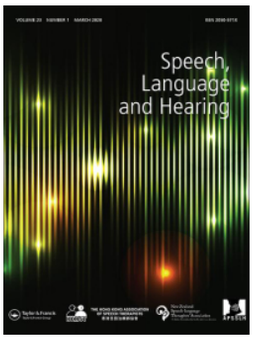

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Exploring South African caregivers' experiences and their perceptions of their role in early hearing detection and early intervention

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ABSTRACT

Early Hearing Detection and Intervention (EHDI) programs are essential for identifying and supporting Deaf and hard-of-hearing (DHH) children. In South Africa, caregivers are central to EHDI success; however, systemic barriers, limited information, and societal stigma impact their ability to engage effectively in these services. This study aimed to explore caregivers' experiences and perceptions of their role in EHDI for their DHH children, identifying barriers they face and the way these influence their engagement with EHDI services. A qualitative, phenomenological research design was employed. Twelve primary caregivers were recruited through purposive, snowball sampling from both public and private healthcare settings. Data were collected using in-depth, semi-structured interviews and analysed through inductive thematic analysis. Four themes were identified through a structured coding process: 1) challenges in accessing healthcare services, with barriers including long distances, high costs, and extended waiting times in public healthcare settings; 2) lack of awareness and guidance; 3) emotional stress due to diagnosis and caregiving responsibilities, with participants highlighting psychological distress, uncertainty about their child's future, and experiences of societal stigma; and 4) positive experiences with private healthcare providers. Findings underscore the need for accessible, family-centred, and culturally sensitive EHDI services in South Africa. Expanding healthcare access, improving provider-caregiver communication, strengthening public awareness campaigns, and integrating structured caregiver support networks are essential steps towards improving outcomes for DHH children. Lessons from global best practices in both low – and middle-income countries (LMICs) and high-income countries (HICs) could inform strategies for enhancing South Africa's EHDI framework.

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Early Hearing Detection and Intervention (EHDI); Deaf and hard-of-hearing (DHH); caregiver experiences; family-centred care; South Africa; healthcare access; advocacy; systemic barriers

Introduction

Early Hearing Detection and Intervention (EHDI) programs are foundational in supporting Deaf and hard-of-hearing (DHH) children by facilitating timely diagnosis, intervention, and long-term developmental support (Health Professions Council of South Africa – HPCSA, 2018). Through early detection, children benefit from optimized language, cognitive, and social development, critical to their overall quality of life and integration within society (Maluleke et al., 2024). However, for EHDI programs to be effective, the role of caregivers is indispensable, as they provide continuous advocacy, emotional support, and engagement in their children's care journey (Kanji & Noorbhai, 2021; Khoza-Shangase, 2022; Maluleke et al., 2024). Particularly within South Africa, caregivers navigate numerous challenges rooted in socio-economic inequalities, limited healthcare access, and cultural influences that shape their perceptions of and engagement with EHDI services (Khoza-Shangase, 2019; Maluleke et al., 2023). This study explores caregivers' experiences within South African EHDI programs, emphasizing the critical role of caregivers as co-drivers in their child's journey and the barriers that complicate their engagement with these services.

Caregivers' involvement in EHDI is instrumental in ensuring that DHH children receive timely and effective intervention, as caregivers are responsible for decision-making, emotional support, and facilitating their child's engagement with healthcare services (Harrison et al., 2016; Szarkowski et al., 2024). Studies have shown that caregivers who understand the importance of early hearing screening and intervention can positively influence outcomes for DHH children, enabling better language, cognitive, and social development (Maluleke et al., 2024). Caregivers serve as primary advocates and interpreters of their child's needs, navigating healthcare systems and overcoming barriers to access. The South African context, with its diverse socio-economic and cultural landscape,

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places unique demands on caregivers, requiring them to fulfill complex roles often without adequate support (Davids et al., 2021; Khoza-Shangase, 2019; Maluleke & Khoza-Shangase, 2022).

Research highlights that caregivers often face substantial emotional, informational, and logistical challenges throughout the EHDI process (Alberg et al., 2006; Khoza-Shangase, 2019; Maluleke et al., 2021). The emotional strain of supporting a child with hearing impairment, compounded by societal stigma and cultural misconceptions, adds to the burden caregivers bear. For example, in some African communities, hearing impairment may be seen through the lens of superstition or attributed to cultural beliefs, leading caregivers to seek alternative healing practices before engaging with formal healthcare systems (Khoza-Shangase, 2022; Swanepoel & Almec, 2008). This cultural context highlights the need for EHDI programs that are not only accessible but also culturally responsive, equipping caregivers with accurate information that respects and integrates their beliefs (Maluleke et al., 2021; Khoza-Shangase & Mophosho, 2018).

In South Africa, several systemic barriers impact caregivers' ability to fully engage in EHDI services. Limited resources in public healthcare settings, insufficient numbers of trained professionals, and geographic barriers in rural areas restrict access to early hearing screenings and follow-up interventions (Khoza-Shangase, 2019; Maluleke et al., 2021). For instance, caregivers in rural areas often need to travel long distances to access screening and treatment services, and the costs associated with travel, lost work time, and medical expenses can be prohibitive. In low-resource settings, these barriers lead to delays in diagnosis and intervention, reducing the effectiveness of EHDI programs and impacting developmental outcomes for DHH children (Khoza-Shangase, 2022; Nicholson et al., 2022).

Moreover, communication between healthcare professionals and caregivers is a crucial aspect that influences caregiver engagement and satisfaction with EHDI services. Maluleke et al. (2024) emphasize that many caregivers report receiving insufficient or unclear information regarding their child's diagnosis, treatment options, and the importance of follow-up care. This communication gap not only leads to confusion but also impedes caregivers' ability to make informed decisions, thus compromizing the overall efficacy of EHDI programs (Maluleke & Khoza-Shangase, 2022). Family-centred communication that considers caregivers' emotional and informational needs has been shown to reduce stress and improve outcomes, as caregivers feel more supported and capable of managing their child's hearing care journey (Moodie, 2018; Maluleke et al., 2021).

Family-centred EHDI services are essential to supporting caregivers and improving developmental outcomes for DHH children. However, implementing family-centred approaches in South Africa and other African contexts remains challenging due to socioeconomic constraints, cultural diversity, and structural limitations within the healthcare system (Khoza-Shangase, 2021; Maluleke, 2022; Maluleke et al., 2021, 2023). Effective family-centred care must account for the caregiver's role within their cultural and social environment, addressing not only the technical aspects of hearing care but also providing emotional support and community resources (Maluleke & Khoza-Shangase, 2022).

Research shows that when caregivers feel empowered and included as key stakeholders in their child's care, they are more likely to engage positively with EHDI services, advocate for timely interventions, and access additional resources as needed (Reed et al., 2023; Woodruff & Lutz, 2020). The importance of caregiver empowerment is underscored by findings that caregivers often lack the necessary information and guidance to fully support their DHH child's needs, which can lead to delays in seeking further support or intervention (Khoza-Shangase, 2022; Maluleke et al., 2024). Addressing these gaps within EHDI programs by providing clear, accessible information, empathetic communication, and culturally sensitive support can enhance caregivers' confidence and engagement in their roles.

The emotional toll of caring for a child with hearing impairment is significant, and caregivers frequently report feelings of isolation, stress, and guilt. Stigma associated with hearing impairment may further exacerbate these emotions, particularly when societal attitudes reflect misconceptions about disability (Khoza-Shangase, 2019). In many cases, caregivers benefit from connecting with other families in similar situations, as peer support can offer valuable coping strategies and emotional resilience (Moodley & Storbeck, 2015; Maluleke et al., 2021). Programs like HI HOPES, a first home based family-centred early intervention program for families with a Deaf infant in South Africa, and other support networks have proven beneficial in providing a platform for caregivers to share their experiences, access resources, and feel less isolated (Störbeck & Pittman, 2008). Integrating such support networks within EHDI frameworks can improve caregiver well-being, which in turn positively impacts their engagement with their child's intervention process (Maluleke et al., 2021). Recent advancements in family-centred early intervention have been encapsulated in the expanded Family-Centred Early Intervention for Deaf and Hard of Hearing (FCEI-DHH) Principles, which build upon the original 2013 Consensus Statement (Moeller et al., 2024a). These updated Principles emphasize foundational values such as respect for diversity, informed family choice, and collaborative decision-making, aiming to enhance family

well-being and optimize developmental outcomes for children who are DHH. The expanded Principles also address cultural and global considerations, highlighting the importance of adapting interventions to diverse contexts and promoting equitable access to services. Incorporating these updated guidelines can provide a comprehensive framework for supporting families and improving early intervention systems.

The role of caregivers in EHDI programs is pivotal, as they are instrumental in shaping the outcomes of DHH children through advocacy, support, and engagement. In the South African context, caregivers face unique challenges that require EHDI services to be both accessible and culturally responsive, acknowledging the socio-economic and cultural dimensions that impact caregiver engagement. By enhancing communication, providing family-centred support, and addressing systemic barriers, EHDI programs can better empower caregivers, thereby improving developmental outcomes for DHH children and fostering inclusive, supportive care frameworks. This study aims to explore these dimensions within South Africa, emphasizing caregivers' perceptions and experiences to identify avenues for improving EHDI practices and policies.

Methodology

Aim

To explore South African caregivers' experiences and their perceptions of their role in early hearing detection and early intervention.

Objectives

- To explore the experiences that caregivers had during early hearing detection and intervention.
- To explore caregivers' perceptions regarding their role in supporting their DHH children in early hearing detection and intervention.

The methodology for this study was designed to provide a clear, in-depth exploration of South African caregivers' experiences and perceptions regarding their roles in EHDI for their DHH children. This section outlines the research design, participant recruitment and sampling, data collection, data analysis, and ethical considerations. The goal is to ensure methodological transparency and replicability for future studies.

Research design

This study employed a qualitative, phenomenological research design to capture the lived experiences and personal perceptions of caregivers in the context of EHDI. A phenomenological approach is suitable for exploring subjective experiences, allowing for a rich, descriptive analysis of caregivers' unique challenges, emotions, and roles in their children's hearing detection and intervention journey (Byrne, 2001). This approach aligns with the study's objectives, providing insights into the social, emotional, and practical dimensions of caregivers' involvement in EHDI services.

Participants and sampling

The following were the including and exclusion criteria for this study.

Inclusion criteria

- Primary caregivers of DHH children who had undergone EHDI within the South African healthcare system in the past five years.
- Caregivers whose children were diagnosed with hearing impairment and were either currently participating in or had previously completed an EHDI program.
- Caregivers willing to discuss their experiences and perceptions in detail.

Exclusion criteria

- Non-primary caregivers (e.g., extended family members without primary caregiving responsibilities) were excluded to maintain consistency in participant roles.
- Caregivers whose children were not diagnosed through an EHDI program were excluded to focus the study on program-related experiences.

Sampling strategy

A purposive, snowball sampling technique was used to recruit participants (Sharma, 2017). Initial participants were identified through audiology clinics and EHDI programs in both public and private healthcare settings within South Africa. These participants were then asked to refer other caregivers who met the inclusion criteria, allowing the researcher to gather a diverse sample that represented various backgrounds, socio-economic statuses, and geographic locations.

Sample size

A total of 12 caregivers were interviewed. The sample size of 12 caregivers was determined based on the principles of data saturation, which is widely used in qualitative research to establish an appropriate number of participants (Saunders et al., 2018). Data saturation occurs when no new themes emerge from additional interviews, indicating that sufficient data has been collected to fully address the research questions (Guest et al., 2006). In qualitative phenomenological studies, sample sizes typically range from 6 to

15 participants, allowing for in-depth exploration of lived experiences while ensuring analytical rigor (Creswell & Poth, 2016). Additionally, prior studies on caregiver experiences in EHDI programs in South Africa have utilized similar sample sizes, achieving meaningful insights into caregiver challenges and perceptions (Khoza-Shangase, 2019; Maluleke et al., 2023; 2024). Given the richness of qualitative data and the need for deep narrative analysis, 12 participants provided a sufficient sample to capture diverse perspectives while ensuring feasibility within the study's scope. To further ensure robustness, thematic saturation was monitored throughout data collection. After the 10th interview, no significant new themes emerged, confirming that additional data collection would yield redundancy rather than novel insights. Thus, the final sample size of 12 was deemed appropriate for this study's objectives of providing a comprehensive understanding of caregiver experiences and perceptions.

Data collection

Data collection method

Data was collected through semi-structured, in-depth interviews conducted in-person and online via video conferencing platforms to accommodate participant preferences and geographical constraints. Semi-structured interviews were selected to allow flexibility in exploring personal narratives while adhering to a set of open-ended questions designed to address the study's objectives.

Interview guide

An interview guide was developed based on the study's objectives, containing open-ended questions structured around the following themes:

- *Experiences with EHDI,* where participants were asked about their first encounters with EHDI services, the diagnosis process, and their experiences navigating the healthcare system.
- *Perceptions of Their Role in EHDI,* where questions focused on caregivers' understanding of their role, including how they perceive their responsibilities, challenges faced, and how they have supported their child through the EHDI journey.
    - *Emotional and Social Aspects of Caregiving,* where participants discussed the emotional impact of caregiving for a DHH child, including societal perceptions, stigma, and support received from family, peers, and healthcare providers.

Each interview lasted approximately 60–90 minutes and was audio-recorded with the participant's consent to ensure accuracy in data transcription. Interviews were conducted in English, with a translator available for non-English interviews.

Data analysis

Demographic profile data were analysed descriptively.

Transcription and familiarization. The recorded interviews were transcribed verbatim. Transcripts were reviewed by the researcher for accuracy and completeness. Initial familiarization with the data was achieved through repeated readings of the transcripts, enabling the researcher to immerse themselves in the narratives and identify initial codes and themes (Belotto, 2018).

Coding and thematic analysis. Data analysis was conducted using inductive thematic analysis, following Braun and Clarke's (2006) six-step process. This included 1) *familiarization with the data,* where the researcher read through the transcripts multiple times to become intimately familiar with the content; 2) *generating initial codes,* where segments of text related to specific experiences, perceptions, and emotions were coded to capture meaningful units of analysis; 3) *searching for themes,* where codes were grouped into broader themes based on shared patterns and insights, focusing on aspects of the caregivers' experiences and perceptions that aligned with the study's objectives; 4) *reviewing themes,* where the themes were reviewed and refined by comparing them with the original data, ensuring they accurately represented the participants' experiences; 5) *defining and naming themes,* where each theme was clearly defined and named to encapsulate the essence of the data it represented; and 6) *producing the report,* where a detailed account of the themes and subthemes was developed, with direct quotes from participants used to substantiate and illustrate each theme. First, all interview transcripts were read multiple times to ensure immersion in the data. Initial open coding was performed, where meaningful phrases and statements were identified. These codes were then grouped into categories based on similarities in content. Subsequently, sub-categories were created to refine the analysis, capturing nuances within the broader themes. The final themes were developed through iterative discussions among the research team, ensuring alignment with the study's objectives. NVivo software was used to manage and organize data systematically, allowing for efficient coding and theme organization. The use of software facilitated transparent tracking of the analytical process, ensuring rigor and consistency in identifying key themes.

Ethical considerations

Ethical approval. The study received ethical clearance from the University's Research Ethics Committee (Non-Medical) (Ethics Approval Number: STA_2024_31), ensuring all research activities were conducted in alignment with ethical guidelines for human research.

Informed consent. Prior to participation, each caregiver was provided with a detailed information sheet outlining the purpose of the study, the voluntary nature of participation, and the right to withdraw at any time without penalty. Written informed consent was obtained from each participant before the interviews began. For participants who preferred online interviews, consent was obtained electronically.

Confidentiality and anonymity. All data collected from participants were treated as strictly confidential. Participants were assigned pseudonyms to protect their identities, and all identifying information was removed from the transcripts. Data was stored securely on password-protected devices accessible only to the researcher and research supervisor, in line with data protection policies.

Emotional and psychological support. Given the emotional nature of the discussions, participants were informed that they could pause or terminate the interview at any time if they felt uncomfortable. A list of support resources, including mental health services and parent support groups, was provided to participants who expressed distress or an interest in additional support.

Trustworthiness and rigor

To ensure trustworthiness and rigor in this qualitative study, over and above the inclusion of the pilot study prior to the main study, four strategies were applied. Firstly, *member checking* was done where after transcription and preliminary analysis, participants were given the opportunity to review and confirm the accuracy of their responses, ensuring their views were accurately represented. Secondly, *peer debriefing* was performed where the researcher engaged in regular debriefing sessions with academic peers and supervisor to discuss emerging themes and any potential biases in interpretation. Thirdly, an *audit trail* was kept where detailed documentation of the research process, from data collection to analysis, was maintained, providing an audit trail for verifying the reliability and transparency of the study's findings. Lastly, *triangulation* was done, where applicable, findings were compared with existing literature on caregiver experiences in EHDI, enhancing the credibility of the themes identified (Tobin & Begley, 2004). By employing these strategies, the study ensured methodological rigor and trustworthiness, capturing an authentic and comprehensive portrayal of South African caregivers' experiences and perceptions within the EHDI framework.

Data management. Appropriate data management procedures were implemented to ensure the security, confidentiality, and organization of data collected during the study. All data collected in this study were managed in accordance with ethical guidelines to ensure participant confidentiality and data integrity. Audio recordings of interviews were securely stored on password-protected devices and transcribed verbatim. Transcripts were anonymized by assigning pseudonyms to participants, and identifying details were removed. Data were organized and analysed using NVivo software, facilitating systematic coding and theme identification. Only the research team had access to the data, which were stored securely and will be retained for five years post-study completion, following institutional data retention policies.

Results

Demographic profile of the sample

As far as the demographic characteristics of the caregivers and their children in this study was concerned, the study included 12 primary caregivers of DHH children, comprizing 8 mothers, 2 fathers, 1 grandmother, and 1 aunt who served as the primary caregiver. The children's ages at the time of diagnosis ranged from 6 months to 6 years, with the majority being diagnosed before the age of 3. The degree of hearing impairment varied among the children, with 3 having mild, 4 moderate, and 5 severe to profound hearing loss. Caregivers were drawn from both public and private healthcare sectors, with 7 utilizing private services and 5 accessing public healthcare. The sample also included a grandmother who had taken on the primary caregiving role.

Experiences of caregivers during early hearing detection and intervention

Caregivers in this study shared diverse experiences navigating the EHDI process, characterized by various emotional, logistical, and informational challenges. Themes (Table 1) that emerged included 1) challenges in accessing healthcare services, 2) lack of awareness and guidance, 3) emotional stress due to the diagnosis and caregiving responsibilities,.and 4) positive experiences with private healthcare providers.

Theme 1: Challenges in accessing EHDI services. Category 1.1: Logistical Barriers.

Table 1. Thematic Overview of Caregivers' Experiences and Perceptions in EHDI.

Themes	Categories	Sub-Categories
Challenges in Accessing EHDI Services	Logistical Barriers	Distance to healthcare facilities
		Long waiting times
	Financial Constraints	Cost of transport and medical visits
		Limited access to assistive devices
Lack of Awareness and Information	Limited Knowledge About EHDI	Absence of newborn hearing screening awareness
		Misconceptions about hearing loss
	Insufficient Communication from Healthcare Providers	Overuse of medical jargon
		Lack of ongoing guidance
Emotional Stress and Stigma	Psychological Impact of Diagnosis	Feelings of shock and denial
		Anxiety about the child's future
	Societal and Family Stigma	Community misconceptions about hearing loss
		Family rejection or misunderstanding
Positive Experiences with Private Healthcare Providers	Timely Access to Services	Shorter waiting times
		Greater availability of hearing technology
	Better Communication and Support	Patient-centred explanations
		Access to counseling and education
Advocacy and Proactive Engagement	Caregivers as Advocates	Seeking second opinions
		Engaging in support groups
		Requesting individualized resources
Emotional Support Role of Caregivers	Providing Emotional Support	Instilling resilience in their children
		Managing caregiver emotional struggles
Perceived Inadequacies in Preparation	Lack of Training and Resources	Need for caregiver education
		Uncertainty in handling hearing aids and communication strategies
Support Networks and Positive Outcomes	Peer and Community Support	Role of peer groups in reducing isolation
		Practical benefits of connecting with other caregivers

- Sub-category 1.1.1: Distance to healthcare facilities – *Caregivers in rural areas described the challenge of traveling long distances for screening and follow-up appointments.*
- Sub-category 1.1.2: Long waiting times – *Participants reported extensive delays in securing appointments, particularly in public healthcare settings.*

Category 1.2: Financial Constraints.

- Sub-category 1.2.1: Cost of transport and medical visits – *Caregivers highlighted the financial burden associated with repeated hospital visits.*
- Sub-category 1.2.2: Limited access to assistive devices – *Some participants noted difficulties in affording hearing aids and related technologies.*

The majority of caregivers reported delays in accessing EHDI services due to systemic barriers within the public healthcare settings. Caregivers, particularly those using public healthcare, recounted difficulties in accessing EHDI services due to long waiting times, geographical distance from clinics, lack of transportation, and the financial burden of traveling long distances to specialized facilities. These barriers often delayed the diagnosis and intervention, with caregivers from rural areas expressing additional challenges in securing appointments and follow-up services.

> We live far from the hospital, and getting there means taking off work, paying for transport … Sometimes we would wait for hours only to be told the specialist is not available. – Caregiver 6

> Getting to the clinic was always a struggle; I had to ask for time off work and figure out how to get there with the little money we had left at the end of the month. – Caregiver 7

Theme 2: Lack of awareness and information. Category 2.1: Limited Knowledge About EHDI.

- Sub-category 2.1.1: Absence of newborn hearing screening awareness – Several caregivers indicated that they had never heard of early hearing detection before their child's diagnosis.
- Sub-category 2.1.2: Misconceptions about hearing loss – Some caregivers initially believed hearing loss was temporary or caused by external factors, such as illness or environmental noise.

Category 2.2: Insufficient Communication from Healthcare Providers.

- Sub-category 2.2.1: Overuse of medical jargon – *Participants described feeling overwhelmed by technical explanations they did not fully understand.*
- Sub-category 2.2.2: Lack of ongoing guidance – *Many caregivers felt unsupported after the initial diagnosis, unsure of the next steps in their child's intervention journey.*

A significant theme was the lack of awareness among caregivers regarding the importance of early hearing screening. Many participants reported that they were unaware of EHDI services until after their

child's diagnosis, indicating a gap in public awareness initiatives.

> Nobody told us about the importance of newborn hearing tests. I only learned about it after the diagnosis, which came as a big shock. – Caregiver 4

> I didn't even know babies could have hearing issues; nobody explained that this was something we should be watching for.' – Caregiver 3

Caregivers also expressed frustration with insufficient guidance from healthcare providers, noting that complex medical terms were often used without adequate explanation, leaving them feeling unprepared to navigate the EHDI process effectively. Caregivers obtained EHDI information from a variety of sources, with healthcare providers being the most frequently mentioned (Table 2). However, many caregivers expressed dissatisfaction with the level of detail and clarity provided, highlighting a need for more accessible and structured guidance.

> They [healthcare providers] gave us pamphlets with medical terms, but I needed someone to explain what this meant for my child's future. – Caregiver 2

Theme 3: Emotional stress and stigma. Category 3.1: Psychological Impact of Diagnosis.

- Sub-category 3.1.1: Feelings of shock and denial – Caregivers recounted an initial emotional struggle upon receiving their child's diagnosis.
- Sub-category 3.1.2: Anxiety about the child's future – Many expressed deep concerns about their child's communication, education, and social integration.

Category 3.2: Societal and Family Stigma.

- Sub-category 3.2.1: Community misconceptions about hearing loss – Some caregivers reported that community members associated hearing loss with witchcraft or divine punishment.
- Sub-category 3.2.2: Family rejection or misunderstanding – A few participants shared experiences of family members minimizing or dismissing their child's hearing impairment.

Caregivers described experiencing significant emotional distress following their child's diagnosis.

Table 2. Caregivers' primary sources of EHDI information and their satisfaction with the information provided.

Information Source	Number of Caregivers ($n = 12$)	Satisfaction Level
Healthcare providers	8	Low
Online resources	3	Medium
Peer support groups	5	High
Audiology centers	4	Medium

The uncertainty of their child's future, coupled with societal stigma around hearing impairment, created a sense of isolation for many caregivers. Some reported being subjected to insensitive comments and misunderstandings from family members and the community.

> I was devastated when I found out. People in my community didn't understand and blamed it on witchcraft. I felt ashamed to talk about it. – Caregiver 10

> After the diagnosis, I felt like I was constantly worried about the future – how he would communicate, make friends, or even go to school. – Caregiver 1

Theme 4: Positive experiences with private healthcare providers. Category 4.1: Timely Access to Services.

- Sub-category 4.1.1: Shorter waiting times – *Caregivers who accessed private healthcare described receiving quicker diagnoses and intervention.*
- Sub-category 4.1.2: Greater availability of hearing technology – *Participants noted that private clinics provided easier access to hearing aids and assistive devices.*

Category 4.2: Better Communication and Support.

- Sub-category 4.2.1: Patient-centred explanations – *Caregivers in private healthcare settings described receiving clearer, more supportive communication from audiologists.*
- Sub-category 4.2.2: Access to counseling and education – *Some participants highlighted that private clinics provided additional counselling and training on how to manage their child's condition.*

While caregivers in the public sector encountered challenges, those accessing private healthcare reported more positive experiences, with shorter waiting times and access to specialized resources. These caregivers also described receiving more thorough guidance from audiologists and support groups, which helped them navigate the EHDI process more confidently.

> Our audiologist was fantastic. She explained everything and even connected us to a support group where I could meet other parents going through the same journey. – Caregiver 9

> Our private doctor was patient and took the time to make sure I understood every step. I finally felt like someone was listening to me and cared about my child. – Caregiver 9

Perceptions of caregivers regarding their role in supporting their DHH children

Caregivers articulated their understanding of their responsibilities within the EHDI framework and shared diverse perspectives on the role they play in their child's development. Themes (Table 1) identified include 1) advocacy, 2) emotional support, 3) perceived inadequacies in preparation, and 4) support networks and positive outcomes.

Theme 1: Advocacy and proactive engagement. Many caregivers emphasized their role as advocates for their children, frequently seeking second opinions and pushing for early intervention despite systemic barriers. This sense of advocacy was particularly strong among caregivers who felt unsupported by the healthcare system.

> It was up to me to push for answers and make sure my child got the help she needed. I can't rely on the system to do that for us. – Caregiver 8

> I realized I had to be her voice. If I didn't keep pushing and asking questions, she wouldn't get the help she needed. – Caregiver 10

Caregivers demonstrated strong advocacy efforts by actively seeking second opinions, reaching out to peer support networks, and requesting additional resources from healthcare providers (Table 3). These actions reflected their determination to secure the best possible care for their children despite facing systemic challenges.

Theme 2: Providing emotional support. A recurring theme was caregivers' perception of their role as emotional supporters, helping their children cope with the diagnosis and managing their emotional well-being. Caregivers described efforts to instill resilience and confidence in their children, despite feeling emotionally unprepared for the challenges of raizing a DHH child.

> It's my job to be strong for her, to show her that her hearing doesn't define her. But there are days when I don't feel strong enough. – Caregiver 5

> Some days are really tough, but I try to be the one she can lean on. I have to be her strength, even when I feel like I'm falling apart. – Caregiver 4

Theme 3: Perceived inadequacies and need for support. Despite their determination, several caregivers expressed a sense of inadequacy in their roles, citing the absence of accessible resources, educational support, and structured guidance. This inadequacy was amplified by limited training on how to handle the practicalities of supporting a DHH child, such as hearing aid management and communication strategies.

> I wish someone would teach us how to handle this better. I'm just figuring things out as I go, but I feel lost. – Caregiver 3

> I feel like I'm just guessing my way through. No one really prepares you for how to handle all these new responsibilities. – Caregiver 6

Table 3. Primary advocacy actions taken by caregivers.

Advocacy Action	Percentage of Caregivers
Seeking second opinions	67%
Engaging in support groups	58%
Requesting individualized resources	42%

Theme 4: Support networks and positive outcomes. Engagement with support networks, such as peer groups and specialized counseling, emerged as a valuable resource for caregivers, providing emotional reassurance and practical advice. Caregivers who accessed support networks reported greater confidence in their roles and a stronger sense of community.

> The support group changed everything. Just hearing from other parents, knowing we're not alone, it gave me the strength to keep going. – Caregiver 11

> Being in the support group helped me feel less alone. Hearing from other parents made me realize there's a whole community facing the same challenges. – Caregiver 12

Most caregivers who engaged with peer support networks described positive experiences, noting that connecting with other parents facing similar challenges helped alleviate feelings of isolation and provided them with practical coping strategies.

The above findings illustrate the diverse experiences and perceptions of caregivers within the South African EHDI framework. Many caregivers faced significant barriers in accessing services, a lack of adequate information, and emotional challenges associated with stigma and isolation. However, those who accessed private healthcare and support networks reported more positive experiences. Overall, the caregivers demonstrated a strong sense of advocacy and commitment to their role, although they also highlighted the need for better resources, emotional support, and culturally sensitive guidance to empower them in supporting their DHH children effectively.

Discussion

This study aimed to explore South African caregivers' experiences and perceptions regarding their role in EHDI for their DHH children. The findings highlight significant challenges faced by caregivers within the EHDI framework, particularly regarding access to services, informational and emotional support, and the

advocacy role they often assume. These findings resonate with and expand on existing literature, particularly studies focusing on caregiver involvement in EHDI in low-resource settings (Khoza-Shangase, 2019; Maluleke et al., 2024).

The study reveals considerable logistical and systemic barriers that limit caregivers' access to EHDI services, particularly in public healthcare and rural areas. Challenges include long travel distances, extended waiting times, and financial burdens associated with healthcare access. These barriers, frequently noted in the literature, underscore the inequalities within the South African healthcare system, where rural and under-resourced areas experience the most significant challenges (Khoza-Shangase, 2019). Similar issues have been reported in other low – and middle-income countries (LMICs) where logistical difficulties delay diagnosis and intervention, compromizing developmental outcomes for DHH children (Olusanya et al., 2006; Swanepoel & Almec, 2008). In comparison, caregivers in this study who accessed private healthcare services reported more positive experiences, including shorter waiting times and better access to resources. This disparity aligns with findings by Kanji and Khoza-Shangase (2021), who observed that EHDI services in South Africa remain inconsistently distributed, with private sector resources far outpacing public offerings. Such disparities highlight the need for policy interventions focused on expanding EHDI services to under-resourced areas and integrating targeted support for rural and remote communities to ensure equitable access. Similar challenges have been documented in other LMICs, where healthcare access is limited by financial constraints, geographical distance, and workforce shortages (Bevilacqua et al., 2010; Olusanya, 2015; Sasikumar et al., 2024; Waterworth et al., 2022). Studies in India and Brazil highlight that community-based hearing screening and telehealth solutions have been introduced as alternative strategies to mitigate these barriers (Alvarenga et al., 2008; Eubank et al., 2022; O'Donovan et al., 2019). Such approaches may hold promise for South Africa's EHDI framework, particularly in rural and under-resourced areas.

The study also found lack of awareness and information, thus highlighting the knowledge gap. Many caregivers in this study reported a lack of awareness regarding the importance of early hearing screening prior to their child's diagnosis, an issue that delayed intervention for several participants. This gap in awareness echoes findings by Maluleke et al. (2024), who emphasize that inadequate public education on hearing impairment limits caregivers' engagement with EHDI services, particularly in under-resourced settings. Research in LMICs shows that the lack of awareness of EHDI services among caregivers is a widespread issue, often exacerbated by limited public health initiatives and outreach (Ayob et al., 2022). Moreover, caregivers frequently expressed frustration with the quality of information provided by healthcare professionals, describing it as overly technical and insufficiently detailed. Consistent with Maluleke et al. (2021), this study found that caregivers feel more equipped to support their children when they receive clear, practical information about hearing impairment and EHDI processes. In the South African context, healthcare providers' reliance on medical terminology without context has been shown to lead to misunderstandings, complicating caregivers' ability to make informed decisions (Kanji & Krabbenhoft, 2018; Khoza-Shangase, 2019). A study in Rwanda found that caregiver awareness of hearing loss screening was similarly low, often due to a lack of national EHDI policies (Mukara et al., 2017). In contrast, countries like Australia and the United States have successfully implemented universal newborn hearing screening (UNHS) policies, leading to significantly higher caregiver awareness and earlier intervention (Ravi et al., 2016; Yoshinaga-Itano, 2014). Lessons from these mature healthcare systems suggest that national mandates for newborn hearing screening, combined with public education campaigns, could significantly improve early detection rates in South Africa Current findings also raize the need for more accessible communication strategies within EHDI, with materials and interactions tailored to caregivers' educational, linguistic, and cultural backgrounds. Such improvements could increase engagement with EHDI services, empowering caregivers to become proactive co-drivers in their child's development.

As far as the emotional stress and stigma, which pointed towards the psychosocial impact on caregivers, found in this study were concerned, the emotional impact of caregiving for a DHH child emerged as a dominant theme in this study, with participants describing feelings of distress, isolation, and stigma. This experience is consistent with findings by Maluleke and Khoza-Shangase (2022) and Swanepoel and Almec (2008), who highlight the profound psychosocial challenges faced by caregivers in South Africa. Many participants reported encountering stigmatizing attitudes within their communities, often attributed to cultural misconceptions about hearing impairment, which affected both their emotional well-being and their willingness to seek external support. Caregivers' experiences with stigma and cultural misunderstandings are particularly relevant in South Africa, where cultural beliefs regarding hearing impairment can discourage caregivers from accessing formal EHDI services (Khoza-Shangase, 2019; Swanepoel & Almec, 2008). For example, several caregivers noted that community members perceived their child's hearing impairment as a form of witchcraft or divine punishment, which added to their emotional burden and impacted their

engagement with healthcare services. These findings are in line with studies in similar LMIC contexts, which indicate that societal attitudes toward disability significantly influence caregivers' help-seeking behaviors (Bright et al., 2018). Studies in Ghana and China have similarly documented cultural stigmas surrounding hearing impairment, where caregivers report feelings of isolation and reluctance to seek medical intervention due to societal misconceptions (Kwok & Kwok Lai Yuk Ching, 2022; Mfoafo-M'Carthy et al., 2024; Mprah et al., 2025). In contrast, high income countries (HICs) such as Canada and the UK have integrated mental health support into EHDI programs, providing structured counseling and peer support for caregivers (Noll et al., 2021). South Africa's EHDI framework could benefit from adapting similar models of psychological support, ensuring that caregivers receive emotional as well as informational guidance. Addressing these stigmas within EHDI programs through culturally informed public awareness campaigns could mitigate the psychosocial strain on caregivers, enabling them to focus on supporting their children as co-drivers of their children's EHDI.

Advocacy and proactive engagement, where caregivers were co-drivers was found in this study. Caregivers in this study demonstrated a strong sense of advocacy, often being co-drivers in the EHDI process to ensure their children received timely diagnosis and intervention. Many participants described seeking second opinions, consulting support networks, and engaging in peer support groups. This finding is consistent with Maluleke et al. (2024) and Balton and Dada (2023), who emphasize the vital role that caregivers play as advocates within EHDI, particularly in systems with limited resources or support. Advocacy behaviors were especially prominent among caregivers who felt that healthcare providers were not responsive enough to their concerns, mirroring findings by Scarinci et al. (2018) that emphasize caregivers' role as primary advocates in EHDI systems. In Uganda, organizations like Hear His Voice Uganda have mobilized families, parents, and caregivers of hearing-impaired children, forming strong parent groups that spearhead family support and advocacy programs. This grassroots effort demonstrates the power of community-driven initiatives in strengthening EHDI programs. Similarly, in Thailand, the Ministry of Education's Special Education Bureau operates numerous schools that provide support for parents of children with special needs, including those with hearing impairments. These government-funded programs enhance caregiver engagement in hearing rehabilitation. Lessons from such initiatives could inform future strategies in South Africa, particularly in establishing caregiver-led advocacy groups and state-supported information hubs. In South Africa, caregivers' advocacy efforts are often hindered by systemic limitations, particularly within public healthcare settings where resources are limited. Despite these barriers, caregivers reported positive outcomes when they engaged with support networks and private healthcare providers, which provided guidance and reassurance. The role of advocacy is crucial, as studies show that caregivers who take active roles in decision-making experience greater satisfaction with EHDI services and report better developmental outcomes for their children (Munoz et al., 2009; Scarinci et al., 2018). Expanding support for caregiver advocacy within EHDI, particularly in under-resourced settings, could enhance program effectiveness by fostering a collaborative approach between caregivers and healthcare providers.

As far as emotional support networks in the form of peer groups and community resources were concerned, this study revealed that the presence of support networks, including peer groups, emerged as a vital resource for caregivers, providing them with emotional reassurance and practical advice. Caregivers in this study who accessed peer support networks reported reduced stress and greater confidence in navigating EHDI. This finding aligns with previous studies that emphasize the value of peer support in reducing caregiver isolation and providing a sense of community, which is particularly important given the emotional demands of raizing a DHH child (Hintermair, 2006; Jackson, 2011). In the South African context, structured support networks like the HI HOPES program have been shown to offer substantial benefits for caregivers, as they facilitate peer engagement and provide essential resources (Störbeck & Pittman, 2008). Maluleke et al. (2021) suggest that peer support and community-based programs can significantly alleviate the psychosocial burden on caregivers, enhancing their resilience and capacity to advocate for their children. Research from HICs suggests that formalized family-centred early intervention programs, such as those in the U.S. and Canada, significantly enhance caregiver confidence and long-term child outcomes (Moeller et al., 2024b). Integrating structured peer mentorship programs into South Africa's EHDI framework – similar to the 'ParentLink' model in Australia – may provide caregivers with the guidance and support needed to navigate early hearing intervention effectively (Mertensmeyer & Fine, 2000). Incorporating more such support networks within EHDI could improve caregivers' emotional well-being and, by extension, their engagement in EHDI services. Moreover, expanding access to community-based support in rural areas would address an important gap, as many caregivers in these areas lack proximity to peer networks.

Despite their proactive roles, many caregivers in this study expressed a sense of inadequacy, often citing a lack of preparation for the challenges associated with

raizing a DHH child. This perception aligns with findings by Maluleke et al. (2021), who report that caregivers frequently lack training and guidance on managing hearing aids, fostering effective communication, and navigating EHDI processes. Caregivers in this study specifically requested practical resources and training on hearing aid maintenance, communication techniques, and advocacy strategies, reflecting a broader need for structured caregiver education within EHDI frameworks. Such inadequacies highlight the importance of family-centred care within EHDI programs, where caregivers are equipped with tools and knowledge to support their children effectively (Maluleke et al., 2021). In South Africa, family-centred care has been inconsistently implemented, with many programs lacking dedicated resources for caregiver education and support (Kanji & Khoza-Shangase, 2021). As suggested by Yoshinaga-Itano (2014), empowering caregivers through training and accessible resources fosters a collaborative approach to EHDI, improving outcomes for both children and families. Integrating caregiver education and support resources into EHDI services, especially in rural and low-resource areas, is essential for maximizing the impact of these programs.

This study has several limitations that may affect the generalizability of its findings. The sample size was small and limited to caregivers who were accessible through purposive and snowball sampling, which may not fully represent the broader population of caregivers in South Africa. Additionally, most interviews were conducted in English, which could limit depth for participants more comfortable in other languages. The reliance on self-reported data may introduce recall bias, as caregivers reflected on past experiences that might have been influenced by time. Future research with a larger, more diverse sample and inclusion of multiple languages would enhance the depth and applicability of these findings. Nonetheless, despite these limitations, the study's findings highlight several implications for improving EHDI services in South Africa. Addressing logistical barriers through policy reforms that expand healthcare access in rural areas, combined with public education campaigns that increase awareness of EHDI, would enhance caregiver engagement. Further, implementing culturally sensitive training for healthcare providers can bridge the communication gap between caregivers and professionals, fostering a supportive environment for caregiver advocacy. Peer support networks and community resources should be expanded, particularly in rural and underserved areas, to alleviate the psychosocial strain on caregivers. Providing structured educational resources, such as training on hearing aid maintenance and communication strategies, would empower caregivers to support their DHH children more effectively. These recommendations align with best practices in EHDI service delivery, highlighting the importance of a family-centred, inclusive approach that prioritizes caregiver empowerment.

Conclusion

This study explored South African caregivers' experiences and perceptions of their role in EHDI for their DHH children. Findings highlight significant challenges in accessing services, limited awareness and guidance, emotional distress and societal stigma, as well as varying experiences across public and private healthcare sectors which collectively hinder caregivers' ability to engage fully in the EHDI process. However, the study also highlights the resilience and advocacy efforts of caregivers, who often act as primary drivers of their children's early hearing intervention. Caregivers in this study exhibited strong commitment to their roles despite systemic limitations, demonstrating their crucial role as partners in achieving successful outcomes for DHH children.

Caregivers in South Africa, particularly those in rural or under-resourced areas, face significant barriers to accessing EHDI services, largely due to socioeconomic disparities and infrastructure limitations within the healthcare system. This study raizes the need for EHDI programs to be inclusive, culturally sensitive, and family-centred, ensuring that caregivers are adequately informed, supported, and empowered throughout the EHDI journey. The proactive engagement of caregivers in advocacy and peer support networks suggests that well-structured support mechanisms can alleviate the psychosocial strain associated with caregiving and improve engagement with EHDI services.

To address the challenges identified, this study makes the next recommendations to enhance the effectiveness and inclusiveness of EHDI programs in South Africa. Firstly, accessibility of EHDI services should be expanded**.** Policy reforms should focus on increasing EHDI service coverage in rural and underserved areas, reducing logistical barriers such as travel distances and long waiting times; and mobile and telehealth services should be integrated into EHDI programs to reach caregivers in remote regions, offering screening, diagnosis, and follow-up consultations. Secondly, public awareness and education should be enhanced. Public health campaigns should promote awareness of the importance of EHDI, especially in communities where awareness is low. These campaigns should use culturally relevant messaging to dispel misconceptions and stigma surrounding hearing impairment. Additionally, educational materials provided by healthcare professionals should be simplified and translated into languages other than English and Afrikaans, making information accessible and comprehensible for caregivers with varying literacy levels. Thirdly, communication

between healthcare providers and caregivers should be improved. Training for healthcare providers should emphasize culturally sensitive, patient-centred communication techniques, where providers are encouraged to use accessible language, ensuring that caregivers understand their child's diagnosis, treatment options, and the importance of early intervention. Additionally, structured communication protocols should be developed within EHDI services to provide caregivers with clear, step-by-step guidance throughout the EHDI process.

Fourthly, family-centred and supportive care should be strengthened. Family-centred care models should be integrated within EHDI programs, focusing on caregiver empowerment, training, and collaboration. This approach should include educational workshops on hearing aid use, communication techniques, and advocacy skills, preparing caregivers to manage their roles more effectively. This supportive care should also include expanding access to peer support networks and other community resources, particularly in rural and underserved areas. These networks can provide emotional and practical support, reducing caregiver isolation and fostering resilience. Fifthly, societal stigma and cultural misconceptions should be addressed. Community outreach initiatives that involve local leaders and cultural influencers and brokers can help address and reduce stigma, encouraging communities to support families with DHH children. Culturally sensitive approaches that respect local beliefs while promoting modern healthcare solutions are critical to fostering community support. Lastly, further research on EHDI implementation should be conducted. Longitudinal studie**s** are recommended to track caregiver and child outcomes over time, evaluating the long-term impact of enhanced EHDI services and caregiver support. Furthermore, research on culturally adapted interventions within EHDI programs would provide further insights into effective ways of engaging caregivers across diverse South African communities.

By addressing these recommendations, through incorporating lessons from global best practices by adapting successful EHDI models from both LMICs and HICs, ensuring culturally appropriate and contextually relevant interventions for South African caregivers; EHDI programs in South Africa can better support caregivers in their critical role. South Africa's EHDI framework can be more inclusive, family-centred, and responsive to caregivers' needs, ultimately improving long-term developmental outcomes for DHH children. This study contributes to the understanding of caregiver roles within EHDI, emphasizing the need for systemic improvements that prioritize caregiver empowerment and family-centred care within the South African context – knowledge that can facilitate the attainment of this goal.

Authors' contributions

PL and KKS co-conceptualized the study. PL performed all data collection and conducted data capturing with KKS supervizing. PL and KKS analysed and interpreted the data. Both authors read and approved the final manuscript.

Availability of data and materials

Data supporting the findings of this study are available within the paper and the rest of the data that support the findings of this study are not openly available due to reasons of sensitivity and are available from the corresponding author upon reasonable request.

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Ethics approval and consent to participate

Prior to commencing any form of data collection, the researcher secured ethical clearance from the University of the Witwatersrand's Human Research Ethics Committee (Non-Medical) (Ethics Approval Number: STA_2024_31).

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