healthcare facility	-0,223	0,638	-1,153 - 0,707

* $p < 0.05$

On average, the attribute of EHDI service delivery which significantly influenced caregivers' choices was the language used for service provision. Caregivers were less likely to choose alternatives with EHDI services when not provided in their home language. This attribute level had the strongest effect on preferences of any EHDI service.

For the first attribute, "language used for service provision"; caregivers preferred that EHDI services be provided in their home language (r = 1.609). Of the two less preferred choices, caregivers would rather receive EHDI services in English (r = 1.466) rather than in any one of the South African languages (base level), if an interpreter would be provided.

For the second attribute, "diagnostic evaluation"; caregivers preferred to receive diagnostic evaluations at their HCF (r = 0.262), rather than being referred for diagnostic evaluations to a HCP of their choice (base level) or receiving diagnostic evaluations via telehealth (r -0.336).

For the third attribute, "aural habilitation, speech and language therapy"; caregivers preferred home-based intervention (base level). Of the two less preferred choices, caregivers would rather receive early intervention services via telehealth (r = -0.336) rather than from their nearest HCF (r = -0.693).

For the fourth attribute; "support services"; caregivers preferred that support services be provided as a regular part of early intervention sessions (r = 0.095) rather than caregivers having to seek the information regarding support services independently (base level) or having to attend regular caregiver information sessions (r = -1.52e-16).

For the last attribute, "reducing the cost of services"; caregivers preferred that the cost of EHDI services decrease (r = 0.262) in order to reduce the costs associated with accessing EHDI services in their entirety. Of the two less preferred choices, caregivers would rather

that the cost of amplification devices decrease (base level) rather than decreasing transport costs (r = -0.223).

Notably, results for “language used for service provision” had a strong degree of associating (r>0.7) and were statistically significant with *p*-value less than 0.05. However, the attribute levels for “mode of service delivery”, “aural habilitation, speech and language therapy”, “support services”, and “reducing the cost of services” had a weak degree of association (r<0.6) between the variables. Furthermore, the *p*-values for these attribute levels were greater than .05 indicating that these results were not statistically significant.

9.5 Discussion

Traditionally, patients’ involvement in decision-making at both the microlevel of patient consultation and macrolevel of program planning and development has been minimal (Ryan & Farrar, 2000; Vahdat et al., 2014). To the best of our knowledge, the current study is the first study to explore caregivers’ preferences for characteristics associated with EHDI services through conjoint analysis. Results from this study indicated that caregivers preferred that EHDI services be (1) conducted in their home language, (2) diagnostic evaluations be conducted at their nearest HCF, (3) early intervention services be provided at their home, (4) support service be provided as a regular part of early intervention services, and that (5) the cost of EHDI services be decreased. It is understandable that caregivers within this context prefer certain conditions for EHDI services to better meet their needs.

Findings of caregivers’ preference that EHDI services be provided in their home language resonates with findings reported by Khoza-Shangase (2019) and Maluleke et al. (2023), where use of English during EHDI services within the South African context was identified as a barrier to accessing these services. These authors argue that caregivers should have access to EHDI services in a language they understand best. This is crucial for effective

communication, comprehension, and active participation in the evaluation and intervention process. Furthermore, caregivers' preference of the use of English, second to use of their home language may be attributed to English being the prominent language in political, educational, and social settings in South Africa (Pascoe et al., 2018). Provision of EHDI services in a family's home language has been recommended as a way of mitigating this language barrier. Furthermore, using the language that the family can understand has been shown to improve the degree of accurate recall and has significant implications for follow-up of treatment options, commitment and adherence to treatment recommendations, and improved health outcomes (Flood & Rohloff, 2018; Watermeyer et al., 2017; Watson & McKinstry, 2009). Global evidence on health indicates that patients who do not form part of the dominant language have worse health outcomes than patients who form part of the dominant language (Flood & Rohloff, 2018). Thus, this finding raises significant implications for robust efforts towards implementation of linguistically congruent EHDI services within the South African context. In the context, such as South Africa, where there is documented mismatch between the languages spoken by audiologists and the majority of the country's population, deliberate efforts towards changing this profile need to be intensified, and EHDI programs should strive to provide language support and trained interpreters as needed to ensure caregivers can fully and efficiently engage in the services (Khoza-Shangase, 2022).

The second finding of the study, revealed caregivers' preference of receiving diagnostic evaluations from their nearest HCF, rather than receiving these services from HCPs of their choice or via telehealth. Accessibility to diagnostic evaluation is important to reduce travel time and inconvenience for caregivers. Distance to HCFs has also been identified as a barrier to accessing healthcare in South Africa (McLaren et al., 2014). In Kanji and Khoza-Shangase's (2018) study, distance from HCFs negatively influenced follow-up return rates in newborn screening programs; while in Maluleke et al.'s (2023) study,

caregivers expressed frustration with having to travel long distances in sometimes hard-to-reach areas in order access EHDI services. Khoza-Shangase (2019) suggest that EHDI programs should ideally have a network of HCFs across the different provinces to ensure caregivers can access evaluations conveniently, minimising barriers to timely diagnosis and intervention.

Telehealth, has also been proposed as a model for improving healthcare access in resource-constrained contexts such as South Africa (Swanepoel & Hall, 2010; Sebothoma et al., 2021); as it would spare patients from having to travel long distances to obtain high-quality care (Krupinski, 2015; Khoza-Shangase & Sebothoma, 2022). However, caregivers in this study demonstrated a reluctance to use this mode of service delivery. Interpretations of this finding is two-fold; (1) if South Africa is to provide healthcare to all South Africans in line with the human resources for health strategy and the National Health Insurance (NHI) Bill, a substantial increase in recruitment, training, and retention of audiologists is warranted especially in the public healthcare sector which caters for 84% of the population (Pillay et al., 2020); (2) careful deliberations on telehealth use within this context is essential, including a focus on awareness of and attitudes towards telehealth, internet access and use, as well as feasibility of this mode of service delivery given the country's current challenges with meeting the population's electrical and network connectivity demands. It is thus not surprising that caregivers are reluctant to prefer telepractice in this study.

The third finding of caregivers' preference for home visits being conducted as part of early intervention is consistent with Rotheram-Borus et al. (2017) and Tubach et al. (2012), who demonstrated that providing intervention in the family's home improves child development as it allows for a familiar and comfortable environment for the child, caregiver involvement, caregiver participation, and caregivers' sense of control and comfort. Home-based interventions also facilitate active involvement of caregivers and family members,

promoting learning and generalisation of skills in the child's daily routines and activities (Balton et al., 2019; Khoza-Shangase, 2022). Furthermore, home visits mitigate the documented distance challenges associated with accessing EHDI services (Khoza-Shangase, 2019; Maluleke et al., 2023); and allow HCPs to offer a more tailored approach to service delivery (Peacock et al., 2013). However, the feasibility of conducting home visits within the South African context requires further exploration given the socio-economic conditions, human resource and financial constraints characteristic of this context (Ferguson, 2018). Furthermore, exploration of government-non-government organisation collaborations with programs such as HI HOPES (Home Intervention: Hearing and language opportunities parent education services) is warranted to better meet the needs of children with hearing loss and their families, within this context. HI HOPES is a family-centred, home-based program that provides family support and language development intervention for children with hearing loss from birth to three years of age (HI HOPES, 2019; Kanji, 2021; Khoza-Shangase, 2021).

The fourth finding of caregivers' preference for information pertaining to support services to be provided as a regular part of early intervention services highlights the importance of support services for caregivers. Support services can include informational counselling for caregivers, caregiver training, support groups and access to relevant resources. Khoza-Shangase (2022) asserts that by incorporating comprehensive support services, caregivers can receive guidance, emotional support, and practical assistance throughout the EHDI process, enhancing the overall outcomes for the child and their family. Ninety percent of children with hearing loss are born to hearing parents who often have little to no knowledge of childhood hearing loss (Birdsey & joseph, 2021; Davids et al., 2020). Thus, informational counselling for example, is vital for these caregivers and has significant implications for follow-up of treatment options, as well as commitment and adherence to treatment recommendations, and reducing the stress and burden of raising a child with

hearing loss (Maluleke et al., 2021; Turan, 2012; Watermeyer et al., 2017). This information should be provided in a responsive and sensitive manner for them to be amenable to accessing follow-up services (Khan et al., 2018; Watermeyer et al., 2017). This finding is significant for the value of informational counselling to be continuous throughout the EHDI process, while being cognisant of the family's needs, as well as the child's requirements and development.

Lastly, caregivers' preference for the cost of EHDI services to be decreased to make these services affordable supports findings by Naidoo and Khan (2022), and Maluleke et al. (2023) where the high cost of EHDI services were identified as a barrier to accessing these services. Reducing the cost of EHDI services can help alleviate financial burdens on caregivers and increased accessibility. South Africa has one of the highest income inequalities in the world, such that the poorest 10% share about R1.1 billion compared with R381 billion shared by 10% of the richest population (Statistics South Africa, 2020). This alarming maldistribution of income means that more than 84% of the population may not be able to access health services due to high costs (McIntyre et al., 2009) and thus be reliant on the overburdened public healthcare system. Thus, affordability of healthcare remains a constraint within the South African context. Post-apartheid, the South African government aimed to improve access to healthcare by abolishing user fees for primary healthcare (Burger & Christian, 2020), and this is the goal of the NHI (South African Government, 2019). However, until universal health coverage is achieved through the NHI, this finding highlights a need for re-structuring and strengthening the policies of addressing healthcare access to ensure that they are all-inclusive in addressing the needs of all children with disabilities including children with hearing loss. The South African government, healthcare system, and relevant organizations should explore strategies to make EHDI services more affordable, such as subsidies, better insurance coverage, or funding initiatives.

Current study findings must be interpreted paying cognizance to the study's identified limitations. Inclusion of caregivers of children from early intervention preschools in the province of Gauteng only is not representative of the general population of caregivers of children with hearing loss in the rest of South Africa. Therefore, it cannot be assumed that the findings of this study are representative of all caregivers and children with hearing loss within the South African context. Furthermore, the conditional logit model yielded weak correlation coefficients ($r < 0.7$) and p-values > 0.05 for the attributes "diagnostic evaluation", "aural habilitation, speech and language therapy", "support services", and "reducing the cost of services"; indicating that there were possibly other factors that may have influenced the observed relationship between the attributes and attribute levels, thus further research may provide a complete understanding of caregiver's preferences. Moreover, an exploration of caregivers' preferences from different geographical locations and healthcare facilities is warranted, particularly where rurality and low socio-economic status may have an influence.

9.6 Conclusion

Understanding caregivers' preferences is essential for evidence-based practice for EHDI programs, especially within the South African context where such programs are limited. By prioritizing these caregiver preferences, EHDI programs can better cater to the needs of families, ensuring that children with hearing loss receive timely and comprehensive services for their optimal development and well-being. Current findings provide valuable insight for the development of context-specific and context-responsive EHDI programs for children with hearing loss and their families.

In chapter 10, the study's contribution to the advancement of knowledge in EHDI, in general, and the provision of FC-EHDI, in particular, is provided. Furthermore, this chapter offers recommendations for improving access to these services within the South African context.

Chapter 10

Early Hearing Detection and Intervention in South Africa: A clarion call for linguistic and culturally-congruent Family-Centred EHDI services for children with hearing impairment

(In Review, Appendix Y)

10.1 Abstract

Early Hearing Detection and Intervention (EHDI) programmes are recognised as the standard of care for newborns and infants presenting with hearing impairment, globally. However, widespread implementation of these programmes is far from being realised and faces numerous challenges within the South African context. The United Nations' sustainable development goal 3.8 and South Africa's national development plan seek to achieve equitable access to healthcare service, including EHDI. However, healthcare access is a complex concept which encompasses the dimensions: availability, affordability, acceptability and accommodation in healthcare. South Africa has made great progress towards universal implementation of EHDI programmes. Despite this progress, availability and affordability of these programmes is limited and their acceptability has received limited research focus in this context. Furthermore, accommodation of caregivers, as co-drivers of EHDI programmes and ensuring that EHDI programmes are linguistically and culturally congruent have also been overlooked within the South African context.

Contribution: Increased robust efforts in improving access through availability and affordability of EHDI programmes are warranted in South Africa. However, improving access to these programmes through availability and affordability initiatives alone will not result in a pragmatic improvement in their accessibility. Acceptability of these programmes and accommodations such as involving caregivers and family members of children with

hearing impairment as equal partners in EHDI programmes and being cognizant of their linguistic and cultural needs must be considered.

Keywords: early intervention**,** EHDI, FCEI, hearing impairment, hearing screening, Ubuntu

10.2 Manuscript

Early Hearing Detection and Intervention (EHDI) programmes are recognised as the standard of care for newborns and infants presenting with hearing impairment (Naidoo & Khan, 2022). EHDI encompasses the earliest possible identification, diagnosis, and intervention for these children, to ensure that they can communicate effectively and develop to their maximum potential (Health Professions Council of South Africa [HPCSA], 2018). These programmes are significant within the South African context, where the prevalence of a permanent hearing impairment is reported to be 3-6 per 1000 births in the public sector (Khoza-Shangase et al., 2017). Despite the high prevalence of infant hearing impairment and global and national healthcare reform initiatives towards equitable access to healthcare, widespread implementation of EHDI programmes is far from being realised in South Africa and faces numerous challenges (Khoza-Shangase, 2019; United Nations General Assembly, 2015; World Health Organisation [WHO], 2021). These challenges, include an over-burdened public healthcare sector, quadruple burden of disease challenges, social determinants of health challenges, resource limitations, poor knowledge and awareness of EHDI amongst healthcare professionals (HCP) and caregivers, and a lack of government mandate for EHDI (Kanji & Khoza-Shangase, 2021; Maluleke et al., 2023a; Naidoo & Khan, 2022; Petrocchi-Bartal et al., 2021; WHO, 2021).

Consistent with the United Nations' sustainable development goal 3.8, South Africa's national development plan aims to provide universal, equitable, and quality healthcare through the National Health Insurance (NHI) Bill (Department of Health, 2017; National Planning Commission, 2013; United Nations General Assembly, 2015). However, healthcare access is a complex concept, with numerous frameworks (Cu et al., 2021; Levesque et al., 2013; Ryvicker, 2019). Consensus amongst the various frameworks and authors is that access to healthcare comprises of four, interdependent dimensions: *(i)* availability (proximity of the

healthcare facility (HCF),and the whether the facility has the necessary technology and personnel to meet the patient's needs); *(ii)* affordability (direct and indirect costs associated with healthcare utilisation and the patient's ability to afford these costs); *(iii)* acceptability (patient's perception of the services' appropriateness and effectiveness in addressing their health concern, and suitability to their lifestyle and convenience); and *(iv)* accommodation (the services' ability to meet the patients' needs for care, preferences and constraints) (Burger & Christian, 2018; Cu et al., 2021; Gordon et al., 2020; Levesque et al., 2013; Sekhon et al., 2017; Wyszewianskin & McLaughlin, 2002).

A review of available literature on EHDI in South Africa highlights ongoing efforts towards universal implementation of EHDI programmes, considering the dimensions of access (Hussein et al., 2018; Kanji, 2016; Khan et al., 2018; Naidoo & Khan, 2022). Current newborn hearing screening programmes are conducted (1) at both private and public HCFs, including primary healthcare clinics; (2) by audiologists or nurses, healthcare workers, and volunteers in what is referred to as task-shifting (or task sharing, upskilling or role release); (3) using otoacoustic emissions, automated auditory brainstem response or mobile health (mHealth) technologies; and (4) for free at public HCFs, or out-of-pocket at private HCFs (Gordon et al., 2020; Hussein et al., 2018; Khoza-Shangase, 2021; Petrocchi-Bartal et al., 2021; Storbeck & Young, 2016; Wilford et al., 2018;). While early intervention services are provided at private and public HCFs, the child's home or in specialised pre-schools and primary schools (Kanji, 2021). Despite these efforts, *availability* and *affordability* of EHDI programmes is limited, resulting in late diagnosis and intervention for children with hearing impairment (Ehlert & Coetzer, 2020; Hussein et al., 2018; Khoza-Shangase, 2019; Swanepoel & Clark, 2019). Human resource capacity challenges and the high cost associated with EHDI services, amplification devices and accessories within the private sector, as well transport costs to public HCFs have been identified as barriers to the availability and

affordability of EHDI programmes (Hussein et al., 2028; Khan et al., 2018; Khoza-Shangase, 2019; Maluleke et al., 2023a).

Acceptability of current EHDI programmes has received limited research focus within the South African context. Maluleke et al. (2023b) was the first study within the South African context to investigate caregivers' perceptions of the acceptability of EHDI programmes. When intervention is considered acceptable, patients are more likely to comply with treatment recommendations, which may impact on the overall effectiveness of the treatment and improved outcomes for patients (Sekhon et al., 2017, Mtimkulu et al., 2023). Thus, further exploration of acceptability of EHDI programmes within this context is warranted, especially considering the reported poor follow-up rates (Kanji & Krabbenhoft, 2018). An understanding of the acceptability of current EHDI programmes would ensure that these programmes are tailored and customised according to community needs and preferences, assist in policy formulation, and successful implementation of these programmes (Sekhon et al., 2017; Khoza-Shangase, 2022; Mtimkulu et al., 2023).

Another dimension that has been overlooked in clinical practice and research efforts is *accommodation* - the ability of current EHDI programmes to accommodate the patient's needs of care and the constraints they encounter. Aspects of accommodation that have been overlooked include recognition of caregivers as co-drivers of EHDI programmes, and ensuring that EHDI programmes are linguistically and culturally congruent. Inclusion of caregivers as active partners in the care and decision making for children with hearing impairment represents a paradigm shift in healthcare (Khoza-Shangase, 2019; Maluleke et al., 2021a; 2021b); and aligns with the HPCSA's (2018) recommendation that early intervention services following diagnosis of hearing impairment must be family-centred, community-based, and culturally congruent for them to be efficacious. This is also in line with an Afrocentric ethos of *ubuntu.*

Caregivers and family members of the child with hearing impairment are the ones who are most involved with the child, provide a rich cultural context, and have a greater influence on the child's development than EHDI personnel who spend small portions of time with the child (Maluleke et al., 2021a; Mantri-Langeveldt et al., 2019; Schlebusch et al., 2019). Hence, incorporating the family's routines, language, culture, and beliefs in intervention practices is recommended to ensure effective family-centred EHDI (FC-EHDI) programmes (Balton et al., 2019; Khoza-Shangase, 2022; Maluleke et al., 2021a; Schlebusch et al., 2016). Maluleke et al. (2021a) argue that establishing FC-EHDI within the South African context may curtail the access challenges associated with EHDI programmes. Children spend a considerable amount of time with their caregivers and families; making them the most cost-effective system for nurturing the child's development. FC-EHDI is a collaboration between professionals and the child's caregivers and addresses the child's needs within the context of their family. FC-EHDI optimises the child's developmental outcomes by educating, supporting and empowering caregivers and family members of the child with hearing impairment (MacKean & Thurston, 2005; Iversen et al., 2003). When caregivers and families are empowered through linguistically and culturally congruent FC-EHDI programmes, they can optimise their child's developmental outcomes while ensuring that these programmes do not distance the child linguistically and culturally from their families and communities (HPCSA, 2018; Khoza-Shange & Mophosho, 2018; Maluleke et al, 2021a).

Implementing FC-EHDI programmes within this South African context would curtail the language constraints experienced by caregivers when accessing EHDI programmes (Khoza-Shangase, 2019; Maluleke et al., 2023a). English is the predominant language in accessing healthcare in most HCFs, despite South Africa having 12 official languages (Constitution of South Africa, 1996; Parliament of the Republic of South Africa, 2023; The

Presidency, 2023). This practice does not respond to the needs of 11 million South Africans receiving healthcare services in English; resulting in poorer health outcomes (Flood & Rohloff, 2018; Khoza-Shangase & Mophosho, 2018; Maluleke et al., 2021a; Mophosho, 2018; Mtimkulu et al., 2023; Steinberg et al., 2016). Linguistic and culturally congruent FC-EHDI programmes can be achieved through (1) conducting EHDI programmes in all of South Africa's official languages, which would in turn facilitate caregiver participation and engagement; (2) education and training for EHDI personnel about language and cultural competence, and inclusive practices so they can effectively meet the needs of the diverse communities they serve; and (3) collaborating with caregivers, community leaders, support groups, etc. to gain insight into their unique challenges and needs.

Ultimately, improving access to EHDI programmes in South Africa requires pragmatic considerations across the four domains of access. Focusing solely on availability and affordability initiatives, is insufficient to achieve the desired universal access to EHDI programmes. Addressing the needs of caregivers and families, while considering the linguistic and cultural congruence, is vital. Embracing linguistically and culturally congruent FC-EHDI does not only improve acceptability of these programmes but also ensures cost-effective, equitable, efficacious, and high-quality EHDI programmes for infants and children with hearing impairment, as well as their families within the South African context.

Chapter 11 is the final chapter of this thesis and provides an integration of the findings this study, including the study's contribution to the body of knowledge and application to the field of EHDI and FC_EHDI.

CHAPTER 11

Synthesis of Findings

11.1 Introduction

This chapter provides a comprehensive summary and integration of the papers presented in Chapter 3 to Chapter 10. The aim and objectives of the study are reviewed, including a discussion of the integration of the findings of the eight papers included in this thesis. This chapter also offers a discussion of the contributions of this research to the body of knowledge in the field of EHDI, particularly in relation to FC-EHDI in South Africa. Furthermore, the study's theoretical and practical contribution to the field of audiology, its design and methodological limitations, and recommendations for future research are made.

11.2 Objectives of the study

Over the last decade, HICs have demonstrated that through EHDI, children with hearing impairment can develop optimal spoken language abilities, thus minimising or reversing the negative effects of an unidentified hearing impairment (DesJardin et al., 2014, Fulcher et al., 2012; Moeller & Tomblin, 2015; Umat et al., 2018). However, South Africa lags far behind HICs in terms of the progress made in EHDI programmes due to widely-documented contextual challenges (Kanji & Khoza-Shangase, 2016; Khoza-Shangase & Kanji, 2021; Naidoo & Khan, 2022). These challenges highlight the importance of context-specific studies within the South African context to guide best practice that is aligned to the contextual realities (Khoza-Shangase, 2021; Khoza-Shangase et al., 2017; Kanji & Khoza-Shangase, 2021). Furthermore, existing literature has demonstrated that for EHDI programmes to be effective, it is not enough to consider the availability, quality and equity of care provided; it is

also necessary to consider the adoption of the FCEI approach and/or principles (Deng et al., 2018; Khoza-Shangase, 2019, 2022).

Therefore, the aim of this study was to explore caregivers' experience and evaluation of the EHDI process and practices in Gauteng, South Africa. The specific objectives of the study included:

1. Describing caregivers' expectations of the EHDI process, from detection to intervention.
2. Describing caregivers' experience of the EHDI process from detection to intervention.
3. Evaluating the success or failure of the EHDI process in relation to caregivers' expectations.
4. Identifying barriers and facilitators to the EHDI process from caregivers' perspectives.
5. Describing caregivers' level of satisfaction with current EHDI programmes.
6. Determining caregivers' perceptions of the extent to which the EHDI services they received are family-centred.
7. Exploring the association between personal, family and socio-demographic factors and caregivers' perceptions of family-centeredness of the EHDI services they received.
8. Exploring caregivers' preferences for characteristics associated with of EHDI services.

11.3 Main findings

The integration of the findings in this chapter illustrates how the findings in each distinctive chapter are interconnected, and at times inform the next chapter. This integration

also demonstrates how together, the chapters provide insight towards a holistic understanding of caregivers' experience and evaluation of the EHDI process and practices in Gauteng, South Africa. The integration of the findings is presented according to the two review papers (current practice models and/or process of FC-EHDI, as well as telehealth and FC-EHDI) and the eight key themes identified from the findings reported in Chapter 5 to Chapter 10 of the thesis; namely, expectations of the outcomes of EHDI programmes, lack of awareness of EHDI, fragmented EHDI services, access to EHDI, lack of linguistically and culturally congruent EHDI, support services, family-centredness of EHDI services, and preferences for characteristics associated with EHDI services.

Current practice models and/or process of FC-EHDI

To contextualize the study, the researcher conducted an integrative review of current trends in FCEI for children with hearing impairment (Chapter 3). The systematic review was conducted in 2019 and the search yielded 22 studies that met the inclusion criteria including; 16 surveys, 4 exploratory cohort studies, 1 prospective short-term longitudinal pretest/post-test design, and 1 retrospective research design study. The review identified five key themes pertaining to FCEI: caregiver involvement (n=5, 16%), caregiver coaching/information sharing (n=12, 38%), caregiver satisfaction (n=4, 13%), challenges of FCEI (n=11, 34%), and telehealth (n=3, 9%).

Findings of the review revealed that there is sufficient evidence for FCEI, with caregivers expressing a desire for their full involvement in their child's intervention efforts. The first theme, *caregiver involvement*, demonstrated that increased curiosity, motivation, perceived social support, and decreased pessimism about a child's potential resulted in increased caregiver involvement. Furthermore, caregiver and family involvement are more likely to occur when services are provided in the home. Caregiver involvement was also

revealed to be multifaceted, and incorporated a broad range of behaviours and practices. Thus, understanding the construct of caregiver involvement from caregivers' own perspective is essential in ensuring that the information provided to them is aligned to their needs. However, due to South Africa's multilingual, multicultural, sociopolitical history, and healthcare constraints; perceptions of the causes of disability and disease; health seeking behaviour; and access to healthcare and support services, the construct of caregiver involvement, as well as the feasibility of home visits need to be explored within this context.

The second theme, *caregiver coaching/information sharing* revealed that caregiver-directed commentaries during intervention and improved caregivers' knowledge of the habilitation process cultivated a positive partnership with caregivers. However, information provided to caregivers was limited and not fully-aligned with recommended practices. The information provided to caregivers is essential in order to ensure caregivers' involvement in the intervention process (Maluleke et al., 2021). Thus, informational counselling should be a reflective practice that is aligned to caregivers' needs. Within the South African context, this practice must be conducted in a language that the caregiver is familiar with since studies in this context have demonstrated poor recall and understanding of information provided by professionals (Watermeyer et al., 2012).

The third theme, *caregiver satisfaction*, revealed that caregivers were generally satisfied with FCEI programmes. Caregivers were particularly satisfied with improved knowledge about hearing impairment, family interactions, parenting and support following enrolment in FCEI programmes. However, the fourth theme (*Challenges*), revealed that caregivers experienced challenges with accessing FCEI programmes including logistical challenges (lack of attention to EHDI, lack of free public EHDI programmes, large number of appointments, long waiting lists, and transport challenges); challenges related to professionals (professionals did not expedite hearing health care, ignored caregiver concerns about the

possible presence of a hearing impairment, and did not know what EI programmes were available); and challenges associated with caregivers (poor awareness and knowledge of hearing impairment and available services, as well as the health-seeking and decision-making dynamics within the family). Investigating caregivers' satisfaction and barriers with accessing FCEI is warranted, especially in the South African context, in order to identify gaps and incongruence in knowledge, beliefs and practices within this context. Furthermore, for FCEI programmes to be effective and efficient, context-specific solutions aimed at mitigating these challenges must be explored; while being cognizant of the complexity of health-seeking-behaviours and decision-making dynamics in this context (Maluleke et al., 2021a).

The last theme, *telehealth*, demonstrated telehealth as a significant promise to improving access to quality healthcare services (Swanepoel & Hall, 2010). There has been an increase in internet access over the past decade (Meaden et al, 2015; Little et al., 2018), and the COVID-19 pandemic highlighted telehealth's immense capability to increase access to healthcare (Garfan et al., 2021; Khoza-Shangase & Sebothoma, 2022; Maluleke & Khoza-Shangase, 2023). However, despite caregivers' satisfaction with telehealth services, only a limited number of professionals reported telehealth-use with children. Furthermore, despite its strengths (flexibility, access to services, fewer appointment cancellations, and heightened family engagement) there were challenges (negative attitude towards telehealth and technology, and limited internet access) associated with telehealth. Deliberations on feasibility and applicability of telehealth within the South African context are essential given the current internet access challenges, especially within the remote contexts which are supposed to gain the most benefit from these services; patients' lack of digital literacy; and load shedding challenges (Constantino et al., 2020; Laher et al., 2019; Maluleke & Khoza-Shangase, 2023; Watkins et al., 2018; Wood, 2023).

Telehealth and FC-EHDI

During the data collection phase of this study, COVID-19 was declared a pandemic by the WHO on 11 March 2020 (Muniyappa & Gubbi, 2020; Teaford et al., 2015; WHO, 2020). In response to this declaration, nationwide lockdowns and regulations around strict controls on movement and physical contact between people were implemented worldwide; with the aim of reducing transmission of the virus (Adom et al., 2020; Chandra et al., 2022; Khoza-Shangase et al., 2021). Thus, rendering practices such as in-person interviews unfeasible and unsafe in some cases for either research purposes or for healthcare service provision (Adom et al., 2020; Khoza-Shangase et al., 2021). Consequently, the researcher had to transition from in-person interviews to videoconferencing interviews for data collection, but realized that like many other HCPs, audiologists lacked advanced preparation or training in this regard (Jones & Abdelfattah, 2020). To address this challenge, the researcher conducted a scoping review to explore the question: "Can videoconferencing be used as a service delivery method in FC-EHDI services in South Africa?" (Chapter 4).

The scoping review search identified 16 studies that met the inclusion criteria including; 10 surveys, 3 ethnographic studies, 2 exploratory qualitative studies, and 1 cross-sectional study. The findings revealed that although the concept of telehealth has existed since the early twentieth century and its benefits are widely reported, the overall uptake of telehealth outside emergency situations such as the COVID-19 pandemic was slow and fragmented (Mahtta et al., 2012; Smith et al., 2019; Poultney et al., 2015). Five key themes were identified from the scoping review namely; videoconferencing use, videoconferencing benefits, need for videoconferencing training, videoconferencing challenges, and recommendations for successful videoconferencing.

The first theme, *videoconferencing use*, indicated that various HCPs such as speech-language pathologists, occupational therapists, doctors, paediatric surgeons, and mental health professionals have used videoconferencing in different contexts. The second theme, *videoconferencing benefits*, identified the perceived benefits of videoconferencing including; videoconferencing consultations being "just as good as" or "better than" traditional in-person medical visit experiences; reduced stress, travel time, employment and school disruptions; can be fitted around the patients' day without the hassle of waiting time; and being flexible when it comes to scheduling appointments and conducting visits during a family's typical routines, such as dinnertime. However, theme three, *need for videoconferencing training*, revealed that HCPs lacked sufficient training in telehealth and as result, they were not knowledgeable about the use of this new approach (Khoza-Shangase et al., 2021; Smith et al., 2019).

Implementing videoconferencing in FC-EHDI would enable the audiologist to provide intervention to families in the comfort of their homes (Bhati, 2021). Furthermore, these videoconferencing home visits may increase the family's sense of control and comfort, allowing them to get the most benefit from the service, and allow HCPs to tailor their approach to service delivery; thus, increasing caregiver participation (Khoza-Shangase, 2019; Peacock et al., 2013). However, the lack of resources, finances, poor infrastructure and technology necessitate careful consideration of these factors when implementing FC-EHDI via telehealth in South Africa. Moreover, due consideration of the content, format and timing of HCPs telehealth education is warranted within this context; while being cognizant of the potential uses of videoconferencing in FC-EHDI, including screening, diagnostic testing, and FCEI (Maluleke & Khoza-Shangase, 2023).

The fourth theme, *videoconferencing challenges*, identified the following challenges associated with telehealth use; limited access to internet connection; lack of familiarity with

online tools; equipment-related or technical challenges; limited visual and auditory cues; lack of physical examinations; privacy and security concerns; and increased administration time for arranging appointments and ensuring that billing is compliant. Conversely, theme five (*recommendations for successful videoconferencing*), identified the following recommendations for successful videoconferencing use; a) conduct telehealth services in the office where there is better access to materials and privacy; b) discuss limitations with clients that they must express their emotions through words; c) technological support must be provided in real time; d) use of 'workarounds' such as when patients can send photos or email test results as an adaptation to the telehealth environment, basic connectivity should be more robust with steady bandwidth; and e) provision of different modalities of telehealth (i.e., intermittent audio-only, video-enabled or in-person visits).

The findings in this scoping review revealed that the notion that telehealth will allow the rural population the same healthcare access as the urban population is an exception rather than the norm (Gajawarala et al., 20012; Jayasinghe et al., 2016). Thus, to implement videoconferencing FC-EHDI, issues of internet use as well as access require due consideration, especially within the rural contexts which are supposed to gain the most benefit from such remotely provided services. Furthermore, the recommendations provided offer significant insight for successful videoconferencing FC-EHDI programmes within the South African context; which will improve healthcare access and outcomes to a heterogeneous population across diverse settings within the South African context.

Expectations of outcomes of EHDI programmes

The narrative interviews revealed that EHDI programmes failed to meet caregivers' *expectations of the outcomes of EHDI programmes* including; age-appropriate acquisition of spoken language, mainstreaming, as well as future education and independence (Chapter 5). EHDI programmes often failed to meet these expectations due to late-diagnosis of the hearing

impairment resulting in late-enrolment in EHDI programmes, which resulted in most of the children being enrolled in schools for LSEN. The success or failure of EHDI programmes with regards to long-term educational and independence outcomes for these children is yet to be determined.

Early access to EHDI services is critical for children with hearing impairment to develop optimal speech and language development (Barr et al., 2019; McCreery et al.,2015). However, providing amplification at an early age is not sufficient to support positive developmental outcomes for these children, given the complexity of childhood hearing impairment (Findlen et al., 2019; McCreery et al., 2015). Caregivers' expectations that amplification devices will result in their child achieving like a child with normal hearing may be misguided when considering the various factors that influence developmental outcomes for children with hearing impairment (Gilliver et al., 2013). Thus, it is important to set realistic expectations for caregivers in relation to the individual characteristics of their child (Gilliver et al., 2013). `

This sentiment also applies to schooling options for the child with hearing impairment. It is crucial that the child with hearing impairment is placed in a setting that is the most enabling rather than administratively expedient (Shaver et al., 2013); which is a common occurrence for these children because far less is known about educating the child with hearing impairment than is commonly believed (Shaver et al., 2013). Therefore, these findings highlight a need for the Departments of Health, Social Development and Basic Education to invest in initiatives that are aimed at appropriately resourcing, coordinating and managing the child with hearing impairment from EHDI, ECD centres, and school through an integrated and collaborative approach that involves the child with hearing impairment, their family and EI professionals.

Lack of awareness of EHDI

The narrative interviews also revealed that HCPs ignored caregivers' concerns pertaining to their child's not reacting to loud sounds or observed delayed speech and language milestones. This finding was identified as a theme in relation to caregivers' expectations of the EHDI process (Chapter 5), caregivers' experiences of the EHDI process (Chapter 6), and barriers to EHDI (Chapter 7). Furthermore, this finding resulted in EHDI programmes not meeting caregivers' expectations that their child's hearing impairment would be diagnosed early and caregivers' dissatisfaction with current EHDI programmes. This finding of HCPs' dismissal of caregiver concerns suggests a lack of awareness on the part of HCPs regarding childhood hearing impairment, its signs and symptoms, and the availability of EHDI services, as well as the need for improved screening and early identification in the South African context.

Successful implementation of any healthcare programme relies on the appropriate knowledge of HCPs (Ravi et al., 2018). Until UNHS is realized within this context, improved awareness of infant hearing impairment, training and coordination among HCPs is vital towards earlier identification of infant and childhood hearing impairment (Khoza-Shangase & Kanji, 2021). Improved HCPs knowledge of paediatric hearing impairment will aid in earlier identification for children who were not screened at birth or who present with late-onset hearing impairment (Maluleke et al., 2023). In addition, aligning NHS with immunization visits has been shown to be a viable option, due to good immunization coverage rates and availability of audiologists during official working hours (Khan et al., 2018; Kanji & Khoza-Shangase, 2018).

The narrative interviews also revealed similar findings of a lack of awareness on the part of caregivers regarding childhood hearing impairment, its signs and symptoms, and the availability of EHDI services (Chapter 6 & 7). This finding suggests a need to expand the health education provided to caregivers during antenatal care to include developmental milestones, paediatric hearing impairment and its impact on speech and language development, as well as available EHDI programmes. Improved maternal awareness of paediatric hearing impairment would prompt earlier identification of their child's hearing impairment (Maluleke et al., 2018; Maluleke et al., 2023).

Fragmented EHDI services

The narrative interviews also revealed that caregivers were referred to numerous appointments with various HCPs before a diagnosis of the hearing impairment was reached (Chapter 5, 6 & 7). An ideal EHDI programme should provide a continuum of care, with a multidisciplinary team of HCPs working together to implement a comprehensive program that includes, newborn hearing screening, diagnosis, and FCEI (Khoza-Shangase, 2021). This finding highlights the need for centralized, non-fragmented, interdisciplinary FC-EHDI programmes. A lack of cohesion has been shown to hamper effective implementation of EHDI services; whereas, through collaborative and interdisciplinary EHDI services, the child with hearing impairment and their family can benefit from timely and comprehensive intervention, while pooling the necessary resources to advance hearing health outcomes (Khan & Joseph, 2020; Scheepers et al., 2016). This interdisciplinary approach of shared knowledge and skill for a common goal, will advance hearing health and developmental outcomes of hearing-impaired children, while pooling the necessary resources into an efficiently run healthcare system – as advocated by WHO (2020).

Access to EHDI

The narrative interviews also revealed that caregivers had to travel vast distances to reach HCFs where EHDI programmes were offered, and often in hard-to-reach areas. Furthermore, accessing EHDI services was associated with high costs of the services and transport charges (Chapter 5, 6, 7 & 10). These findings resulted in EHDI programmes not meeting caregivers' expectations that EHDI services would be accessible and resulted in caregivers' dissatisfaction with these services. Inequity in accessing healthcare is a global challenge and affects the performance of any healthcare system (Vergunst et al., 2017), South Africa's healthcare system included (Khoza-Shangase, 2022; Maphumulo & Bhengu, 2019). Despite a waiver of user fees being implemented at public healthcare facilities; EHDI services are not affordable to the general public due to the high costs associated with EHDI services, amplification devices and accessories within the private sector, as well transport costs to public HCFs (Gordon et al., 2020; Khoza-Shangase, 2019; Maluleke et al., 2023a). Findings of EHDI programmes not being accessible raises implications for improving access to these services through improving affordability of healthcare, and proximity to HCFs. One of the proposed models for improving healthcare access in resource-constrained contexts like South Africa is through tele-audiology (Swanepoel & Hall, 2010; Sebothoma et al., 2021). However, deliberations regarding feasibility and applicability of this tele-audiology as discussed in Chapter 4 are warranted.

Lack of linguistically and culturally congruent EHDI

The narrative interviews also revealed that caregivers received services in English throughout the EHDI process (Chapter 5, 6, 7 & 10). This finding raises implications for improving access to healthcare services, through robust efforts to embrace linguistically- and culturally-congruent EHDI services so as to respond to the needs of more than 11 million

South Africans who do not speak English as their home language (EHDI, 2018; Khan et al., 2018; Khoza-Shangase & Mophosho, 2018; Scheepers et al., 2016). Recognition of caregivers as co-drivers of EHDI programmes and providing these services in the caregivers' home language can facilitate understanding, and influence caregiver recall and understanding; which may affect the uptake of recommended services (Davids et al., 2021; Scheepers et al., 2016; Watermeyer et al., 2017).

In order to ensure effective EHDI programmes, a receptive, cohesive and integrated system that centres caregivers and families of children with hearing impairment through family-centred EHDI (FC-EHDI), must be in place (Khoza-Shangase, 2022). Maluleke et al. (2021a) argue that establishing FC-EHDI within the South African context may mitigate the inequities associated with access to EHDI services. FC-EHDI programmes would mitigate the language constraints experienced by caregivers when accessing EHDI services as reported by Khoza-Shangase (2019) and Maluleke et al. (2023a). Furthermore, linguistically and culturally-congruent FC-EHDI would also address acceptability of current EHDI programmes; resulting in economical, equitable, efficacious, quality EHDI programmes for infants and children with hearing impairment, as well as their families within the South African context.

Support Services

Despite EHDI programmes' failure to meet some of the caregivers' expectations and caregivers' dissatisfaction with their experience of various aspects of EHDI, they expressed satisfaction with the support that they received, although this support was deemed not to be sufficient (Chapter 6 & 7). Caregivers were satisfied with the informational counselling that they received, which enabled them to understands their child's hearing impairment; support services provided during home-visits from HI HOPES; sign language training; financial

assistance through free healthcare services at public hospitals and clinics, the CDG, and independent donations which enabled them to access EHDI services for their child; and the EHDI HCPs that they interacted with throughout the EHDI process. However, caregivers expressed frustration with accessing ongoing support for their child once they were in school.

According to Davids et al. (2021), caregivers need diverse information about hearing impairment including; their child's development, the needs for family-centred service provision, and their child's education and future opportunities. This information should be provided in a responsive and sensitive manner that is linguistically- and culturally-congruent, in order for them to be amenable to accessing follow-up services (Khan et al., 2018; Davids et al., 2021). Caregivers also expressed satisfaction with the CDG; however, literature suggests that the CDG is not enough to compensate for the disability-related costs faced by households with disabled members (Kidd et al., 2021). Thus, the Department of Social Development needs a re-structuring of the current CDG in order to ensure comprehensive support for children with disabilities, including hearing impairment (Maluleke et al., 2023).

Furthermore, provision of services in the family's home has been linked to improved child development and parenting; and allows families to get the most benefit from tailored service delivery (Ingber et al., 2010; Sakardi et al., 2008). Thus, wide implementation of these services through FC-EHDI is recommended in order to improve hearing healthcare access and outcomes (Maluleke et al., 2021a). Moreover, this finding suggests a need for re-structuring the policies of addressing healthcare access need to be strengthened in order to ensure that they are all-inclusive in addressing the needs of all children with disabilities including children with hearing impairment. With adherence to evidence-based principles and guidelines in EHDI programmes; as well as evidence to support best practice within the South African context. Contextual best practice guidelines would improve access to EHDI,

the quality of EHDI programmes and outcomes for children with hearing impairment within this context.

Family-Centredness of EHDI Programmes in South Africa

Chapter 8 presents the caregivers' perceptions of the family-centredness of the EHDI services they received, as well as the exploration of the association between caregivers' perceptions of the family-centeredness of the EHDI services they received and personal, family and socio-demographic factors. The mean sub-scale scores of the MMPOC-56, supported by quotes from the narrative interviews indicate that EHDI services were perceived to be family-centred across the five domains: *respectful and supportive care* (5.5) , *enabling and partnership* (5.8), *providing general information* (6.0), *coordinated and comprehensive care* (6.2), and *providing specific information* (6.3). However, statistical associations between gender, employment status, language used for EI, and various domains of family-centredness were not significant. A larger sample size might reveal significant associations.

The findings suggest that EHDI programmes within the South African context are embracing the values of FCEI, to various degrees across the five domains. The integration of family-centredness in EHDI recognises the importance of considering the child and family in their context (Saunders et al., 2018; Stewart et al., 2021), which is very much linked to the African spirit of *ubuntu* that places significant value on family and community rather than the individual. Providing care that is respectful and responsive to the child and their family's needs, preferences, and values is an integral principle in FCEI (Epley et al., 2010; Khan et al., 2018). Therefore, these findings highlight a need for HCPs to consider caregivers as partners in the intervention process; allowing them to share their opinions, expertise, needs and preferences through FC-EHDI (Maluleke et al., 2021a; Moeller et al., 2013; Yoshinaga-Itano, 2014). Secondly, HCPs lack of prompt action based on caregiver concerns significantly compromises the EHDI process and necessitates improved regard for caregiver concerns by

HCPs. Furthermore, EHDI services should be provided in a language that the child, caregiver, and family can understand as discussed under “lack of linguistically and culturally congruent EHDI”.

Inherently, EHDI programmes aim to support families with the information they need to make informed decisions throughout their journey of raising a child with hearing impairment (Stewart et al., 2021; Ward et al., 2019). Thus, caregivers require HCPs to provide general and specific information pertaining to the child’s hearing impairment. Provision of relevant and necessary information can empower families to make decision about their children and alleviate the stress that arises from uncertainty (Antunes & Vaz, 2021; Lotze et al., 2010). Informational counselling during the EHDI process is crucial for caregivers, as they need diverse information about hearing impairment including; developmental outcomes, the needs for family-centred service provision, education, and future opportunities (Davids et al., 2021; Maluleke et al., 2021a; Watermeyer et al., 2017). This research also highlighted the lack of informational counselling for fathers due to their absence during consultations. Thus, paternal involvement in EHDI services in South African requires careful deliberation, if better health outcomes have been linked to it.

This research did not find any statistically significant associations between personal, family and socio-demographic factors and caregivers’ perceptions of family-centeredness of the EHDI services. The higher socio-economic status associated with greater caregiver expectations for information from HCPs may explain this lack of significant association. The difference between these findings, as well as Stewart et al.’s (2021) and Shevell et al.’s (2018) findings may be attributed to the different contexts and populations included in this research compared to previous research.

Preferences for EHDI Services

Chapter 9 presents caregivers' preferences for characteristics associated with of EHDI services. This objective was addressed through a pilot study to a main study that will be conducted as post-doctoral research at a later stage.

The findings revealed that caregivers preferred that EHDI services be conducted in their home language (r = 1.609); diagnostic evaluations be conducted at their nearest healthcare facility (r = 0.262); early intervention services be provided at their home (r = base level); support services be provided as a regular part of EI services (r = 0.095); and that the cost of EHDI services be decreased in order to ensure affordability of these services (r = 0.262). A strong degree of association and statistically significant *p*-value were obtained for the "*language used for service provision*" attribute. However, weak degrees of association and *p*-values that are not statistically significant were obtained for the "*mode of service delivery*", "*aural habilitation, speech and language therapy*", "*support services*", and "*reducing the cost of services*" attributes, indicating that there were possibly other factors that may have influenced the observed relationship between the attributes and attribute levels. Thus, further research may provide a complete understanding of caregiver's preferences.

The first finding of caregivers' preference that EHDI services be provided in their home language resonates with the discussion under "*lack of linguistically and culturally congruent EHDI*". The second finding revealed caregivers' preference of receiving diagnostic evaluations from their nearest HCF, rather than receiving these services from HCPs of their choice or via telehealth. Accessibility to diagnostic evaluation is important to reduce travel time and inconvenience for caregivers. Thus, in addition to the discussion under "*access to EHDI*", ideal EHDI programmes should have a network of HCFs across the different provinces to ensure caregivers can access evaluations conveniently, minimising barriers to timely diagnosis and intervention (Khoza-Shangase, 2019).

Telehealth, has also been proposed as a model for improving healthcare access in resource-constrained contexts such as South Africa, as discussed under "*telehealth and FC-EHDI*" and "*access to EHDI*". However, results in this research indicate caregivers' reluctance to use this mode of service delivery. The findings of this research have two main implications. If South Africa is to provide healthcare to all South Africans in line with the human resources for health strategy and the NHI bill, there is a need for a substantial increase in the recruitment, training, and retention of audiologists, especially in the public healthcare sector which caters for 84% of the population (Pillay et al., 2020). Second, careful deliberations on telehealth awareness and attitudes, internet access and use, as well as the feasibility of this mode of service delivery given the country's current challenges with meeting the population's electrical and network connectivity demands.

The third finding of caregivers' preference for home visits being conducted as part of early intervention is consistent with Rotheram-Borus et al. (2017) and Tubach et al. (2012). Intervention provided in a familiar and comfortable environment such as the family's home improves child development, caregiver involvement, caregiver participation, and caregivers' sense of control. Furthermore, home-based interventions have been shown to promote learning and generalisation of skills in the child's daily routines and activities (Balton et al., 2019; Khoza-Shangase, 2022). Home visits would also mitigate the documented distance challenges associated with accessing EHDI services (Khoza-Shangase, 2019; Maluleke et al., 2023); and allow HCPs to offer a more tailored approach to service delivery (Peacock et al., 2013). However, the feasibility of conducting home visits within the unique socio-economic and infrastructural context of South Africa necessitates further exploration (Ferguson, 2018). Furthermore, considerations of possible collaborations between government and non-government organisation such as HI HOPES is warranted to better meet the needs of children with hearing impairment and their families, within this context.

The fourth finding of caregivers' preference for the inclusion of support services as an integral part of EI services highlights the important role of caregiver support in EHDI. It is crucial that caregivers receive support services throughout the EHDI process, in light of the fact that ninety percent of children with hearing impairment are born to hearing parents who often have little to no knowledge of childhood hearing impairment (Birdsey & Joseph, 2021; Davids et al., 2020). This information should be provided in a responsive and sensitive manner for them to be amenable to accessing follow-up services, as discussed under "*lack of linguistically and culturally-congruent EHDI*".

The last finding of caregivers' preference for a reduction in the cost of EHDI services so that these services affordable resonates with the discussion under "*access to EHDI*". However, the finding in this research highlights the continued need for comprehensive re-structuring of healthcare policies to ensure equitable access for all children with disabilities, including children with hearing impairment. Furthermore, this finding urges the South African government, healthcare system, and relevant organizations to explore innovative strategies such as subsidies, improved insurance coverage, or funding initiatives to ensure that EHDI services more affordable.

11.4 Theoretical and Practical Contributions of the study

This thesis provides substantial theoretical and practical contributions to research in FC-EHDI. Given that this research is the first study to employ mixed methods to explore caregivers' experiences and evaluation of the EHDI process and practices, this research contributes to advancing understanding of FC-EHDI in South Africa, highlights the importance of integrating family-centred principles and practices in EHDI programmes, and identifies areas of strength and areas for improvement of these programmes. Furthermore, this research recognises the importance of caregivers and families in supporting the development of their child with hearing impairment.

Early access to EHDI is crucial for children with hearing impairment to develop optimum speech and language development (Barr et al., 2019; McCreery et al., 2015). However, delayed provision of habilitation services can hinder a child's overall development (Gmmash & Faquih. 2022). The findings from this research offer sufficient evidence to supplement existing knowledge relating to the need for interdisciplinary collaboration in EHDI programmes in South Africa. Integrating HCPs including; audiologists, speech-language pathologists, nurses, and doctors in a cohesive and coordinated manner can optimize the provision of timely, comprehensive EHDI services and improve developmental outcomes for children with hearing impairment.

In implementing comprehensive EHDI services, provision of care that is respectful and responsive to the child and their family's needs, preferences, and values is vital (Epley et al., 2010; Khan et al., 2018). The findings from this research highlight the caregiver's challenges in accessing EHDI services in a language that is not their home language. Thus, HCPs need to consider language and culture as essential components of effective EHDI programmes. This information offers insight into aligning FC-EHDI programmes with the families' language and cultural beliefs and can guide policy makers, HCPs and all the relevant stakeholders in implementing evidence-based strategies that align with the South African context to improve the quality, effectiveness, acceptability, and accessibility of these services. Addressing language and culture barriers through linguistically and culturally-congruent EHDI promotes inclusive EHDI services and can improve caregiver satisfaction, adherence to intervention, long-term engagement with EHDI services, and ultimately improve outcomes for the child with hearing impairment and their family.

A child with hearing impairment presents unique communication challenges for hearing parents (Davids et al., 2021), and audiologists are uniquely poised to support healthy family functioning from the start of the child's life by supporting all members of the family

and eliminating ineffective communication, as well as strained caregiver-child interactions (Hintermair & Sarimski, 2014). However, this research highlights the challenges related to affordability of EHDI services in South Africa which hinder timely intervention for children with hearing impairment and the necessary support for the caregivers and families of these children. This research, therefore, offers insight into the need for a multi-pronged approach in reducing the financial burden and improving affordability of EHDI services. There is a need for the Departments of Health, Social Development and Basic Education to invest in initiative's that are aimed at properly resourcing, coordinating and managing the child with hearing impairment including telehealth and community-based initiatives, to ensure equitable access and better outcomes for children with hearing impairment in the South African context.

Ultimately, this research offers a multi-pronged recommendation to ensure context-relevant and responsive FC-EHDI programmes that are tailored to the diverse needs of children with hearing impairment and their caregivers, in South Africa. These recommendations include; implementing FC-EHDI principles and practices; considering the importance of linguistically and culturally-congruent EHDI services; providing comprehensive support services; promoting interdisciplinary collaborations; and improving accessibility, affordability, and acceptability of EHDI services in South Africa.

11.5 Limitations of the study

Although this study offers significant contributions to the body of knowledge and implications for practice, training, and policy formation; the findings in this study must be interpreted paying cognizance to the study's identified limitations. These limitations are presented in each paper from Chapter 3 to Chapter 9. This section outlines the main limitations of this study.

This study was non-experimental in nature. However, experimental research would not have enabled the researcher to employ both quantitative and qualitative measures to explore caregivers' experiences and evaluation of the EHDI process and practices. Furthermore, incorporating multiple methods into a single evaluation resulted in a stronger, more complete evaluation than conventional evaluation approaches that rely on only one method. Furthermore, incorporating multiple method increased confidence in the validity and reliability of the evaluation results (USAID, 2013). The purpose of the narrative inquiry was to reveal the meaning on the individual, as opposed to objective, decontextualized truths.

This study employed non-random purposive sampling when recruiting participants. In purposive sampling, the researcher specifies the characteristics of the population of interest and then locates the individuals who have those characteristics (Johnson & Christensen, 2017). Thus, purposive sampling can be prone to researcher bias (Sharma, 2017). Furthermore, due to use of reflexive thematic analysis to analyse the narrative interview data, findings in this study do not provide a single or 'correct' answer, therefore, it cannot be assumed that the findings of this study are representative of all caregivers and children with hearing impairment within the South African context. However, these findings provide a foundation for further research.

Lastly, the study comprises of a relatively small sample size. The study sample also comprises of caregivers of children from EI preschools in the province of Gauteng only and is not representative of the general population of caregivers of children with hearing impairment in the rest of South Africa. Data collection for phase 1 of this research commenced in January 2020, two months prior to the COVID-19 pandemic being declared a pandemic and national lockdown restrictions being implemented. Consequently, online data collection measures had to be implemented. Which made scheduling interviews challenging because participants were both working from home and assisting their children with home-

schooling at the same time. Furthermore, data collection for the second phase of the study was conducted during Stage 6 loadshedding, which made it challenging for participants to complete the online survey due to network interruptions during periods of loadshedding. However, the small sample size allowed the researcher to obtain in-depth information about the research question, which is not achievable with a large sample size (Creswell & Plano Clark, 2019).

Notably, the small sample size may have contributed to the weak statistical correlation between caregivers' socio-demographic factors and the domains of family-centeredness (Chapter 8), and the weak correlation coefficients for the conjoint analysis results (Chapter 9). Thus, an exploration of caregivers' evaluation and preferences of EHDI services with caregivers from different geographical locations and healthcare facilities is warranted, particularly where rurality and low socio-economic status may have an influence.

11.6 Conclusion

The current study explored caregivers' experiences and evaluation of the EHDI process and practices in Gauteng, South Africa. This study is the first study to evaluate caregivers' perceptions of the family-centredness of EHDI services using the MMPOC-56 and caregivers' preferences for characteristics associated with of EHDI services using a conjoint analysis. This research offers a deeper understanding of caregivers' lived experiences, expectations, needs, challenges and emotions during the EHDI process. Findings of this research emphasize the need for increased and robust efforts in improving accessibility, acceptability, affordability and responsiveness of EHDI programmes within the South African context through FC-EHDI. FC-EHDI programmes would allow for linguistically and culturally congruent EHDI services, where caregivers are involved as equal partners in intervention services. Furthermore, by addressing caregivers' expectations,

experiences, levels of satisfaction, family-centeredness, and preferences of EHDI programmes; EHDI programmes can be tailored to ensure quality, effective, and contextually responsive services that enhance the EHDI process, resulting in improved outcomes for children with hearing impairment and their families.

11.7 Recommendations for Further Research

- Findings in Chapter 3 highlight that audiologists are not adequately trained to use telehealth. Therefore, there is a need for further research to explore the feasibility of offering telehealth training to qualified audiologists.
- Telehealth is in its infancy, especially within the South African context, thus, there is a need for further research to explore the feasibility of implementing telehealth services within the South African context.
- Findings in Chapter 9 highlight the need for further research investigating family-centredness of various models of care for EHDI with caregivers from varied socio-economic backgrounds and geographical locations across South Africa.
- Findings in Chapter 10 highlight the need for a complete understanding of caregiver's preferences, thus further research to determine caregivers' preferences including caregivers from varied socio-economic backgrounds and geographical locations across South Africa is warranted.

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APPENDICES

Appendix A: The Centre Permission Letter

The Children's Communication Centre

5 Jubilee Road Parktown, 2193
PO Box 87177, Houghton, 2041
Tel- 011 484 3408/9
Email-reception@thecentre.org.za.
NPO No: 001 288

8 August 2019

Dear Mrs N. Maluleke

Permission letter

Thank you for coming to present your research topic and the way I which you wish to conduct the research.

Upon entering *The Children's Communication Centre,* parents/caregivers are made aware of the affiliation that we have with The University of the Witwatersrand, the student training that we offer as well as the research that may be conducted. *The Children's Communication Centre*, therefore, gives the researcher permission to conduct her research project within the ethical guidelines provided by the university.

We will provide the names of potential parent/caregiver participants to the researcher as well as make initial contact in order to obtain permission for the research to contact the parents/caregivers.
This is a very exciting and insightful topic which can help all of us in the field of early intervention.

Yours sincerely,

Phillipa Nilsson
Centre Head

Appendix B: Whispers Centre Permission Letter

Whispers Speech and Hearing Centre
LEARNING LANGUAGE FOR LIVING

P O Box 35661 Menlo Park, Pretoria 0102 Gauteng - Fax: 086 233 3839



22 July 2019

Dear Ms. Maluleke

Research permission

Thank you for coming to meet with me on 18 July 2019 to present your research topic and the way in which you wish to conduct the research.

We, at the Centre, are willing to participate in the study and will make our files available.

This is a very exciting and insightful topic which can help all of us in the field of early intervention. Best of luck with all three stages of the study.

Yours sincerely

Brenda Schmid
Centre Manager

Appendix C: Participant Recruitment Poster

Invitation to participate in a Research Project

You are invited to participate in a research project which aims to explore caregivers' experiences and evaluation of the EHDI process and practices in Gauteng, South Africa. As a parent and/or caregiver of a child with hearing impairment enrolled at this centre you already meet one of the criteria to participate in this research project.

What is involved?

- There are 3 stages involved in this research project
- You are invited to participate in any one or ALL of the stages.

Stage 1:

- Individual interview (Duration: 1-2 hours)
- Two questionnaire (Duration: 20 minutes each)

Stage 2:

- Questionnaire (Duration: 20 minutes)

Stage 3:

- Focus group interview (Duration: 1-2 hours)

Who can participate?

- Caregivers must be 18 years old and older.
- Caregivers must be the primary caregiver of the child with hearing impairment.
- Caregivers of children diagnosed with a mild to profound, bilateral or unilateral hearing impairment.
- Caregivers of children with hearing impairment who have been fitted with amplification devices such as, hearing aids and/or cochlear implants., in order to compensate for the hearing impairment.

Interested in participating?

- For more information, please contact Ntsako Maluleke on 079 954 4279 or email precious.slp@gmail.com
- Potential participants will also be contacted telephonically with permission from *Whispers Centre*.

Appendix D: Narrative Interview Script

- Tell me YOUR story.
- What were your expectations of the EHDI process?
- What were the successes and failures of this process based on your experience?
  - *What do you think worked well or did not work so well with the EHDI process based on your experience?*
- What are the facilitators and barriers to the EHDI process?
  - *What made the EHDI process work well and what made it not work so well?*

Appendix E: Participant Demographic Questionnaire

PLEASE ANSWER THE FOLLOWING QUESTIONS BY PUTTING A TICK IN THE RELEVANT BLOCK OR WRITING DOWN YOUR ANSWER IN THE SPACE PROVIDED.

SECTION A: Caregiver demographic information

This section refers to your background information and your family's demographical information.

1. Ethnicity?

Black	White	Coloured	Indian	Asian

2. Age? (in years)

_____

3. Gender?

Male	Female

4. Marital status?

Single	Married	Separated	Divorced	Widowed

5. Your highest education qualification?

Grade 11 or lower (Std 9)	Grade 12 (Matric)	Post-Matric Diploma or	Baccalaureate Degree(s)	Post Graduate Degree(s)

6. Employment?

Student	Unemployed	Self-employed	Employed

7. How would you describe your economic status?

Poor	Below average	Average	Above average	Affluent

8. Size of your household i.e., the number of people, including yourself who live in your house/dwelling for at least three months of the year?

_____

Please specify their relation to you (e.g., spouse, son, etc.)

_____

_____

_____

_____

9. Specify your relation to the child with hearing impairment (e.g., mother, aunt, grandfather, etc.)

10. Where do you live? (Area)

SECTION B: Child demographic information

This section of the questionnaire refers to your child's background or biographical information and hearing impairment.

1. Gender?

Female	Male

2. Age (years, months)

3. Date of birth? (CCYY-MM-DD)

				-			-		

4. Ethnicity?

Black	White	Coloured	Indian	Asian

5. Home language?

6. When was the hearing impairment identified? (Please provide details)

7. When was the hearing impairment diagnosed? (Please provide details)

8. When did your child start receiving intervention services? (Please provide details)

9. In which language did your child receive intervention services?

10. If the language in question 9, above is different from your child's home language; how was this language chosen?

11. When was your child fitted with amplification device/s? (Please provide details)

12. What type of amplification device/s is your child fitted with?

_____

_____

_____

13. Has your child changed amplification devices? (Please provide detail)

_____

_____

_____

14. Where does your child receive audiological services?

_____

Thank you for your cooperation in completing this questionnaire.

Appendix F: MMPOC-56

MEASURE OF PROCESSES OF CARE (MPOC-56)

I would like to understand and measure the experience of parents and/or caregivers who have a child with hearing impairment. In particular, I wish to know about your perceptions of the care you have been receiving over the past year from your child's **Treatment (Rehabilitation) Centre**.

The questions in this section are based on what parents and/or caregivers, like yourself, have said about the way care is sometimes offered. I would like you to indicate how much the event or situation happens (or doesn't happen) to you at your treatment centre. You are asked to answer each question on a scale from 7 (To a Very Great Extent) to 1 (Not at All).

The care that you and your child received from the centre may have put you into contact with many individuals. The questions on this form are grouped by who these contacts are as described below.

PEOPLE: refers to those individuals who work directly with you and your child. These **may include** audiologists, psychologists, therapists, social workers, doctors, teachers, etc.

CENTRE: refers to all staff from the centre, whether involved directly with your child or not. In addition to health care, people they **may include** support staff such as office staff, administrative personnel, etc.

The following is an example of the kinds of questions you will be asked. This example also shows what your answer could mean.

IN THE PAST YEAR, TO WHAT EXTENT DO THE PEOPLE WHO GIVE YOU QUESTIONNAIRES…	**Indicate how much each event or situation happens to you.**							
	To a very Great Extent	To a Great Extent	To a fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
… provide you with clear instructions on how to complete them?								

If you circled #7 (To a Very Great Extent), it means that the people who give you questionnaires provide very clear instructions in what they ask you to do.

If you circled #4 (To a Moderate Extent), it means that the people who give you questionnaires are clear in what they want you to do some of the time, and some of the time the instructions are not clear.

If you circled #1 (Not at All), it means that although you have received questionnaires, the instructions are never clear.

If you circled #0 (Not Applicable, it means that you have never received a questionnaire and so you cannot answer the question. It does not apply to you.

I would like you to think about your experiences over the past year at your child's Centre. I am interested in your personal thoughts and would appreciate your completing the questionnaire on your own without discussing it with anyone.

For each question, please indicate how much the event or situation happens to you by circling **one** number (from 1to 7) that you feel fits your experience.

IN THE PAST YEAR, TO WHAT EXTENT DO THE *PEOPLE* WHO WORK WITH YOUR CHILD….	Indicate <u>how much</u> each event or situation happens to you.							
	To a very Great Extent	**To a Great Extent**	**To a fairly Great Extent**	**To a Moderate Extent**	**To a Small Extent**	**To a Very Small Extent**	**Not at All**	**Not Applicable**
1. …suggest therapy plans that fit with your family's needs and lifestyle?	7	6	5	4	3	2	1	0
2. …fully explain treatment choices to you?	7	6	5	4	3	2	1	0
3. …offer you positive feedback or encouragement (e.g., in carrying out a home programme)?	7	6	5	4	3	2	1	0
4. …explain things to your child in a way that your child understands?	7	6	5	4	3	2	1	0
5. …take the time to establish rapport (relationship) with you and your child when changes occur in your services?	7	6	5	4	3	2	1	0
6. …discuss with you everyone's expectations for your child, so that all agree on what is best?	7	6	5	4	3	2	1	0

7. …make sure that your child's skills are known to all persons working with your child, so these skills are carried cross services and service providers?	7	6	5	4	3	2	1	0
IN THE PAST YEAR, TO WHAT EXTENT DO THE *PEOPLE* WHO WORK WITH YOUR CHILD…	Indicate <u>how much</u> each event or situation happens to you.							
	To a very Great Extent	**To a Great Extent**	**To a fairly Great Extent**	**To a Moderate Extent**	**To a Small Extent**	**To a Very Small Extent**	**Not at All**	**Not Applicable**
8. …tell you about options for treatment or services for your child (e.g., equipment, school, therapy)?	7	6	5	4	3	2	1	0
9. …accept you and your family in a nonjudgmental way?	7	6	5	4	3	2	1	0
10. …provide ideas to help you work with the health care "system"?	7	6	5	4	3	2	1	0
11. …recognize the demands of caring for a child with special needs?	7	6	5	4	3	2	1	0
12. …trust you as the "expert" on your child?								

	7	6	5	4	3	2	1	0
13. …look at the needs of your "whole" child (e.g., at mental, emotional, and social needs) instead of just physical needs?	7	6	5	4	3	2	1	0
14. …show sensitivity to your family's feelings about having a child with special needs (e.g., your worries about your child's health or function)?	7	6	5	4	3	2	1	0
15. …anticipate your concerns by offering information even before you ask?	7	6	5	4	3	2	1	0
16. …make sure you have a chance during visits to the centre to say what is important to you?	7	6	5	4	3	2	1	0
17. …let you choose when to receive information and the type of information you want?	7	6	5	4	3	2	1	0
18. …remember personal details about your child or family when speaking with you?	7	6	5	4	3	2	1	0

19. …tell you about the reasons for treatment or equipment?	7	6	5	4	3	2	1	0
20. …follow up at the next appointment on any concerns you discussed at the previous one?	7	6	5	4	3	2	1	0

IN THE PAST YEAR, TO WHAT EXTENT DO *PEOPLE* WHO WORK WITH YOUR CHILD…	Indicate <u>how much</u> each event or situation happens to you.							
	To a very Great Extent	**To a Great Extent**	**To a fairly Great Extent**	**To a Moderate Extent**	**To a Small Extent**	**To a Very Small Extent**	**Not at All**	**Not Applicable**
21. …make sure at least one team member is someone who works with you and your family over a long period of time?	7	6	5	4	3	2	1	0
22. …provide opportunities for you to make decisions about treatment?	7	6	5	4	3	2	1	0
23. …answer your questions completely?	7	6	5	4	3	2	1	0

24. …explain what they are doing when you are watching your child in therapy?	7	6	5	4	3	2	1	0
25. …recognize that your family has the final say when making decisions about your child's treatment?	7	6	5	4	3	2	1	0
26. …tell you about the results from assessments?	7	6	5	4	3	2	1	0
27. …provide you with written information about what your child is doing in therapy?	7	6	5	4	3	2	1	0
28. …consult with you when discussing equipment or services?	7	6	5	4	3	2	1	0
29. …provide a caring atmosphere rather than just give you information?	7	6	5	4	3	2	1	0
30. …tell you details about your child's services, such as the reasons for them, the type of therapies and the length of time?	7	6	5	4	3	2	1	0

31. …treat you as an individual rather than as a "typical" parent of a child with hearing impairment?	7	6	5	4	3	2	1	0
32. …develop both short-term and long-term goals for your child?	7	6	5	4	3	2	1	0
33. …treat you as an <u>equal</u> rather than just as the parent of a patient (e.g., by not referring to you as "Mom" and "Mama" or "Dad" and "Papa")?	7	6	5	4	3	2	1	0
IN THE PAST YEAR, TO WHAT EXTENT DO THE *PEOPLE* WHO WORK WITH YOUR CHILD…	Indicate <u>how much</u> each event or situation happens to you.							
	To a very Great Extent	**To a Great Extent**	**To a fairly Great Extent**	**To a Moderate Extent**	**To a Small Extent**	**To a Very Small Extent**	**Not at All**	**Not Applicable**
34. …plan together so they are all working in the same direction?	7	6	5	4	3	2	1	0
35. …make sure you have the opportunities to explain what you think are important treatment goals?	7	6	5	4	3	2	1	0
36. …make you feel like you are a partner in your child's								

care?	7	6	5	4	3	2	1	0
37. …make sure you are informed ahead of time about any changes in your child's care (e.g., therapists, progress, equipment)?	7	6	5	4	3	2	1	0
38. …help you feel competent as a parent and/or caregiver?	7	6	5	4	3	2	1	0
39. …provide you with written information about your child's progress?	7	6	5	4	3	2	1	0
40. …seems aware of your child's changing needs as he/she grows?	7	6	5	4	3	2	1	0
41. …provide enough time to talk to you so you don't feel rushed?	7	6	5	4	3	2	1	0
42. …treat you and your family as people <u>rather</u> than as a "case" (e.g., by not referring to you by your child's diagnosis)	7	6	5	4	3	2	1	0

43. …listen to what you have to say about your child's needs for equipment, services, etc.?	7	6	5	4	3	2	1	0
44. …make themselves available to you as a resource (e.g., emotional support, advocacy, information)?	7	6	5	4	3	2	1	0
45. …give you information about your child that is consistent from person to person?	7	6	5	4	3	2	1	0

CENTRE: refers to <u>all staff</u> from the centre whether involved directly with your child or not. In addition to health care professionals, these people **may include** support staff such as office, cleaners, administrative personnel, etc.

IN THE PAST YEAR, TO WHAT EXTENT DOES THE *CENTER* WHERE YOU RECEIVE SERVICES…	7	6	5	4	3	2	1	0
46. …have information available to you in various forms, such as a booklet, kit, video, etc.?	7	6	5	4	3	2	1	0
47. …have support staff that are polite and courteous to you and your family?	7	6	5	4	3	2	1	0

48. …give you information about the types of services offered at the Centre or in your community?	7	6	5	4	3	2	1	0
49. …promote family-to-family gatherings for social, informational or shared experiences?	7	6	5	4	3	2	1	0
50. …provide opportunities for special guests to speak to parents and/or caregivers on topics of interest?	7	6	5	4	3	2	1	0
51. …provide support to help cope with the impact of childhood hearing impairment (e.g., by advocating on your behalf or informing you of assistance programmes)?	7	6	5	4	3	2	1	0
52. …notify you about the reasons for upcoming case conferences, meetings, etc. about your child?	7	6	5	4	3	2	1	0
53. …have information available about your child's hearing impairment (e.g., its cause, how it progresses, future outlook)?	7	6	5	4	3	2	1	0

54. …provide advice on how to get information or to contact other parents and/or caregivers?	7	6	5	4	3	2	1	0
55. …provide opportunities for the entire family to obtain information?	7	6	5	4	3	2	1	0
56. …have general information available about different concerns (e.g., financial costs or assistance, genetic counselling, dating and sexuality)?	7	6	5	4	3	2	1	0

Appendix G: Conjoint Analysis Questionnaire

CONJOINT ANALYSIS: CAREGIVERS' PREFERENCES FOR CHARACTERISTICS ASSOCIATED WITH EHDI SERVICES

Description of questionnaire and instructions

I would like to find out from parents and/or caregivers the type of service model they would prefer for their child with a hearing loss. This survey contains types of service models **for families with young children with a hearing loss**. The survey was designed based on information collected from parent and/or caregiver interviews. Parents and/or caregivers described their experiences with services they received for their child with a hearing loss.

The questionnaire consists of **10 scenarios** for services that might be offered for children with a hearing loss. **The scenarios describe different service models with SLIGHTLY DIFFERENT FEATURES, please read the service models carefully before you make your selection**. Based on your experience, we would like you to look at the choices and select what service you would have liked for your child with hearing loss.

We expect that the questionnaire will take about 20 to 25 minutes to complete. For each scenario, there are two choices, Service A or Service B. **Please choose which ONE you would prefer** by selecting **ONLY ONE OPTION** for each scenario.

Definitions of each feature are provided. Please read the definitions carefully and refer to them when making your choice.

Description of terms and abbreviations used in the questionnaire

Term/ Abbreviation	Description
EHDI	Early Hearing Detection and Intervention
HCW	Healthcare worker HCW includes nurses, doctors, audiologists, speech therapists, paediatricians, psychologists, social work, etc.
ENT	Ear-Nose-Throat Specialist
Healthcare facility	Any place where healthcare services are offered i.e., clinics, hospitals, doctors' rooms, etc.
Telehealth	Telehealth is the use of digital information and communication technologies to access healthcare services remotely (away from the

	healthcare facility). Technologies can include computers, laptops and mobile devices, like tablets and smartphones.
Mode of service delivery	The way in which you receive EHDI services.
Support services	Provision of services to the child and/or caregiver such as emotional support, counselling, information about hearing loss, information about speech and language development, schools, school placement, etc. throughout the EHDI process
Caregivers information sessions.	Caregivers attend group education sessions with a HCW (e.g., monthly, 3-month intervals) to learn about hearing, speech and language development, schools, school placement, etc. throughout the EHDI process.
Direct therapy	One-on-one therapy with the audiologist and/or speech therapist with targeted activities to address affected areas of speech and/or language development.
Child	Child with hearing loss
Caregiver	Parent and/or caregiver

Attributes and attribute level for the conjoint analysis questionnaire

This table does not form part of the questionnaire it's for your reference, it forms part of the methodology of developing the questionnaire. Each attribute level appears 6 times in the questionnaire.

Attributes	**Attribute level**		
Language used for service provision	English	Home language	Any one of the South African languages, with an interpreter if needed.
Mode of service delivery	Child receives EHDI services and is referred to other HCWs (i.e., pediatrician, social worker, psychologist) of the caregiver's choice for all the other services that the child/and or caregiver need.	Child receives EHDI services at the nearest healthcare facility that offers all services (i.e., ENT, psychology) that the child/and or caregiver need.	Child receives all EHDI services (i.e., audiology, speech therapy, ENT, psychology) via telehealth. Child and caregiver might be required to go to the healthcare facility for some tests/procedures.

Aural habilitation, speech and language therapy	Regular direct therapy sessions (i.e., once a week) at the nearest healthcare facility.	Regular sessions (i.e., once a week) at home with the child, caregiver and HCW.	Regular sessions (i.e., once a week) at home with the child, and caregiver via telehealth. Direct therapy is then offered if there is a speech and/or language delay or no progress.
Support services	Caregivers information sessions.	Regular part of services according to the child, caregiver, and family's needs.	Caregivers seek information independently.
Reducing the cost of services	Decrease transport cost to healthcare facility.	Decrease cost of services i.e., screening, evaluation, aural habilitation, speech and language therapy, etc.	Decrease cost of amplification devices, FM systems, etc.

QUESTIONNAIRE

Please click one box only for each question, that is, select Service A or Service B for each scenario.

The services may look the same for some or all the scenarios, **each scenario has a different combination of features and therefore provides a unique service model**.

Scenario 1: Which service do you prefer?

Scenario 1	**Service A**	**Service B**
Language used for service provision	Home language	Any one of the South African languages, with an interpreter if needed.
Mode of service delivery	Child receives EHDI services at the nearest healthcare facility that offers all services (i.e., ENT, psychology) that the child/and or caregiver need.	Child receives EHDI services and is referred to other HCWs (i.e., pediatrician, social worker, psychologist) of the caregiver's choice for all the other services that the child/and or caregiver need.
Aural habilitation, speech and language therapy	Regular sessions (i.e., once a week) at home with the child, and caregiver via telehealth. Direct therapy is then offered if there is a speech and/or language delay or no progress.	Regular sessions (i.e., once a week) at home with the child, caregiver and HCW.

Support services	Caregivers information sessions.	Caregivers seek information independently.
Reducing the cost of services	Decrease cost of services i.e., screening, evaluation, aural habilitation, speech and language therapy, etc.	Decrease transport cost to healthcare facility.

Scenario 2: Which service do you prefer?

Scenario 2	**Service A**	**Service B**
Language used for service provision	Any one of the South African languages, with an interpreter if needed.	English
Mode of service delivery	Child receives EHDI services and is referred to other HCWs (i.e., pediatrician, social worker, psychologist) of the caregiver's choice for all the other services that the child/and or caregiver need.	Child receives all EHDI services (i.e., audiology, speech therapy, ENT, psychology) via telehealth. Child and caregiver might be required to go to the healthcare facility for some tests/procedures.
Aural habilitation, speech and language therapy	Regular sessions (i.e., once a week) at home with the child, caregiver and HCW.	Regular direct therapy sessions (i.e., once a week) at the nearest healthcare facility.
Support services	Caregivers seek information independently.	Caregivers information sessions.
Reducing the cost of services	Decrease cost of amplification devices, FM systems, etc.	Decrease cost of services i.e., screening, evaluation, aural habilitation, speech and language therapy, etc.

Scenario 3: Which service do you prefer?

Scenario 3	**Service A**	**Service B**
Language used for service provision	English	Home language
Mode of service delivery	Child receives all EHDI services (i.e., audiology, speech therapy, ENT, psychology) via telehealth. Child and caregiver might be required to go to the healthcare facility for some tests/procedures.	Child receives EHDI services at the nearest healthcare facility that offers all services (i.e., ENT, psychology) that the child/and or caregiver need.

Aural habilitation, speech and language therapy	Regular direct therapy sessions (i.e., once a week) at the nearest healthcare facility.	Regular sessions (i.e., once a week) at home with the child, caregiver and HCW.
Support services	Regular part of services according to the child, caregiver, and family's needs.	Caregivers information sessions.
Reducing the cost of services	Decrease transport cost to healthcare facility.	Decrease cost of amplification devices, FM systems, etc.

Scenario 4: Which service do you prefer?

Scenario 4	**Service A**	**Service B**
Language used for service provision	Home language	Any one of the South African languages, with an interpreter if needed.
Mode of service delivery	Child receives EHDI services and is referred to other HCWs (i.e., pediatrician, social worker, psychologist) of the caregiver's choice for all the other services that the child/and or caregiver need.	Child receives all EHDI services (i.e., audiology, speech therapy, ENT, psychology) via telehealth. Child and caregiver might be required to go to the healthcare facility for some tests/procedures.
Aural habilitation, speech and language therapy	Regular sessions (i.e., once a week) at home with the child, caregiver and HCW.	Regular direct therapy sessions (i.e., once a week) at the nearest healthcare facility.
Support services	Caregivers seek information independently.	Regular part of services according to the child, caregiver, and family's needs.
Reducing the cost of services	Decrease cost of amplification devices, FM systems, etc.	Decrease cost of services i.e., screening, evaluation, aural habilitation, speech and language therapy, etc.

Scenario 5: Which service do you prefer?

Scenario 5	**Service A**	**Service B**
Language used for service provision	Any one of the South African languages, with an interpreter if needed.	English
Mode of service delivery	Child receives all EHDI services (i.e., audiology, speech therapy, ENT, psychology) via telehealth. Child and caregiver might be required to go to the healthcare facility for some tests/procedures.	Child receives EHDI services at the nearest healthcare facility that offers all services (i.e., ENT, psychology) that the child/and or caregiver need.

Aural habilitation, speech and language therapy	Regular direct therapy sessions (i.e., once a week) at the nearest healthcare facility.	Regular sessions (i.e., once a week) at home with the child, and caregiver via telehealth. Direct therapy is then offered if there is a speech and/or language delay or no progress.
Support services	Regular part of services according to the child, caregiver, and family's needs.	Caregivers seek information independently.
Reducing the cost of services	Decrease transport cost to healthcare facility.	Decrease cost of amplification devices, FM systems, etc.

Scenario 6: Which service do you prefer?

Scenario 6	**Service A**	**Service B**
Language used for service provision	English	Home language
Mode of service delivery	Child receives EHDI services at the nearest healthcare facility that offers all services (i.e., ENT, psychology) that the child/and or caregiver need.	Child receives EHDI services and is referred to other HCWs (i.e., pediatrician, social worker, psychologist) of the caregiver's choice for all the other services that the child/and or caregiver need.
Aural habilitation, speech and language therapy	Regular sessions (i.e., once a week) at home with the child, and caregiver via telehealth. Direct therapy is then offered if there is a speech and/or language delay or no progress.	Regular direct therapy sessions (i.e., once a week) at the nearest healthcare facility.
Support services	Caregivers information sessions.	Caregivers seek information independently.
Reducing the cost of services	Decrease cost of services i.e., screening, evaluation, aural habilitation, speech and language therapy, etc.	Decrease transport cost to healthcare facility.

Scenario 7: Which service do you prefer?

Scenario 7	**Service A**	**Service B**
Language used for service provision	Any one of the South African languages, with an interpreter if needed.	English
Mode of service delivery	Child receives EHDI services at the nearest healthcare facility that offers all services (i.e., ENT, psychology) that the child/and or caregiver need.	Child receives EHDI services and is referred to other HCWs (i.e., pediatrician, social worker, psychologist) of the caregiver's choice for all the other services that the child/and or caregiver need.

Aural habilitation, speech and language therapy	Regular sessions (i.e., once a week) at home with the child, and caregiver via telehealth. Direct therapy is then offered if there is a speech and/or language delay or no progress.	Regular sessions (i.e., once a week) at home with the child, caregiver and HCW.
Support services	Caregivers information sessions.	Regular part of services according to the child, caregiver, and family's needs.
Reducing the cost of services	Decrease cost of services i.e., screening, evaluation, aural habilitation, speech and language therapy, etc.	Decrease transport cost to healthcare facility.

Scenario 8: Which service do you prefer?

Scenario 8	**Service A**	**Service B**
Language used for service provision	Home language	Any one of the South African languages, with an interpreter if needed.
Mode of service delivery	Child receives all EHDI services (i.e., audiology, speech therapy, ENT, psychology) via telehealth. Child and caregiver might be required to go to the healthcare facility for some tests/procedures.	Child receives EHDI services at the nearest healthcare facility that offers all services (i.e., ENT, psychology) that the child/and or caregiver need.
Aural habilitation, speech and language therapy	Regular direct therapy sessions (i.e., once a week) at the nearest healthcare facility.	Regular sessions (i.e., once a week) at home with the child, and caregiver via telehealth. Direct therapy is then offered if there is a speech and/or language delay or no progress.
Support services	Regular part of services according to the child, caregiver, and family's needs.	Caregivers seek information independently.
Reducing the cost of services	Decrease transport cost to healthcare facility.	Decrease cost of amplification devices, FM systems, etc.

Scenario 9: Which service do you prefer?

Scenario 9	**Service A**	**Service B**
Language used for service provision	English	Home language
Mode of service delivery	Child receives EHDI services and is referred to other HCWs (i.e., pediatrician, social worker, psychologist) of the caregiver's choice for all the other services that the child/and or caregiver need.	Child receives all EHDI services (i.e., audiology, speech therapy, ENT, psychology) via telehealth. Child and caregiver might be required to go to the healthcare facility for some tests/procedures.

Aural habilitation, speech and language therapy	Regular sessions (i.e., once a week) at home with the child, caregiver and HCW.	Regular sessions (i.e., once a week) at home with the child, and caregiver via telehealth. Direct therapy is then offered if there is a speech and/or language delay or no progress.
Support services	Caregivers seek information independently.	Regular part of services according to the child, caregiver, and family's needs.
Reducing the cost of services	Decrease cost of amplification devices, FM systems, etc.	Decrease cost of services i.e., screening, evaluation, aural habilitation, speech and language therapy, etc.

Thank you for completing the questionnaire.

Appendix H: Focus Group Interview Script

1. What do you think of the results presented to you (conjoint analysis findings)?

   Do you agree or disagree with the results? (Explain)

Appendix I: Ethical Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Research Office

HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)
R14/49 Maluleke

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER: H19/06/16**
PROJECT TITLE	Family-centred EHDI services: Caregivers' experience and evaluation of the process and practices in the South African context
INVESTIGATOR(S)	Mrs N Maluleke
SCHOOL/DEPARTMENT	Human and Community Development/
DATE CONSIDERED	21 June 2019
DECISION OF THE COMMITTEE	Approved Two Year Extension Only
EXPIRY DATE	21 August 2024

DATE 22 August 2019 **CHAIRPERSON** _____
(Professor J Watermeyer)

cc: Supervisor : Prof K Khoza-Shangase and Dr A Kanji

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **A SIGNED COPY** returned to the Secretary electronically. Unreported changes to the application may invalidate the clearance given by the HREC (Non-Medical)

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure be contemplated from the research procedure as approved I/we undertake to submit an amendment of the protocol to the Committee. **I/we agree to completion of a regular progress report. For Minimal and Low Risk studies, this is due annually on 31 December. For Medium and High Risk studies, this is due twice annually on 30 June and 31 December.**

_____ 06 / 04 / 2023
Signature **Date**

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

Appendix J: Informed Consent Letter and Form (Phase 1)

SPEECH PATHOLOGY & AUDIOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4577 • Fax: 011 717 4572 • E-mail: sppa.SHCD@wits.ac.za

June 2019

Good day

My name is Ntsako Precious Maluleke and I am a PhD student in the Department of Audiology at the University of the Witwatersrand. As part of my studies, I have to undertake a research project, and I am investigating Family-Centered Early Hearing Detection and Intervention (Family-Centered EHDI) in the South African context. The aim of this research project is to find out caregivers' experiences and evaluation of the process and practices of EHDI in Gauteng.

As part of this project, I would like to invite you to take part in an interview and answering a questionnaire. This interview will involve you describing your experience with the early hearing detection and intervention process and practices and will take between 1-2 hours; the questionnaire involves evaluating if EHDI services are family-centered and takes around 20 minutes. With your permission, I would also like to audio record the interview using a Phillips Voice Tracer audio recorder.

You will not receive any direct benefits from participating in this research, and there are no disadvantages or penalties for not participating. You may withdraw at any time or not answer any question if you do not want to. The interview and questionnaire will be completely confidential and anonymous as I will not be asking for your name or any identifying

information, and the information you give to me will be held securely and not disclosed to anyone else. I will be using a pseudonym (false name) to represent your participation in my final research report. If you experience any distress or discomfort at any point in this process, we will stop the interview or resume another time. If you need some support or counselling services following the interview and questionnaire you will be referred to the necessary services free of charge.

If you have any questions, please feel free to contact me on the details listed below. This study will be written up as a research report which will be available online through the university library website. It will also be published in various journals and presented at conferences. If you wish to receive a summary of the research report, I will be happy to send it to you. If you have any concerns or complaints regarding the ethical procedures of this study, you are welcome to contact the University Research Ethics Committee (Non-Medical), telephone 011 717 1408, email Shaun.Schoeman@wits.ac.za.

Yours sincerely,

_____

Precious Maluleke
PhD (Audiology) Student
precious.slp@gmail.com
079 954 4279

_____ _____

Prof K Khoza-Shangase
Research Supervisor
Katijah.Khoza@wits.ac.za

Dr. A Kanji
Research Supervisor
Amisha.Kanji@wits.ac.za

Consent form

Title of the study: Family-centred EHDI services: Caregivers' experience and evaluation of the process and practices in the South African context

Name of researcher: Ntsako Precious Maluleke

I, _____ in my capacity as _____'s Caregiver agree to participate in this study. The research has been explained to me and I understand what my participation will involve.

(Please circle)

I agree that the researcher may access my child's pre-school and therapy records.	YES	NO
I understand that participation is voluntary and should I wish to withdraw I may do so with no negative consequences.	YES	NO
I agree that my participation will remain anonymous. All information gathered during the study is confidential and no mention will be made of mine or my child's personal details.	YES	NO
I agree that the researcher may use anonymous quotes in her research report, journal articles or conference presentations.	YES	NO
I agree that the interview may be audio-recorded.	YES	NO

Signature: _____

Name of participant: _____

Date: _____

Appendix K: Information Letter (Phase 2)

SPEECH PATHOLOGY & AUDIOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4577 • Fax: 011 717 4572 • E-mail: sppa.SHCD@wits.ac.za

June 2019

Good day

My name is Ntsako Precious Maluleke and I am a PhD student in the Department of Audiology at the University of the Witwatersrand. As part of my studies, I have to undertake a research project, and I am investigating Family-Centered Early Hearing Detection and Intervention (Family-Centered EHDI) in the South African context. The aim of this research project is to find out caregivers' experiences and evaluation of the process and practices of EHDI in Gauteng.

As part of this project, I would like to invite you to take part in answering a questionnaire. The questionnaire involves indicating your preferences for characteristics associated with of EHDI services and takes around 20 minutes.

You will not receive any direct benefits from participating in this research, and there are no disadvantages or penalties for not participating. You may withdraw at any time or not answer any question if you do not want to. The interview and questionnaire will be completely confidential and anonymous as I will not be asking for your name or any identifying information, and the information you give to me will be held securely and not disclosed to anyone else. I will be using a pseudonym (false name) to represent your participation in my final research report. If you experience any distress or discomfort at any point in this process,

we will stop the interview or resume another time. If you need some support or counselling services following the interview and questionnaire you will be referred to the necessary services free of charge.

If you have any questions, please feel free to contact me on the details listed below. This study will be written up as a research report which will be available online through the university library website. It will also be published in various journals and presented at conferences. If you wish to receive a summary of the research report, I will be happy to send it to you. If you have any concerns or complaints regarding the ethical procedures of this study, you are welcome to contact the University Research Ethics Committee (Non-Medical), telephone 011 717 1408, email Shaun.Schoeman@wits.ac.za.

Yours sincerely,

_____

Precious Maluleke

PhD (Audiology) Student

precious.slp@gmail.com

079 954 4279

_____ _____

Prof K Khoza-Shangase

Research Supervisor

Katijah.Khoza@wits.ac.za

Dr. A Kanji

Research Supervisor

Amisha.Kanji@wits.ac.za

Appendix L: Informed Consent Form (Phase 2)

Consent form

Title of the study: Family-centred EHDI services: Caregivers' experience and evaluation of the process and practices in the South African context

Name of researcher: Ntsako Precious Maluleke

I, _____ in my capacity as _____'s Caregiver agree to participate in this study. The research has been explained to me and I understand what my participation will involve.

	(Please circle)	
I agree that the researcher may access my child's pre-school and therapy records.	YES	NO
I understand that participation is voluntary and should I wish to withdraw I may do so with no negative consequences.	YES	NO
I agree that my participation will remain anonymous. All information gathered during the study is confidential and no mention will be made of mine or my child's personal details.	YES	NO
I agree that the researcher may use anonymous quotes in her research report, journal articles or conference presentations.	YES	NO
I agree that the interview may be audio-recorded.	YES	NO

Signature: _____

Name of participant: _____

Date: _____

Appendix M: Information Letter (Phase 3)

SPEECH PATHOLOGY & AUDIOLOGY
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4577 • Fax: 011 717 4572 • E-mail: sppa.SHCD@wits.ac.za

June 2019

Good day

My name is Ntsako Precious Maluleke and I am a PhD student in the Department of Audiology at the University of the Witwatersrand. As part of my studies, I have to undertake a research project, and I am investigating Family-Centered Early Hearing Detection and Intervention (Family-Centered EHDI) in the South African context. The aim of this research project is to find out caregivers' experiences and evaluation of the process and practices of EHDI in Gauteng.

As part of this project, I would like to invite you to take part in a focus group interview. The focus group will be made up of other caregivers of children with hearing impairment and will involve discussing caregivers' preferences for characteristics associated with of EHDI services and will take between 1-2 hours. With your permission, I would also like to audio record the interview using a Phillips Voice Tracer audio recorder.

You will not receive any direct benefits from participating in this research, and there are no disadvantages or penalties for not participating. You may withdraw at any time or not answer any question if you do not want to. Please be advised that I will take every precaution to maintain confidentiality of the data; however, the nature of focus groups prevents me from guaranteeing confidentiality. In addition, I would like to request that you respect the privacy

of your fellow participants and not repeat what is said in the focus group to others. The information you provide during the interview will be held securely and not disclosed to anyone else. I will be using a pseudonym (false name) to represent your participation in my final research report. If you experience any distress or discomfort at any point in this process, we will stop the interview or resume another time. If you need some support or counselling services following the interview you will be referred to the necessary services free of charge.

If you have any questions, please feel free to contact me on the details listed below. This study will be written up as a research report which will be available online through the university library website. It will also be published in various journals and presented at conferences. If you wish to receive a summary of the research report, I will be happy to send it to you. If you have any concerns or complaints regarding the ethical procedures of this study, you are welcome to contact the University Research Ethics Committee (Non-Medical), telephone 011 717 1408, email Shaun.Schoeman@wits.ac.za.

Yours sincerely,

_____

Precious Maluleke
PhD (Audiology) Student
precious.slp@gmail.com
079 954 4279

_____

Prof K Khoza-Shangase
Research Supervisor
Katijah.Khoza@wits.ac.za

_____

Dr. A Kanji
Research Supervisor
Amisha.Kanji@wits.ac.za

Appendix N: Informed Consent Form (Phase 3)

Consent form

Title of the study: Family-centred EHDI services: Caregivers' experience and evaluation of the process and practices in the South African context **Name of researcher:** Ntsako Precious Maluleke

I, _____ in my capacity as _____'s Caregiver agree to participate in this study. The research has been explained to me and I understand what my participation will involve.

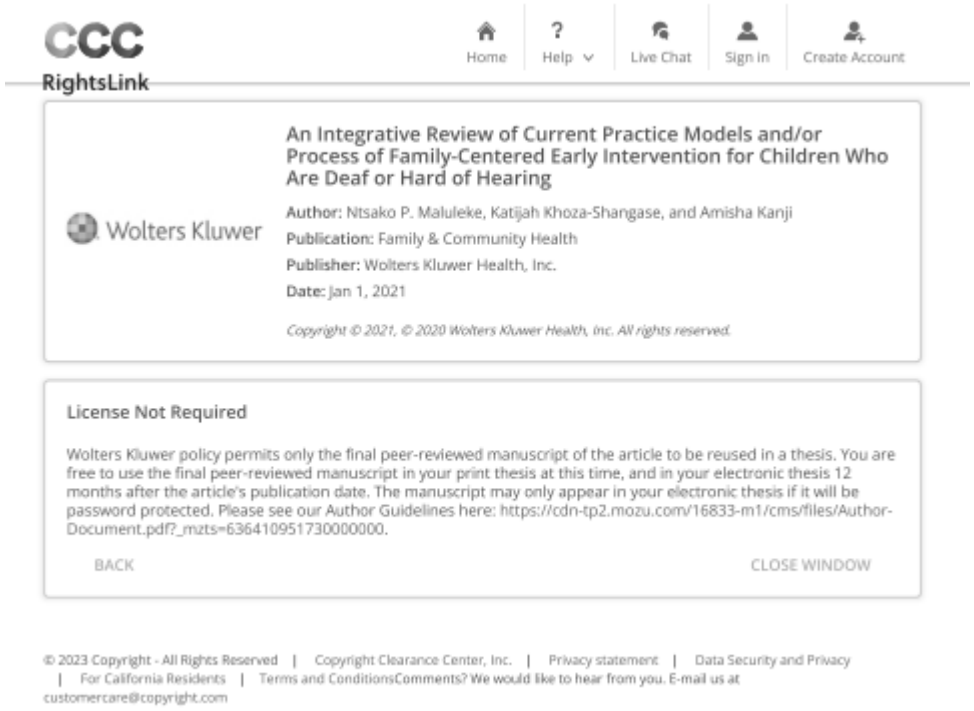
	(Please circle)	
I understand that participation is voluntary and should I wish to withdraw I may do so with no negative consequences.	YES	NO
I agree that my participation will remain anonymous. All information gathered during the study is confidential and no mention will be made of my child's personal details.	YES	NO
I agree that the researcher may use anonymous quotes in her research report, journal articles or conference presentations.	YES	NO
I agree that the interview may be audio-recorded.	YES	NO

Signature: _____

Name of participant: _____

Date: _____

Appendix O: Reprint Permission for Chapter 3



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An Integrative Review of Current Practice Models and/or Process of Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing

Author: Ntsako P. Maluleke, Katijah Khoza-Shangase, and Amisha Kanji
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Appendix P: Papers Included in Chapter 3

Research focus/targets	Author(s)	Context	Method of implementation/format	Outcomes
1. Caregiver involvement (n=4)	Inger, Al-Yagon & Dromi (2011)	Kesher EI programme, Israel	Kesher philosophy is adopted whereby: *a)* the responsibility of the habilitation process is attributed to the caregivers *b)* caregivers participate in meetings, advocacy training, lectures on high-priority topics *c)* caregivers enrol in a parent group for emotional support, to share experiences & brainstorm possible solutions for raising a child who is DHH *d)* individualized implementation of intervention plan in collaboration with caregivers and relevant professionals	*1.* Increased curiosity, motivation and perceived social support, as well as decreased pessimism about child's potential resulted in increased caregiver involvement in EI. *2.* Increased anger resulted in decreased caregiver involvement in EI

	Harrison et al. (2016)	National Institute of Deafness and other Communication Disorders, USA	122 Caregivers of children who are DHH enrolled in EI services at various centres through USA participated in a telephonic interview to investigate caregiver involvement as a function of setting (home vs not in the home)	Family involvement was significantly more likely to occur when services were delivered in the home
	Erbasi, Scarinci, Hickson & Ching (2018)	3 states in Australia	2 Families of children who are DHH accessed a range of centre-based, home-based and telepractice services that included medical, audiology, speech therapy, physiotherapy and occupational therapy EI services through programmes that followed an auditory-verbal therapy, auditory-oral, total communication or bilingual-bicultural approach prior to the child's third birthday	Caregiver involvement is multifaceted and incorporates a broad range of behaviours and practices: *1.* caregivers work behind the scenes *2.* Caregivers act as case managers *3.* Caregivers support their child's language development *4.* Caregivers ' role extends to advocacy for all children with hearing loss *5.* caregivers serve a number of roles, but at the end of the day they are caregivers

	Cruz, Quittner, Marker, DesJardin, & CDaCI Investigative Team (2013)	6 clinical implant centres across USA	*a)* Caregivers of children who are DHH were videotaped during free play or structured play with their child at baseline, 12-months, 24-months, and 36-months post implantation. *b)* Caregivers also completed psychosocial questionnaires about their child. The videotaped language sample were then transcribed and analysed.	Higher level facilitation techniques such as parallel talk, open-ended questions, expansion, expatiation and recast were more facilitative than lower level facilitative techniques such as linguistic mapping, comment, imitation, labelling, directives and closed ended-questions.
	Ambrose, Walker, Unflat-Berry, Oleson & Moeller (2015).	USA	*a)* 156 children who are DHH and 59 children with typical hearing and their caregivers participated in a 5-minute semi-structured conversation at 18 months and 3 years. *b)* The conversations were transcribed and analysed.	*1.* Caregivers exposed children who are DHH to greater proportions of directing utterances as compared to children with typical hearing at 18 months. *2.* Children who are DHH were exposed to fewer words and lower quality input from their caregivers compared to children with typical hearing at 3 years
2. Caregiver coaching/information sharing (n=12)				
a) Caregiver coaching (n=3)	Eckberg, Scarinci, Hickson & Meyer (2018)	3 clinical sites, Australia	Health professional provides commentary for the caregiver during(professional directs talk to the caregiver) interaction with the child in an assessment or intervention tasks	Health professionals describes what the caregiver is observing during the appointment which enhances the caregivers' knowledge of habilitation procedures and goals

	Sacks, Shay, Repplinger, Leffel, Sapolich, Tannenbaum & Suskind (2014)	Rural & remote USA	One 60-minute PowerPoint education session conducted in the family's home four on-going linguistic feedback via phone sessions following analysis of each submission of a 16-hour caregiver-child interaction at home	Caregiver-directed intervention influenced a rich, nuanced component of the habilitation process: *1.* Average Adult Word Count (AWC) increased by 20% above baseline measure *2.* Average Conversation Turn count (CTC) increased by 53% from baseline *3.* Average Child Vocalization Count (CVC) increased by 43% above baseline
	Lam-Cassettari, Wadnekar-Kamble & James (2015)	Chicago, USA	*a)* 14 caregivers with typical hearing of children who are DHH completed three sessions of video interaction guidance intervention. *b)* Families were assessed in spontaneous free play interactions at pre and post intervention using the Emotional Availability (EA) Scales.	Increased caregiver sensitivity, caregiver structuring, caregiver non-hostility, caregiver self-esteem, child responsiveness and child involvement following video-feedback intervention for caregiver-child interaction during free play.
b) Information provided to caregivers (n=5)	Elpers, Lester, Shinn & Bush (2010)	Appalachian Region in Kentucky, USA	Children who failed NHS received paediatric hearing healthcare through state-supported EHDI clinics	Poor communication of NHS results: *1.* Most did not receive results while in the hospital *2.* Results were received a few days-weeks after discharge or by mail

	Larsen, Munoz, DesGeorges, Nelson & Kennedy (2018)	43 states, USA	Caregiver support organization for families of children who are DHH	*1.* 91% degree & severity of hearing loss *2.* 58% hearing aids *3.* 56% Early Intervention (EI) *4.* 48% resources about childhood hearing loss *5.* 45% recommended medical referrals *6.* 33% caregiver support organizations
	Decker & Valloton (2016)	Michigan, USA	Families were receiving EI within the state of Michigan under Part C of the Individuals with Disabilities Education Act	*1.* The importance of talking frequently throughout the day in everyday routines and activities *2.* Promoting listening skills and language by focusing on sound *3.* Incorporating other communication channels *4.* The essential role of caregivers in EI

	Jackson (2011)	39 states, USA	Families were receiving EI services from various organizations across the United States	Caregivers preferred the following informational resources: *1.* discussion with other caregivers of children with hearing loss *2.* Internet sources *3.* Explanations provided by professionals *4.* parent-friendly books *5.* discussion with adults who are DHH *6.* Videos and DVDs *7.* Brochures and pamphlets *8.* detailed professional books
	Findlen, Mahowu & Adunka (2019)	Columbus, USA	*a)* Children who are DHH received multidisciplinary assessment and monitoring services from the Hearing programme clinic at least annually. *b)* Single-provider outpatient appointments such as weekly speech therapy, etc. are scheduled as needed.	Caregivers identified the following information/resources as being the most useful: *1.* written materials (N=14) *2.* Verbal/visual demonstrations (N=5) *3.* Written material incl. type & degree of HL (N=6) *4.* Hearing aid resources (N=6)

c) Information needs of caregivers (n=4)	Jackson, Wegner, Turnbull (2010)	42 states, USA	Family members of children who are DHH aged 0 to 6 years who were receiving EI services from agencies in 24 states in the US. A questionnaire was used and data was analysed using descriptive statistics	*1.* Families were generally satisfied with the areas of family life surveyed. Participants reported improved family interaction, parenting and support. *2.* Participants had low satisfaction levels for having a way to take care of expenses, inclusion in the community, support to relieve stress and time to pursue their interests. *3.* Participants reported that their child's hearing loss had the largest impact on having time to pursue interests, having the time to take care of the individual needs of every child, taking care of the special needs of all family members and having the support to relieve stress.

	Jackson (2011)	39 states, USA	Families were receiving EI services from various organizations across the United States	Caregivers preferred the following informational resources: *1.* discussion with other caregivers of children with hearing loss (63.3%) *2.* Internet sources (55%) *3.* Explanations provided by professionals *4.* Caregiver-friendly books (34.3%) *5.* discussion with adults with a hearing loss *6.* Videos and DVDs (26%) *7.* Brochures and pamphlets (18%) *8.* detailed professional books
	Decker & Valloton (2016)	Michigan, USA	Families were receiving EI within the state of Michigan under Part C of the Individuals with Disabilities Education Act	*1.* Need for more support to use signs or Sign Language *2.* Need for more specific information
	Alyami, Soer & Pottas (2018)	2 hospitals, Saudi Arabia	Children who are DHH receive EI services at two main hospitals in Riyadh, Saudi Arabia	*1.* Majority need information relating to children's development and community services *2.* 50 (60%) support from professionals who work with children to explain the diagnosis to siblings, other kids, friends, etc. *3.* Reported less need for financial support

3. Caregiver satisfaction (n=4)	Ingber & Dromi (2010)	6 educational centres, Israel	Kesher philosophy is adopted whereby: a) the responsibility of the habilitation process is attributed to the caregivers b) caregivers participate in meetings, advocacy training, lectures on high-priority topics i.e. promoting child's conversational skills in everyday activities, monitoring and developing communication competencies for their child c) caregivers enrol in a parent group for emotional support, to share experiences & brainstorm possible solutions for raising a child with hearing loss d) individualized implementation of intervention plan in collaboration with caregivers and relevant professionals	*1.* Mothers expressed satisfaction with professional's attitude and practices towards family participation in the programme. *2.* Professionals were willing to collaborate with caregivers , encouraged caregivers to participate in assessing the child, and empowering them in the process of EI

	Jackson et al. (2010)	42 states, USA	Family members of children who are DHH aged 0 to 6 years who were receiving EI services from agencies in 24 states in the US. A questionnaire was used and data was analysed using descriptive statistics	*1.* Families were generally satisfied with the areas of family life surveyed. Participants reported improved family interaction, parenting and support. *2.* Participants had low satisfaction levels for having a way to take care of expenses, inclusion in the community, support to relieve stress and time to pursue their interests. *3.* Participants reported that their child's hearing loss had the largest impact on having time to pursue interests, having the time to take care of the individual needs of every child, taking care of the special needs of all family members and having the support to relieve stress.

	Alyami et al. (2018)	2 hospitals, Saudi Arabia	Children who are DHH receive EI services at two main hospitals in Riyadh, Saudi Arabia	**EI services:** *1.* 60 (94%) satisfied with services provided to them *2.* 45 (75%) programme helped them learn activities to use with their child at home i.e., language activities and auditory training *3.* Some were dissatisfied regarding the time taken to find professionals providing intervention services and services to commence **No. therapy sessions:** 40 (60%) said the no. of therapy sessions was not sufficient: *1.* 20 (33.3%) weekly sessions *2.* 15 (25%) Weekly sessions *3.* 1 (1.7%) 3 x a week *4.* 9 (15%) 1 x a month *5.* 15 (25%) other
	Findlen et al. (2019)	Columbus, USA	Children who are DHH received multidisciplinary assessment and monitoring services from the Hearing programme clinic at least annually. The average appointment length is 75 minutes. Single-provider outpatient appointments such as weekly speech therapy, etc. are scheduled as needed.	*1.* 93% length of appointment is the right amount of time *2.* Appointment length is too short (N=3) *3.* Appointment length is too long (N=3) *4.* 86% overall good satisfaction with services provide

4. Challenges (n=10)				
a) Logistical challenges (n=5)	Adedeji, Tabih, Sogebi & Daniel (2015)	Osogbo, Nigeria	Children who are DHH received EI services from the ENT department of the LAUTECH Teaching Hospital	Lack of attention to early diagnosis, making treatment and rehabilitation elusive
	Merugumala, Pothula & Copper (2017)	Hyderabad, India	17 caregivers of children who are DHH receiving free EHDI from Shravana Children's Deafness Rehabilitation Centre in India	Lack of NHS services, thus caregivers are usually the first to suspect the hearing loss, alternatively there is a lack of public services and private services were too expensive for caregivers
	Elpers et al. (2010)	Appalachian region in Kentucky, USA	Children who failed NHS received paediatric hearing healthcare through state-supported EHDI clinics	*1.* Travel distance to areas of healthcare *2.* Difficulty for extended family members to travel to hearing healthcare *3.* Travelling distance makes it difficult to attend follow-up exams when there is no consistent mode of transport *4.* Financial constraints Insurance coverage delays resulted in delays

	Larsen et al (2012)	43 states, USA	Parent support organization for families of children who are DHH	**Location:** *1.* 71% all diagnostic procedures completed in one location *2.* 29% two or three locations to get all testing competed through two or three appointments **Challenges with completing hearing evaluation by 3 months:** *1.* 36% delayed appointment availability *2.* 28% other medical/health problems and middle ear fluid *3.* 23% noisy test/repeat test needed *4.* 14% not sure where to go for testing *5.* 14% distance to test facility
	Khoza-Shangase (2019)	Johannesburg, South Africa	Caregivers of children who are DHH receiving EI services in hospitals in Johannesburg, Gauteng	*1.* 10 (53%) large number of different appointments that their children have to attend *2.* 36% long waiting lists

b) Professional related challenges (n=3)	Elpers et al. (2010)	Appalachian region in Kentucky, USA	Children who failed NHS received paediatric hearing healthcare through state-supported EHDI clinics	1. Paediatricians or healthcare providers did not expedite the hearing healthcare and ignored concern for infant hearing loss 2. Others felt marginalized by paediatrician 3. paediatrician was unaware of programmes offered which resulted in the child not receiving timely intervention
	Merugumala et al. (2017)	Hyderabad, India	17 caregivers of children who are DHH receiving free EHDI from Shravana Children's Deafness Rehabilitation Centre in India	Caregivers struggled to find the right professional to evaluate their child's hearing when referred from general children's clinics
	Khoza-Shangase (2019)	Johannesburg, South Africa	Caregivers of children who are DHH receiving EI services in hospitals in Johannesburg, Gauteng	1. 9 (48%) felt that the professional did not seem to know or understand what was wrong with their child 2. 9 (48%) numerous different tests recommended and done that caused delays in diagnosis and intervention

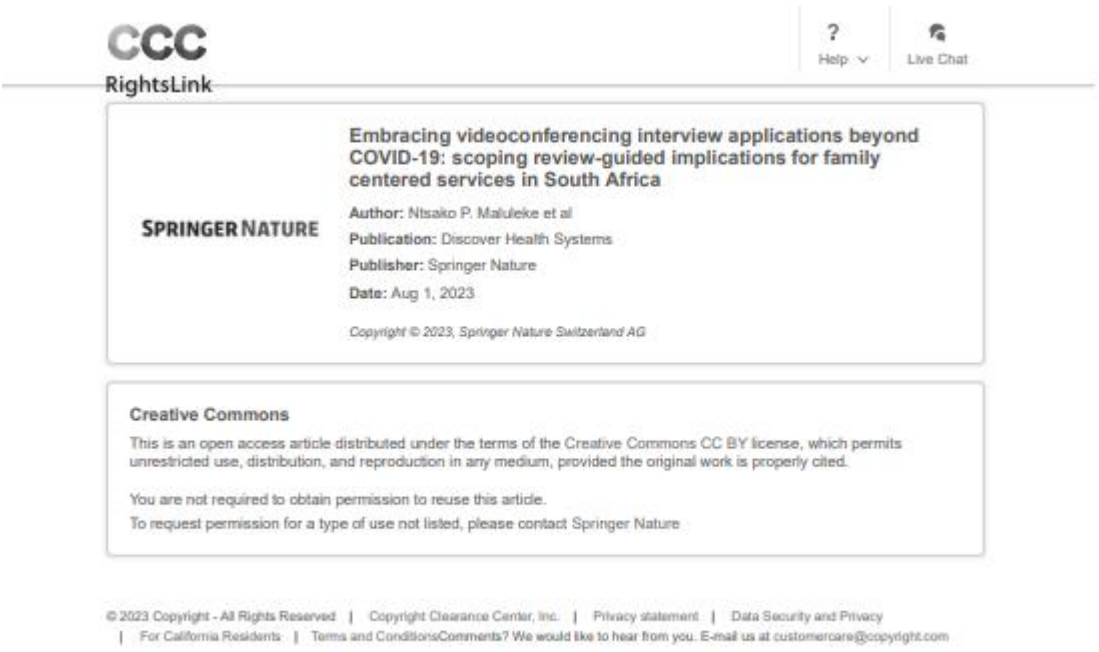
c) Caregiver related challenges (n=3)	Elpers et al. (2010)	Appalachian region in Kentucky, USA	Children who failed NHS received paediatric hearing healthcare through state-supported EHDI clinics	**Conflict with work or family responsibility:** Difficulty with follow-up because of work, school and other family responsibility **Hearing healthcare knowledge and willingness to seek care:** *1.* 50% had no knowledge of treatment options for hearing loss such as CI *2.* 100% felt that follow-up after NHS was of extreme importance 3. Many participants conveyed a sense of urgency for hearing evaluation in spite of the barriers to timely care 4. Most expressed a desire to utilize telemedicine as an option to obtain hearing healthcare
	Merugumala et al. (2017)	Hyderabad, India	17 caregivers of children who are DHH receiving free EHDI from Shravana Children's Deafness Rehabilitation Centre in India	Professionals did not know where caregivers had to go, thus they were sent from one professional to the next.
	Khoza-Shangase (2019)	Johannesburg, South Africa	Caregivers of children who are DHH receiving EI services in hospitals in Johannesburg, Gauteng	13 (68%) Poor awareness and knowledge of hearing loss and the suitable services available

5. Telehealth (n=3)	Cole, Pickard & Stredler-Brown (2019)	Colorado, USA	Caregivers of children who are DHH (n=2) and EI providers (n=112) participated in an online survey investigating factors that influence providers' utilization of telehealth in Colorado's Part C Early Intervention programme (EI Colorado).	Only 20% of EI providers reported that children who are DHH on their case load received services via telehealth; 97% of service coordinators reported that less than 25% of children who are DHH on their case load received services via telehealth. Participants identified flexibility, access to providers from rural areas, and heightened family engagement through use of coaching practices as strengths of telehealth. Use of internet technology and video conferencing platforms; as well as negative attitude towards the use of telehealth were identified as barriers.

	Behl et al. (2017)	5 EI programmes across USA	A comparison group design study. Children who are DHH and their families received EI services in-person or via telehealth for 6 months after which the children's listening and language scores were measured as well as family and service deliver outcomes.	*1.* statistically significant difference in favour of the telepractice group compared with the in-person group for norm-referenced, standardized language test scores; *2.* no statistically significant differences between groups with regards to family outcomes; however, in-person home visits resulted in higher scores for provider responsiveness and parents' engagement ;and *3.* The number of visits and minutes of intervention were higher for telepractice with fewer cancellations due to weather or transportation.

	Constanescu (2012)	Rural & remote areas of Australia	Service provision through Outreach AVT which involves: *a)* Remote delivery of AVT sessions via computer-based videoconferencing between the therapist and parent *b)* Planning sessions on the alternate week over videoconferencing between the therapist and parent *c)* Provision of themed "lesson boxes" on a monthly rotation to families, with materials to support the sessions and carry-over tasks *d)* Two visits a year by a therapist to the child's home and/or education setting for face-to-face contact, lessons, progress evaluation, attend a playgroup and parent education setting.	*1.* 61% audio quality was excellent or good 2. 58% video quality was excellent or good *3.* 61% often or always experienced technical difficulties that required troubleshooting during the session *4.* 61% comfortable with using equipment 5. 100% comfortable as face-to-face sessions *6.* 91% child as comfortable as face-to-face sessions *7.* 100% comfortable with videoconferencing as face-to-face sessions when discussing matters with therapist online and satisfied with level of interaction/rapport with the therapist and child *8.* 92% confident that the therapist gained an adequate understanding of their child's development and progress through Outreach AVT *9.* 89% Outreach AVT is often or always a better alternative to travelling regularly to receive fate-to-face sessions

Appendix Q: Reprint permission for Chapter 4



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Embracing videoconferencing interview applications beyond COVID-19: scoping review-guided implications for family centered services in South Africa

Author: Ntsako P. Maluleke et al

Publication: Discover Health Systems

Publisher: Springer Nature

Date: Aug 1, 2023

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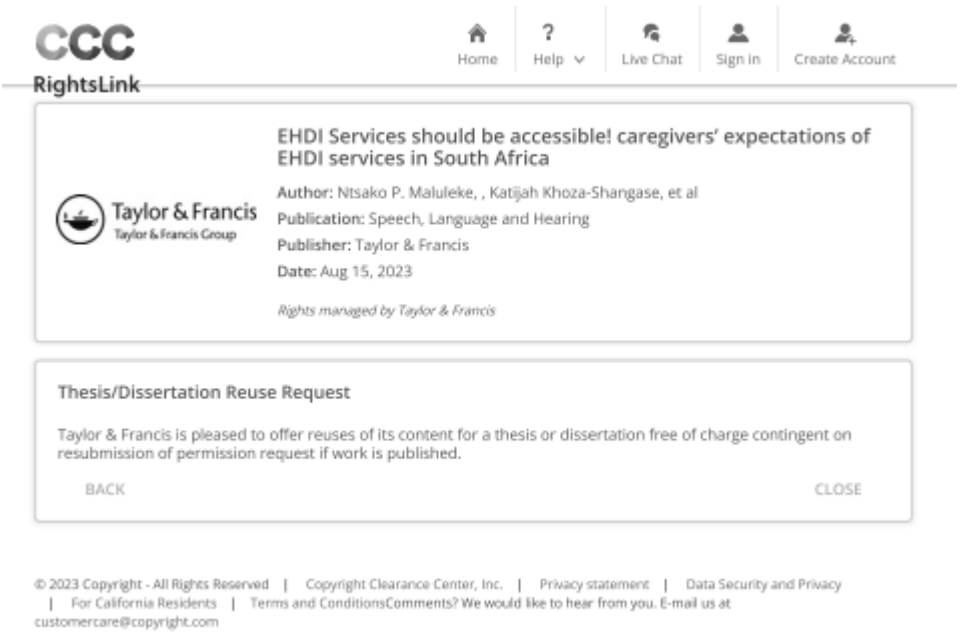
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Appendix R: Reprint permission for Chapter 5



Appendix S: Demographic and Audiological Profile of the Children

Child	Race	Gender	Home Language	Degree of hearing loss	Age when hearing loss was diagnosed (in months)	Age when fitted with amplification device(s) (in months)	Age when EI was initiated (in months)	Type of amplification device(s)	HCF where EHDI was received	Distance to HCF	Risk factors	Circumstances that lead to the diagnosis
*Thabo**	Black	Male	English & SASL	Severe	18	19	22	Bilateral cochlear implants	Private sector	30 km	Chronic otitis media	*Thabo*'s* preschool teacher noticed that he does not always respond when called and prompted his mother to assess his hearing.
*Lerato**	Black	Female	Sesotho	Severe	24	26	24	Hearing aid & Cochlear implant	Public sector	48 km	Prematurity	During the immunisation visits at the clinic, *Lerato*'s* mother noticed that other children *Lerato*'s* age had started talking while *Lerato** was only using gestures to communicate. The nurses at the clinic dismissed the mother's concerns, but the mother's employer then urged her to take Lerato to the hospital for a hearing evaluation.
*Karabo**	Black	Male	Setswana	Moderately severe	4	5	4	Hearing aid & Cochlear implant	Public sector	28 km	Waardenburg syndrome (white forelock, 1½ blue eye, ½ brown eye)	Karabo*'s sister was diagnosed with a hearing loss and his mother insisted that his hearing be evaluated as well.

*Dimpho**	Black	Female	Setswana & SASL	Profound	20	24	27	Hearing aid & Cochlear implant	Public sector	28 km	Prematurity, NICU, Waardenburg syndrome (white forelock, 1 blue eye)	On a day where there was thunder and lightning, *Dimpho*'s* family was frighted by the thunder, except *Dimpho**. Her uncle was concerned about her lack of reaction to the thunder and urged her mother to take her to the hospital. The nurses at Hospital X dismissed the mother's concerns and she eventually went tot Hospital W for a hearing assessment.
*Sizwe**	Black	Male	Sepedi	Severe	18	18	18	Bilateral hearing aids	Private sector	<3 km	-	The paediatrician referred *Sizwe** to the Occupational Therapist (OT) due to delayed developmental milestones because he was not crawling at 15 months. The OT then referred him to the Speech Therapist because he was not talking yet. The Speech Therapist then referred him to the audiologist for a hearing evaluation.
*Andrew**	Indian	Male	English	Severe	27	27	27	Bilateral hearing aids	Private sector	<5 km	Chronic otitis media	Teacher at *Andrew*'s* play school noticed that he is not able to follow instructions if the teacher is standing behind him. *Andrew*'s* mother had also had similar suspicions, but the paediatrician dismissed the mother's concerns. The mother eventually found an Audiologist to assess *Andrew*'s* hearing.
*Paige**	Indian	Female	English	Severe	6	6	6	Bilateral hearing aids	Private sector	<5 km	-	*Paige*'s* brother was diagnosed with hearing loss and her parents insisted that her hearing be assessed as well.

*Josh**	White	Male	Portuguese	Moderately severe	22	23	24	Bilateral cochlear implants	Private sector	<5 km	-	*Josh*'s* mother raised concerns with various doctors that her son can hear her sometimes, but not all the time. All the doctors dismissed her concerns. Eventually one doctor contacted an Audiologist during *Josh*'s* consultations based on the mother's concerns.
*Boikanyo**	Black	Female	Setswana	Profound	14	20	24	Hearing aid & Cochlear implant	Private sector	26 km	Jaundice, NICU	*Boikanyo** mother started having concerns when *Boikanyo*'s* twin sister started talking and she didn't. She also did not respond to noise like a lid falling on the ground. Her mother then took her to an Audiologist.
*Zack**	White	Male	Afrikaans	Profound	24	26	26	Bilateral cochlear implants	Private sector	77 km	-	*Zack*'s* mother suspected that he may be 'deaf' when he did not start speaking at 12 months, but it took her 6 months to get an appointment with an audiologist and it took 6 appointments for his mother to accept the diagnosis and start with intervention.
*Mandla**	Black	Male	Sepedi	Moderately severe	30	36	36	Bilateral cochlear implants	Private sector	<5 km	NICU	*Mandla*'s* hearing was screened at birth and the results were normal. But at 24 months he started 'not listening' when spoken to and would bite if people did not understand when he was trying to communicate. His hearing was later screened again at preschool and he was referred to the Ear-Nose-Throat Specialist and Speech Therapy becasue his pseech was delayed. There was no improvemnt with this intervention, so the Speech Therapist referred him to an Audiologist.

Appendix T: Proof of Submission to BMC Health Services Research



From: In Review at BMC Health Services Research <noreply@springernature.com>
Date: 22 March 2023 at 13:14:18 SAST
To: Mrs Ntsako Maluleke <precious.slp@gmail.com>
Subject: Your submission to BMC Health Services Research: Preprint Confirmation
Reply-To: info@researchsquare.com

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Journal submission ID for reference: 83b28b18-545d-40a2-a17e-432b76a5939f
Submission title for reference: Caregivers' experiences of the Early Hearing Detection and Intervention (EHDI) process from detection to intervention in South Africa

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Appendix U: Themes, Sub-themes and Supporting Quotes

Themes	Sub-themes	Quotations
Timely access to EHDI denied	A long journey of no's and maybes	“The next time I went to the clinic I tried to ask the nurses why my child is not yet talking. She showed us on the clinic card that there was nothing wrong with my child because according to the chart at the back of the card, she has until the age of 3 years to start talking, maybe she is just slow.” (CG 3)
		“No one took it on very quickly because they thought I was talking nonsense. All these doctors must have thought, that’s when they thought there is something wrong with this woman. They thought this woman must go to like a looney bin. She is one of those mommies that want the child to always be sick and want all that attention to themselves, type of story.” (sic) (CG 6)
		"I had taken him several times to the paediatrician uhm with those concerns. She basically did a normal tympanogram and she said that she did not have any concerns with his language development because at that point, at 18 months his speech development was slower than what I had expected and uhm his range of words were less” (CG 5)
		"This doctor, I think he just wasted our time. And you know as a parent, you will always ask for referrals and like I said within that year, we [attended] so many appointments. And only at the end of it he told us *Thabo** is deaf." (CG 1)
		“We went to *Hospital A*, but no one picked up that she is deaf.” (CG 4)
		"I took him for routine audiological screening. He was screened at birth and they said the next one (screening) was at 6 weeks and then at 6 months. So, I took him, it was almost like a routine thing. He did all his ear tests and everything was coming out perfect, everything was coming alright. Even after his routine check-ups, after the 6 months were done we still carried on going to *Audiologist C* because I said there is something not right." (CG 6)
	Going “here and there” for.	"When it was diagnosed, refer us to the right people at the right time, not for us to go here and there. We had to go to doctor, to doctor, there were so many people” (CG 1)

		"They said we must start going to the ENT, normal ENT to check what is going on. So, we were advised to take Sello* for speech therapy because he was very late with the speech and all that. The OT was also organised, but *Sello** couldn't improve." (CG 9)
		"She receives speech therapy from *Speech Therapist D*. She gets audiology at *Hospital C* and the (cochlear) mapping is done at School G." (CG 7)
		"Before, therapy sessions were a problem because it's 2 kids. Each child had their own appointment date. So, I used to be absent sometimes 3 to 4 days not going to work. You would find that *Nkele** had a session on Monday, *Tshwarelo** had a session on Tuesday. There were also asthma check-ups and appointments with the Child Psychologist. (CG 3)
		"The speech therapist suspected that he might have ADHD and referred us to the Child Psychologist at *Hospital B*. He is a busy child. *Nkele** attends neuro [neurology appointments], speech [therapy] and she is asthmatic. She is also receiving medication for epilepsy" (CG 3)
		"The issue was, he doesn't only have a hearing problem, even the eyes are a problem." (CG 5)
	Nothing is within reach	"None of the doctors were like close-by we go. They always refer further away. All the tests we did, he send us. It's a doctor further away." (sic) (CG 1)
		"You find that appointments are each and every week. From what I have seen, most of the parents of children who are deaf or with ADHD don't work and they have to take their children to appointments where they have to take 2-3 taxis to get to the hospital." (CG 3)
		In terms of transport, I have to take a taxi to *Suburb U* [for speech therapy] and I didn't really have transport. So, it really was not working out." (CG 7)
		"It was quite a road to travel. I would drive 350 km a day to get him to talk." (CG 8)
		"But why don't they have here in the East Rand, the same as the school where he is. Why aren't the schools close by?" (sic) (CG 1)
		"There was no transport from where we stayed to the school, so she would catch a lift with one of the kids that she went to school with. I would catch a taxi from *Suburb Y* to *Suburb Z* and the family would pick her up from there and drop her off at school with their daughter. And then I would pick her up from *Suburb Z* in the afternoons as well" (CG 2)

		"He used [scholar] transport to get to *Preschool A*. He had to wake up at 4 and leave at 5 to go to *Preschool A*. He would then come back around 4 or 5. The school at *Preschool A* ended at 12 or 1 so the transport driver would pick him up and stay with him until it was time to fetch the older kids from the other schools." (CG 3)
		"But due to distance and the fees, she moved to *School C*." (CG 3)
		"It's also very challenging living so far from the school." (CG 6)
		"The school is very far. And anyway there is no other school that is best for audio." (CG 9)
	It's not pocket change	"It really comes down to, are you financially able to give your child the support they need?" (CG5)
		"In terms of affording a hearing aid and the fact that technology is changing every few years. For 2 [hearing] aids it's 55 000, Sarah's is sitting at 30 (000), I think. Both of them have FM systems that's 30 000 each. So, hearing aids alone, and their devices alone exceed 100 000 rands. Then you also have to think about moulds, and with a growing child, you have to, especially from that like birth to 6 years, you have to change moulds every 6 months. Medical aids don't cover moulds at all. Even with us on comprehensive medical aid." (sic) (CG5)
		"It's not pocket change that we gonna throw in, and we are working one person's salary here because I don't work because of my son". (CG 6)
		"Another frustration that I have, yoh, it's the device, yoh. The things are so expensive. Yoh, you know they are so expensive, you know. Like the cable. The cable is fragile, it breaks, you know. I think that is the only frustration I have because even with the other one, I wanted her to get another one as soon as she lost the first one. As soon as they told me its R140 000, I was like, you know what, let me just let it be." (CG 7)
		"As soon as that cable breaks, you start stressing. You need to make sure you have R2500 in your bank account, especially if it's out of warranty, you know. You have to have that amount in your bank account to buy that small cable. Because you get frustrated when your child can't hear." (CG 7)
		"If you don't have financial aid, you will never get something like this. If you are lucky, maybe you might. At *Hospital C*, we can only help you when you have medical aid. If you don't have medical aid, we can't help you." (CG 7)
		"The speech therapy was a lot of money which was being claimed from the medical aid. The medical aid was getting depleted. So, it was not working out for me as well. (CG 7)

		“I had to resign from *Medical Aid A* and I went with *Medical Aid B*. And *Medical Aid B* has only been good for us because, I told them that I’m only coming to them for the cochlear implants and would they help me and they said yes. And they did, they were with me from day one.” (CG 8)
		"Thank you, Jesus, that we were able to fund a lot of this ourselves. It cost us moving house and to pay for the first op, you know. So a lot we had to do out of our own." (CG 8)
		“We wrote to medical aid because medical aid didn’t want to pay and all that. But at last, they did do it with motivational letters and report from the audiologist.” (CG 9)
		“The most frustrating thing for me about this whole process was how expensive the schools were. And there was no way that I would ever be able to afford them” (CG 2)
		“The fees, financial that's a burden I face.” (CG 9)
		"She went to *School B*, when she was 4, but later moved to *School C* because of fees and the distance." (CG 3)
		"He had to move from *Preschool A* to *School C* because he no longer had a sponsor and I could not afford the fees." (CG 3)
		"I was just like, you know what, I can't do this. I don’t have that kind of money. So I took her to a normal daycare where she wasn't getting any speech therapy, nothing. An then I would take her to a private speech therapist who was paid by the medical aid." (CG 7)
	Stick to one language	“She speaks English because she was receiving speech therapy in English at the clinic and the hospital. The speech therapists also told us that schools that cater for children with hearing loss usually use English, so it will be easier for her at school if she has already acquired the language. Now we also speak English with her at home.” (CG 2)
		“Speech therapy was in English because at the time there were no Black speech therapists, it was only White and Indian.” (CG 3)
		"Maybe they should try to have 3-4 black therapists at each hospital so they can be able to speak the same language as the patient." (CG 3)
		“When we started this, I was trying to tell the kids and everyone else in the house to try and speak English so she can make progress with her speech. So, that thing was so hard for them so I left it. So surprisingly now she understands both languages, you know. With me I think I just told myself that when I’m with her I must speak English.” (CG 7)

		“Because the schooling indicates that you have to be English and Afrikaans, our biggest struggle was just for *Steven** to speak English. Although my husband is Afrikaans, we were advised by the audiologist and that to stick to the one language so that we could, you know just benefit him with the one language only and not to confuse him.” (sic) (CG 8)
		“We use speech when we speak to him, because he can hear us, it’s just that he can’t respond [verbally]. Cause Sign Language is his first language and English is his second language.” (CG 1)
		“Nkele* uses Sign language and speech, but her speech is low [poor]. Tshwarelo* also knows Sign Language, he learnt it at school.” (CG 3)
There’ s support, but not sufficient support	Awareness for hearing impairment and EHDI is key	"He said sit on the chair. I sat on the chair. He turned the chair around after he asked me to close my ears tight. I think he said something, but I did not hear him. I said to him that I did not hear anything because I had closed my ears. Then he explained that was the same thing that was happening with my daughter, that is why she can't hear." (CG 2)
		"They gave me an indication that if they had to start a Boeing 747 next to his head, he would hear it as a pin drop. That was pretty much deaf, deaf." (CG 8)
		"Her father was reluctant about having the cochlear implant fitted. I had received counselling when I went to *Hospital B*. They also showed me a child who was using cochlear implants." (CG 2)
		"At that time, he really did not understand because he didn’t receive counselling. So, he really did not understand." (CG 7)
		"During the process [receiving EHDI services for *Nkele**], I found out I was pregnant. I received genetic counselling and they told me that there is a 50/50 chance that this child would also have the syndrome. I also received counselling from speech therapy. So, when *Tshwarelo** was born I asked them to do the tests immediately so that if he also has a hearing loss, it will be best if he can be fitted with the cochlear implant while he is still young.” (CG3)
		“Soon after he [*Andrew**] was diagnosed, we took *Sarah** as a precaution to be tested and also have an ABR. They picked up that she also has a hearing loss.” (CG5)

	"Believe it or not. I have actually determined two kids have been deaf since my experience with *Steven**. Just seeing interactions with what I was being given at that point, to what in my domestic helper at the time. She had a little kid and the kid was like 6 months old and was not saying 'boo' or 'baa' or whatever. I asked, have you had this kid's ears tested. [She said] No. So, I took her through, we have a local hearing institution here in *Suburb V*. I took her there and it was determined that she was deaf." (CG 8) "My friend now, her son is due to be fitted with his first cochlear [implant] now on the 30th March [2021]. Her kid was, I think about 2 months old and she said to me she doesn't understand. The kids will drop something near him and he won't flinch. So, I said, please go and have a second opinion done, you know. And it turned out that he was deaf and he needed cochlear implants." (CG 8)
	"One of the challenges has been to access external therapy. When *Andrew** was experiencing a lot of his issues, with integrating socially, we contacted Hi-Hopes again. But because he was older than their group that they normally see, they referred us to a hearing-impaired professor and he started visiting *Andrew**, just to interact with him. That was really useful that they extend that services. But we had to pay him privately [for his time]." (CG 5) "My concern is *Nkele** because I can see that she is not adjusting to literacy [coping at school] so I want to find out what I can do for her because she is not adjusting [coping]. I was thinking of finding something that she can do like make-up or cooking." (CG 3) "My fear is, is he going to be able to provide for himself when he is old? Or what kind of job? That's why I am researching, wanting to know who is working where." (CG 9)
Family counselling and support	"Only Hi-Hopes that came and you know the counselling part. Hi-Hopes came and visit us and speak about a child who is deaf and how to accept it. Hi-Hopes came in very Saturday to our house to [provide] intervention and stuff like that. Which is good, I think." (CG 1)
	"Hi-Hopes helped a lot you know having that hands-on support both for the parents and the child. So, we had a facilitator that would come. She was a speech therapist as well and she saw him on a fortnight basis at home. " (CG5)
SASL training	"The first year, we did go to *School B* for Sign Language classes. It was every Saturday. Like basic things we sign for him." (CG1)

		“I know Sign Language, but I am not 100%, that much. But I can communicate with them. I learnt it at the school, I would go there very Saturday for lessons.” (CG3)
Successes amongst the challenges	He did improve, but there is still a gap	"Now her speech is clear." (CG 2)
		"*Nkele** received her cochlear implant when she was older, that has attributed [contributed] to her language being delayed. But with *Tshwarelo**, he received his cochlear implant when he was younger, so he developed [spoken] language normally." (CG3)
		"He still struggles, as much as language development is good. His pronunciation is what he still struggles with. He has that lateral 's' that we have worked and worked with him." (CG5)
		"She was about 6 months, so we picked it up very early with her, hence she doesn’t have an issue in terms of language gaps, not as severe. And we aided her early so she hasn’t had any issues with her language development or anything like that." (CG5)
		"Her issues with her sound has been the higher frequency sounds. So like the 's', sometime the 'k'. She struggles with those or sometimes and 'f'. You know, struggles with those sounds. But otherwise, her language development has been completely normal." (sic) (CG5)
		"He is still behind in his speech. There's still a big gap because he has to start from scratch. At that age he was already 5 and by then he should have had a full on language level on talking, where he missed all of that." (CG 6)
		“He is 15. He doesn’t read or write the English language fluently, but he definitely does speak it.” (CG 8)
		“He did improve. Let me just say. He did improve a lot. It's just those high sounds like “s”, “f” and all that, that he can’t pronounce very well.” (CG 9)
	Schooling has been a struggle	"He failed grade 4, twice. He did grade 4 twice. He is actually supposed to be in grade 7. He failed Sign Language and English. So even now, he just passed with a 3, both of them last year. So yah, we pushing him with his languages to read more." (CG1)
		He loves his school work. He is very independent with his school work. [He] will do his work by himself, I only have to check it. The only thing he struggles with is reading." (CG3)

		“Schooling has been a struggle, you know because it really is a mission for him to read the language. But the school has got therapist that he is at now because he is in a school for learners with special educational needs, like a technical school.”(sic) (CG 8)
		"At the school, he does very well. Obviously, the attention and that, he has to still have a therapist write his test for him. He can’t read the work himself. He got to wait for somebody to teach him the work. So school is a big challenge." (CG 8)
		"He is struggling with his English, although he does Sign Language, also he is struggling with Sign Language. He is doing very well with maths. He loves maths." (CG1)
		“He also has an FM system that he uses in conjunction with the hearing aid in the classroom environment because we did notice that he was struggling to focus in the class. Initially, the school felt that his focus issues were a result of an attention issue and they wanted him to be medicated, which we refused because we didn’t pick up the same issue in terms of focus at home. We then took him to a clinical psychologist who agreed with us that in terms of medication, that wasn’t the option. So, then we decided with *Audiologist F* to try the FM system and that has helped a lot. What we realised was that, he was actually listening to all the sounds around the classroom during a lesson and that was distracting him from focusing on his work." (CG 5)
		"In grade 1, her teacher referred her for speech therapy. It was largely around their concern they had was her ability to follow instructions, and I think it does come down to the hearing." (sic) (CG5)
		“*Preschool A** recommended that we enrol her at *School H**. They accepted her at the school and she is doing well. She is in grade 6 now.” (CG 2)
		"When he left *Preschool A* for *School C*, he was supposed to go to grade R. But they assessed him at *School C* and said he is too advanced from grade R, he should be in grade 1. They took him to grade 1, and it was in July when he went to *School C*, when the schools re-opened. And he has been doing well ever since, he has never repeated a grade." (CG 3)
		“Sarah* has managed to integrate into a mainstream schooling environment.” (CG 5)

	I am grateful for the progress I keep seeing	"I don’t want to lie. They have played a big part of my life, specially *Audiologist E*. I don’t see her as an audiologist. I see her as my sister or mother because she was always there for me." (CG 3)
		" Even *Preschool A** is good. I must say the *Preschool A* was very supportive. They will tell us feedback, how he is doing. I remember the teachers, even the teachers were very nice, very nice." (CG 1)
		"He is very happy. He says he doesn’t want to go to any school except *School B*." (sic) (CG1)
		"I mean that has been our benchmark with *Andrew**'s experience. Even now at 10, he still talks about how he misses *Preschool A*. He really loved it there. So, it is the benchmark in terms of learning experience." (CG 5)
		"At first I was not very keen on the school, but when my son was in there, he was a different child." (CG 6)
		"*Preschool A* helped her. I could see that her speech was improving." (CG 2)
		"Indeed *Nkele** was helped because after being fitted with the cochlear implant at least you could see improvement in her speech. She could understand better when you spoke to her and her speech was a bit more understandable." (CG 3)
		"He started at *Preschool A* last year (2019) and from there it’s been a normal child. You'd never say that this child actually has a hearing problem." (CG 6)
		"Once he got into *Preschool A,* within the first 4 months, this child started like booming with talking and he was different. I can actually speak to him and have a full on conversation with my own child and he can understand what I'm saying." (CG 6)
		"Everything so far has been working out quite well. It’s all positive, everything is just working out to what he need." (CG 6)
		"I am happy, my child has improved a lot. I see progress." (CG 7)
		"I am grateful for the progress that I keep seeing." (CG 7)
		“*Steven** now, today. You would never know he was deaf if you didn’t know, or see the cochlears [cochlear implants]. Because of the intense therapy, yah that we did. It was really a struggle, but now it’s a blessing” (CG 8)

		“It’s been a hell of a road, but yah we are able to sit back and breathe and think my goodness, he has come such a far way, you know.” (CG 8)
		I’m really happy, I don’t want to lie.” (CG9)
		"So, it’s been a long journey….(laugh). Financial draining, but I'm happy to be honest now that he is improving." (CG 9)

Appendix V: Proof of Submission to BMC Pediatrics



ɜent from my iPhone

ɜegin forwarded message:

From: BMC Pediatrics <bmcpediatrics@biomedcentral.com>
Date: 31 May 2023 at 01:03:58 SAST
To: precious.slp@gmail.com
Subject: BMC Pediatrics - Receipt of Manuscript 'Barriers and facilitators...'

Ref: Submission ID 755996d1-a458-44dd-aaad-aeaad7d65c6e

Dear Dr Maluleke,

Thank you for submitting your manuscript to BMC Pediatrics.

Your manuscript is now at our initial Technical Check stage, where we look for adherence to the journal's submission guidelines, including any relevant editorial and publishing policies. If there are any points that need to be addressed prior to progressing we will send you a detailed email. Otherwise, your manuscript will proceed into peer review.

You can check on the status of your submission at any time by using the link below and logging in with the account you created for this submission:

https://researcher.nature.com/your-submissions?utm_source=submissions&utm_medium=email&utm_campaign=confirmation-email&journal_id=12887

To help with your article processing charge at acceptance, and to see if you're eligible for any waivers or BMC membership discounts, please click here:

https://payment.springernature.com/quote/identify/submission/755996d1-a458-44dd-aaad-aeaad7d65c6e

Kind regards,

Peer Review Advisors
BMC Pediatrics

Springer Nature offers an open access support service to make it easier for our authors to discover and apply for APC funding. For further information please visit http://www.springernature.com/gp/open-research/funding

Appendix W: Proof of Submission to Brazilian Journal of Otorhinolaryngology

PM Precious Maluleke <precious.slp@gmail.com>
To Precious Maluleke

Reply | Reply All | Forward

Thu 2023/08/31 13:12

Date: 25 May 2023 at 19:46:21 SAST
To: Ntsako Maluleke <precious.slp@gmail.com>
Subject: Submission Confirmation
Reply-To: BJORL <revista@aborlccf.org.br>

Dear Mrs Maluleke,

We have received your article "Family-Centeredness of Early Hearing Detection and Intervention Programs in South Africa" for consideration for publication in Brazilian Journal of Otorhinolaryngology.

Your manuscript will be given a reference number once an editor has been assigned.

To track the status of your paper, please do the following:

1. Go to this URL: https://www.editorialmanager.com/bjorl/

2. Log in as an Author

3. Click [Submissions Being Processed]

Thank you for submitting your work to this journal.

Kind regards,

Editorial Manager
Brazilian Journal of Otorhinolaryngology

This journal uses the Elsevier Article Transfer Service. This means that if an editor feels your manuscript is more suitable for an alternative journal, then you might be asked to consider transferring the manuscript to such a journal. The recommendation might be provided by a Journal Editor, a dedicated Scientific Managing Editor, a tool assisted recommendation, or a combination. For more details see the journal guide for authors.

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Please note that the editorial process varies considerably from journal to journal. For more information about the submission-to-publication lifecycle, click here: http://help.elsevier.com/app/answers/detail/p/7923/a_id/160

For further assistance, please visit our customer support site at http://help.elsevier.com/app/answers/list/p/7923. Here you can search for solutions on a range of topics, find answers to frequently asked questions and learn more about EM via interactive tutorials. You will also find our 24/7 support contact details should you need any further assistance from one of our customer support representatives.

Appendix X: Proof of Submission to Ear and Hearing

PM Precious Maluleke <precious.slp@gmail.com>
To Precious Maluleke

Reply | Reply All | Forward | ...
Wed 2024/02/14 16:26

RE: EANDH-D-23-00292, entitled "Caregivers' preferences for EHDI Services in South Africa: Evidence from a conjoint analysis"

Dear Mrs Maluleke,

I have received the comments of the reviewers on your manuscript, a copy is included below. The reviewers believe that your studies are of potential interest to our readers but feel that substantial revision would be necessary before the paper could be considered again for publication in Ear and Hearing.

If you are willing to revise the manuscript taking into consideration the suggestions of the reviewers, please submit your revisions by **Mar 08, 2024.** I will send the revised paper to the original reviewers for their appraisal.

Please include with your revised submission an itemized, point-by-point response to the comments of the reviewers. Include the revision number at the top of the response document. Each of the reviewers' comments will need to be clearly and completely addressed before the paper can be considered further for publication. Please include updated page and line numbers for each comment in your response letter to indicate exactly where each comment is addressed. **Do not include author information on your response.**

In addition, please include two copies of your revised manuscript. One copy should include highlighting in red font color to show where additions were made (please DO NOT use italics or 'track changes').The other copy should be a clean version of your revised paper. Please note that failure to follow all of these instructions will result in delays in processing your revision. The revisions should be completed within the above timeline to avoid being considered as a new submission.

Note that submissions with more than 5 authors must include an author contribution statement in the acknowledgments.

To submit a revision, go to https://www.editorialmanager.com/eandh/ and log in as an Author. You will see a menu item called "Submission Needing Revision." Please click on this item to obtain your submission record and begin the revision process.

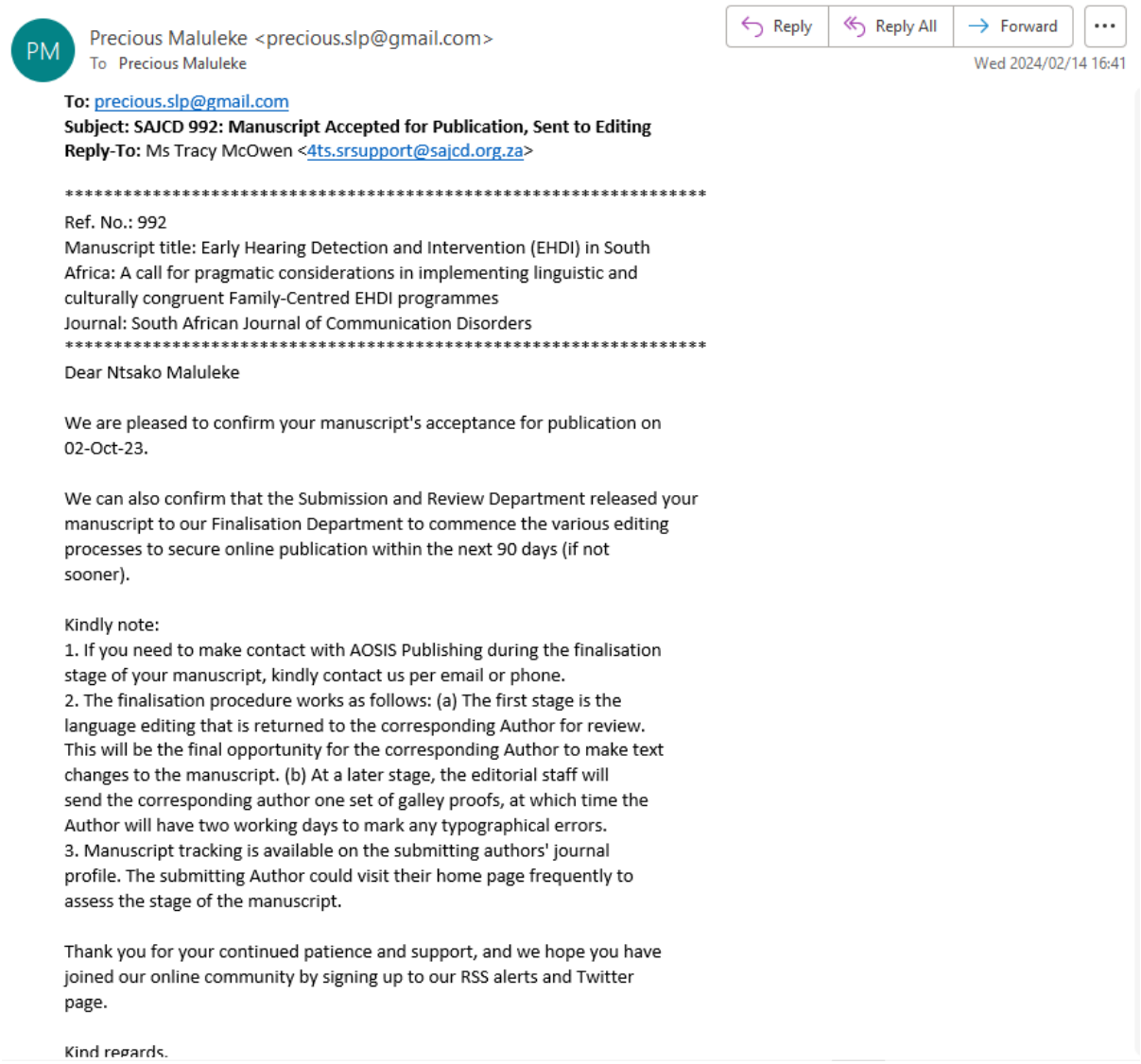
Your username is: Ntsako
click here to reset your password

OPEN ACCESS
If you would like your submission, if accepted, to be open access, please complete the following steps. An information sheet is available at http://links.lww.com/LWW-ES/A48.
1. A License to Publish (LTP) form must be completed for your submission to be made open access. Please download the form from http://links.lww.com/LWW-ES/A49, sign it, and submit the file as part of your revision (using the Attach Files submission step in Editorial Manager).
2. Upon acceptance of your submission, you will receive an Open Access Publication Charge letter from the Journal's Publisher, Wolters Kluwer, with instructions on how to submit any open access charges. The email will be from no-reply@copyright.com with the subject line 'Please Submit Your Open Access Article Publication Charge(s)'. The cost for publishing an article as open access can be found at https://wkauthorservices.editage.com/open-access/hybrid.html

With Kind Regards,

Ruth Litovsky, PhD

Appendix Y: Proof of acceptance of manuscript for publication by the South African Journal of Communication Disorders (SAJCD)



PM

Precious Maluleke <precious.slp@gmail.com>
To Precious Maluleke

Reply | Reply All | Forward | ...

Wed 2024/02/14 16:41

To: precious.slp@gmail.com
Subject: SAJCD 992: Manuscript Accepted for Publication, Sent to Editing
Reply-To: Ms Tracy McOwen <4ts.srsupport@sajcd.org.za>

****
Ref. No.: 992
Manuscript title: Early Hearing Detection and Intervention (EHDI) in South Africa: A call for pragmatic considerations in implementing linguistic and culturally congruent Family-Centred EHDI programmes
Journal: South African Journal of Communication Disorders
****

Dear Ntsako Maluleke

We are pleased to confirm your manuscript's acceptance for publication on 02-Oct-23.

We can also confirm that the Submission and Review Department released your manuscript to our Finalisation Department to commence the various editing processes to secure online publication within the next 90 days (if not sooner).

Kindly note:
1. If you need to make contact with AOSIS Publishing during the finalisation stage of your manuscript, kindly contact us per email or phone.
2. The finalisation procedure works as follows: (a) The first stage is the language editing that is returned to the corresponding Author for review. This will be the final opportunity for the corresponding Author to make text changes to the manuscript. (b) At a later stage, the editorial staff will send the corresponding author one set of galley proofs, at which time the Author will have two working days to mark any typographical errors.
3. Manuscript tracking is available on the submitting authors' journal profile. The submitting Author could visit their home page frequently to assess the stage of the manuscript.

Thank you for your continued patience and support, and we hope you have joined our online community by signing up to our RSS alerts and Twitter page.

Kind regards.