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Original Article

Evaluating family-centered early hearing detection and intervention practices in South Africa: Caregiver perceptions and challenges

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Abstract

Background: Early hearing detection and intervention (EHDI) services are essential for the timely identification and management of hearing loss in children. Family-centered early intervention (FCEI), which prioritizes caregiver involvement and culturally responsive care, is associated with improved developmental and psychosocial outcomes. However, in low- and middle-income countries such as South Africa, systemic barriers such as linguistic mismatches, fragmented service delivery, and inadequate caregiver engagement hinder the effective implementation of FCEI principles. Limited paternal involvement and inconsistent informational support further compromise service accessibility and quality.

Objective: This study evaluated the family-centeredness of EHDI services in South Africa from the perspective of caregivers, with a focus on their experiences and the systemic, linguistic, and cultural challenges affecting service delivery.

Methods: A mixed-methods convergent design was used. The qualitative strand involved narrative interviews with nine caregivers of children who are deaf or hard of hearing (DHH), analyzed using reflexive thematic analysis. The quantitative strand employed the modified measurement of the processes of care-56 (MPOC-56) to assess family-centeredness across five domains, with 16 caregivers completing the survey. Descriptive statistics summarized survey responses, and findings from both strands were integrated to provide a comprehensive evaluation of caregiver experiences.

Results: Caregivers reported the varying levels of satisfaction across the MPOC-56 domains. Providing specific information and coordinated and comprehensive care received the highest scores, indicating positive caregiver experiences with information provision and care integration. However, respectful and supportive care and enabling and partnership domains had lower scores, revealing critical gaps in service delivery. Key challenges included: (1) healthcare providers dismissing caregiver concerns, (2) language barriers where English is used as the primary language for services despite caregivers speaking African languages, (3) fragmented service delivery, (4) limited paternal involvement, and (5) inadequate follow-up support.

Conclusion: While South Africa's EHDI services are gradually adopting family-centered principles, systemic, linguistic, and cultural barriers continue to undermine equitable access and caregiver engagement.

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Submitted: 24-Jan-2025 **Revised:** 10-Feb-2025 **Accepted:** 11-Feb-2025 **Published:** 23-Apr-2025

Access this article online	
Quick Response Code:	Website: https://journals.lww.com/hbcm
	DOI: 10.4103/HBC.HBC_1_25

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How to cite this article: Maluleke NP, Khoza-Shangase K. Evaluating family-centered early hearing detection and intervention practices in South Africa: Caregiver perceptions and challenges. Hear Balance Commun 2025;23:27-39.

Addressing these barriers requires training healthcare providers in cultural competence, recruiting multilingual professionals, fostering interdisciplinary collaboration, developing strategies to involve fathers, and expanding services to rural and under-resourced areas. These measures are essential to improve the accessibility, responsiveness, and effectiveness of South Africa's EHDI services, ensuring equitable, family-centered care for all children who are DHH.

Keywords: Caregiver experiences, cultural competence, early hearing detection and intervention, family-centered care, hearing loss, linguistic accessibility, paternal involvement, service integration, South Africa

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INTRODUCTION

Early hearing detection and intervention (EHDI) continues to present the significant challenges in low- and middle-income countries (LMICs), including South Africa.[1-3] EHDI programs are essential for the early identification and management of hearing loss, yet their successful implementation is often hindered by systemic and contextual barriers. These barriers include shortages of skilled professionals, lack of equipment, insufficient newborn hearing screening (NHS) programs, and broader socio-economic factors that limit access to healthcare. Inadequate policy enforcement and fragmented healthcare infrastructure further exacerbate these challenges, resulting in inconsistent implementation of EHDI programs across different regions. For families of children who are deaf or hard of hearing (DHH),[1,4-7] these challenges are further exacerbated by linguistic and cultural mismatches between service providers and the populations they serve.[6,8,9] Without effective EHDI programs, children with hearing loss face delays in language acquisition, cognitive development, and social integration, which can have lifelong consequences.

In recognition of the importance of family involvement in the EHDI process, the Health Professions Council of South Africa (HPCSA)[10] recommends that early intervention (EI) services for DHH children adopt a family-centered approach. Family-centered EI (FCEI) is grounded in the principle that caregivers play a central role in their child's development and should be active partners in the intervention process. FCEI emphasizes respect for family values, preferences, and cultural contexts while prioritizing caregiver empowerment and collaboration with healthcare providers.[11] Evidence from high-income countries has demonstrated that FCEI yields numerous benefits, including improved developmental outcomes for children and enhanced psychological well-being, self-efficacy, and decision-making capabilities for caregivers.[12-15] Despite these benefits, the successful integration of FCEI within existing EHDI frameworks depends on the adaptability of healthcare systems to accommodate diverse cultural and linguistic needs, a factor that remains a challenge in LMICs. However, the applicability of these findings to LMICs such as South Africa remains underexplored, given the distinct socio-economic, linguistic, and healthcare challenges in these contexts.

In South Africa, where cultural and linguistic diversity is vast, the implementation of FCEI requires tailored strategies that address local realities. Many caregivers of children who are DHH come from socioeconomically disadvantaged backgrounds may face additional barriers such as limited healthcare literacy, lack of access to specialized services, and communication challenges arising from language mismatches with healthcare providers. Despite the HPCSA's recommendations, research on FCEI in South Africa is sparse, and there is limited understanding of how these services align with family-centered principles from the perspective of caregivers. This gap in the literature is particularly concerning given that caregiver experiences and perceptions are the key indicators of service quality and accessibility.

Existing studies on EHDI in South Africa have primarily focused on technical and structural aspects of service delivery, such as screening protocols and referral systems,[1] without adequately addressing the relational and participatory dimensions of care that are central to FCEI. Caregivers' voices, which are critical to understanding the impact of EHDI services, have largely been overlooked. Furthermore, systemic challenges such as fragmented service delivery, inadequate integration of cultural and linguistic considerations, and limited paternal involvement have not been sufficiently addressed in the research. These challenges highlight the need for an evaluative approach that examines not only the effectiveness of EHDI services but also the barriers that hinder their successful implementation.

Evaluating EHDI services through the lens of family-centeredness offers an opportunity to identify the key areas for improvement. Caregivers provide invaluable insights into the strengths and weaknesses of current practices, including the extent to which healthcare providers respect their cultural

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values, communicate effectively, and collaborate meaningfully with families. Understanding caregivers' perceptions also sheds light on systemic inequities that perpetuate disparities in access to and quality of care. For example, the use of English as the default language in EHDI services often alienates caregivers who speak African languages, limiting their ability to participate fully in the intervention process.[8,9] Similarly, the absence of fathers in many EHDI interactions reflects broader societal norms and constraints that must be addressed to ensure holistic family involvement.[1,11]

The current study seeks to fill these critical gaps by evaluating the family-centeredness of EHDI services in South Africa from the perspective of caregivers. Specifically, the study aims to: (1) assess the extent to which caregivers perceive EHDI services as family-centered; (2) explore the relationship between caregivers' socio-demographic factors and their perceptions of service quality; and (3) identify systemic, linguistic, and cultural challenges that impact the implementation of FCEI practices. By adopting a mixed-methods approach, this study provides a comprehensive evaluation of EHDI services and offers actionable recommendations for improving family-centered care within the South African context. By incorporating both qualitative and quantitative methods, this study provides a robust evaluation that captures not only caregiver experiences but also the broader systemic and policy-related barriers that influence the effectiveness of EHDI services. The findings will contribute to a growing body of literature on the importance of culturally and linguistically responsive EHDI practices in LMICs and will inform strategies for enhancing caregiver satisfaction and participation in the intervention process. This study 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".

METHODS

A mixed-methods convergent design was employed to evaluate the family-centeredness of EHDI services and to identify the key challenges experienced by caregivers in the South African context Narrative interviews and survey research were conducted for the qualitative and quantitative strands, respectively. The use of a mixed-methods approach was essential to ensure a comprehensive understanding of caregiver experiences, capturing both the depth of qualitative insights and the broader patterns identified through quantitative data analysis. By integrating these methods, the study was able to triangulate findings, enhancing validity and reliability.

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. Given the study's focus on systemic and cultural challenges, particular attention was paid to ensuring that participants felt safe sharing their experiences, especially regarding language barriers and perceived inadequacies in service delivery.

Participants

A nonprobability purposive sampling approach was used to recruit caregivers who met specific inclusion criteria relevant to the study's objectives. Different sample sizes were used for the qualitative and quantitative strands of the convergent design.

Inclusion criteria

Caregivers were eligible to participate in the study if they met the following criteria:

- They were the primary caregiver (i.e., biological parent, legal guardian, or primary family member responsible for the child's care)
- Their child had a confirmed diagnosis of mild to profound, bilateral, or unilateral hearing impairment as documented in medical or audiological records
- Their child was enrolled in an EI preschool center in Gauteng, South Africa, between 2010 and 2020
- They had participated in the EHDI process, meaning they had engaged with healthcare providers regarding their child's diagnosis, intervention, and ongoing care
- They were able to provide informed consent and participate in either the narrative interview, the survey, or both.

Exclusion criteria

Participants were excluded from the study if they met any of the following criteria:

- Caregivers whose children were diagnosed with additional disabilities (e.g., cognitive impairments, neurological disorders, or syndromic conditions) that could significantly influence communication and development, as this might introduce confounding variables beyond the study's focus on hearing impairment
- Caregivers who had minimal or no engagement with the EHDI process, such as those who had not received formal audiological diagnosis or intervention services
- Caregivers who were unable to complete the interview or

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survey due to linguistic or cognitive barriers that could not be accommodated within the study's research design
- Children who had only received intervention outside of South Africa, as healthcare system differences would make their experiences noncomparable to those within the South African context.

Sample characteristics

- Nine (n = 9) caregivers participated in the narrative interviews. Their sociodemographic profile is presented in Table 1
- Twenty-one (n = 21) caregivers participated in the survey research, including the nine caregivers from the narrative interviews. Of these, 16 caregivers completed the modified measurement of the processes of care-56 (MPOC-56) questionnaire (57% response rate), while 21 caregivers completed the demographic questionnaire (75% response rate). Their sociodemographic profiles are summarized in Table 2.

Qualitative strand (narrative interviews)

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

The content of the narrative interviews was structured around key themes related to FCEI. The interview guide included open-ended questions designed to explore caregivers' lived experiences, their involvement in the EHDI process, and challenges they encountered. Specific topics covered included:

- Caregivers' expectations of EHDI services before their child's diagnosis
- Experiences with healthcare providers and the extent to which they were involved in decision-making
- Barriers to accessing and participating in EHDI services, including systemic, linguistic, and financial challenges
- The role of fathers and other family members in the intervention process
- Recommendations caregivers had for improving the family-centeredness of EHDI services.

The full interview guide is reported below in the "Data Collection" section.

Quantitative strand (survey research)

Twenty-one (n = 21) participants, including the nine caregivers who participated in the narrative interviews, took part in the survey. The survey research focused on caregivers' perceptions of family-centered care within EHDI services, using the modified MPOC-56, a validated tool designed to assess family-centered practices.[13] The survey consisted of the following five domains:

1. Respectful and supportive care– assessing whether healthcare providers treat caregivers with dignity, listen to their concerns, and value their knowledge of their child
2. Enabling and partnership evaluating the extent to which caregivers feel actively involved in decision-making and supported in their role

Table 1: Caregiver's sociodemographic profile (narrative interviews)

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
	Colored (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
	Postmatric diploma	3
	Baccalaureate degree (s)	0
	Postgraduate degree (s)	1
Employment status	Employed	5
	Self-employed	2
	Student	0
	Unemployed	2
Number of children with hearing loss	One	7
	Two	2

Table 2: Caregiver's sociodemographic profile (survey)

Category	Sub-category	n (%)
Gender	Male	2 (9.5)
	Female	19 (90.5)
Age (years)	25–30	3 (14.3)
	31–36	8 (38.1)
	37–42	8 (38.1)
	43–48	2 (9.5)
Ethnicity	Black	10 (47.6)
	Colored (mixed race)	3 (14.3)
	Indian	1 (4.8)
	White	7 (33.3)
Marital status	Married	14 (66.7)
	Single	7 (33.3)
Highest qualification	Grade 11 or lower (std 9)	2 (9.5)
	Grade 12 (matric)	6 (28.6)
	Postmatric diploma	8 (38.1)
	Baccalaureate degree (s)	2 (9.5)
	Postgraduate degree (s)	3 (14.3)
Employment status	Employed	14 (66.7)
	Self-employed	4 (19.0)
	Student	1 (4.8)
	Unemployed	2 (9.5)

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3. Providing general information measuring caregivers' access to general information about hearing loss, intervention options, and future expectations
4. Providing specific information assessing whether caregivers receive individualized, child-specific information tailored to their needs
5. Coordinated and comprehensive care examining how well different aspects of EHDI services are integrated and whether caregivers receive seamless support from different professionals.

Each item was rated on a 7-point Likert scale ranging from 0 ("Never") to 7 ("To a very great extent").

The demographic questionnaire collected information on:

- Caregivers' age, gender, marital status, employment status, and education level
- Children's audiological profiles, including severity and type of hearing impairment
- Language spoken at home and whether caregivers received EHDI services in their home language.

The MPOC-56 and demographic questionnaire are reported in the "Survey Research" section below. To ensure rigor in statistical analysis, the difference in sample sizes across the study was accounted for during data analysis. All statistical tests were conducted using appropriate weighting methods to maintain accuracy and reliability in findings.[18] Thus, the sample size for all statistical analyses was 16. Participants' sociodemographic profile is summarized in Table 2.

Data collection

Data collection was conducted using the narrative interviews following a structured interview guide (below) and the modified MPOC-56, which measured caregivers' perceptions of family-centeredness across the five domains listed in the previous section. The interview guide included:

- 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?
- How satisfied were you with the services that you received?

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 second researcher conducted all the interviews and is proficient in all these South African languages, thus an interpreter was not needed. All interviews were audio-recorded, transcribed verbatim, and anonymized by allocating a participant number for participants and pseudonyms for the children. 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.

Survey research

The family-centeredness of pediatric habilitation services was measured using the modified MPOC-56; a 56-item, standardized tool that measures the family-centeredness of the behaviors of healthcare service providers (HCPs).[13,19,20] The modified MPOC-56 survey instrument was used to measure caregivers' perceptions of family-centeredness across five domains. In addition, sociodemographic data were analyzed to identify the patterns and challenges that may influence caregiver perceptions, such as language mismatches, employment status, and marital status.

Data analysis

Initially, the qualitative and quantitative data were analyzed independently before being compared, interpreted, and integrated to provide a comprehensive understanding of caregiver experiences with EHDI services. The analysis followed a triangulation approach, where findings from both methods were examined for convergence, divergence, and complementarity.[17] The integration of qualitative and quantitative data was crucial to ensuring a comprehensive understanding of caregiver experiences. By combining insights from both methods, the study was able to highlight patterns that may not have been evident through either approach alone [see Figure 1].

Data collection and data analysis were conducted simultaneously to ensure that participant recruitment and data collection were discontinued once data saturation was reached.[21]

Reflexive thematic analysis was used to analyze the narrative interviews, specifically to identify systemic and contextual barriers. Themes identified in the data were analyzed using the Braun and Clarke's guidelines.[22,23] A deductive-inductive approach was used, where themes were first identified based on existing literature and then refined to capture emergent insights from caregiver experiences. To prevent bias and ensure intersubjective validity, three researchers

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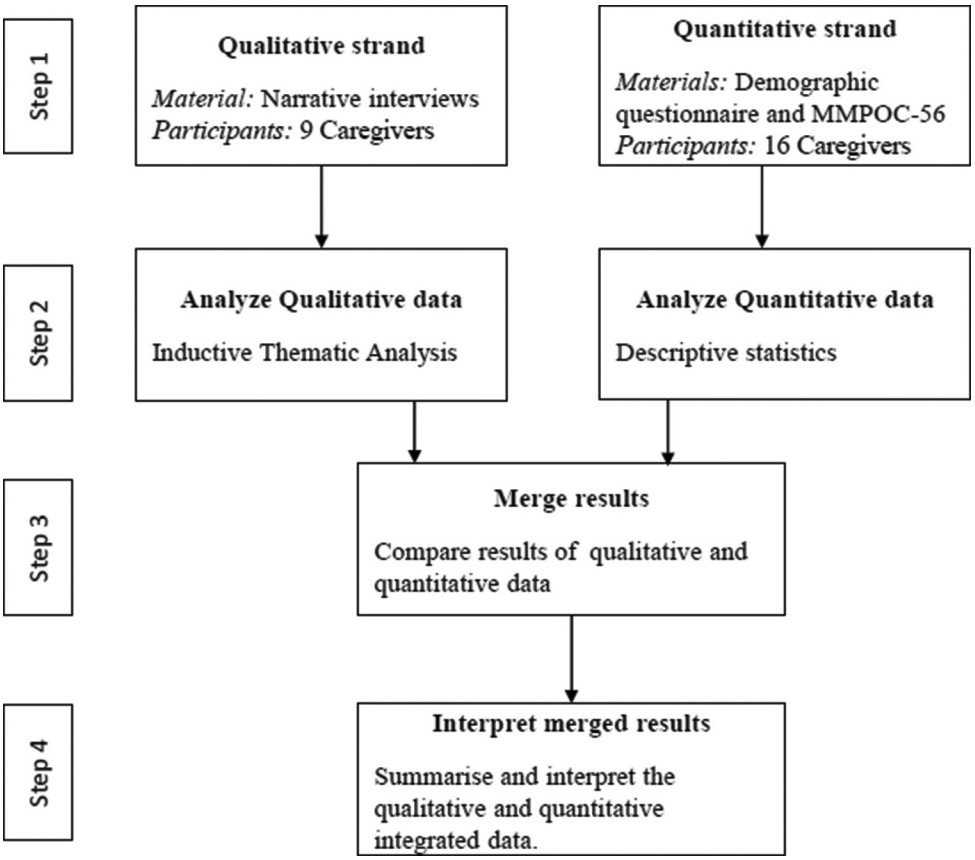


Figure 1: Illustration of the data analysis process

independently coded the data, and discrepancies were resolved through discussion.[24,25] Data were managed and organized using the qualitative analysis software (NVivo).

The survey data were analyzed using the descriptive and inferential statistical methods to assess caregiver perceptions of FCEI services. Descriptive statistics (means, standard deviations, and frequency distributions) were used to summarize responses for each domain of the modified MPOC-56. To examine the association between caregiver sociodemographic factors and perceptions of family-centeredness, the Kruskal–Wallis test was applied to determine the differences in MPOC-56 domain scores across categorical variables such as caregiver education level, employment status, and language spoken at home. In addition, Spearman's rank correlation coefficient was calculated to assess the relationship between the continuous variables (e.g. child's age and caregiver's age) and MPOC-56 scores. All statistical analyses were conducted using the STATA software. A significance threshold of $P < 0.05$ was used for all inferential tests.

As far as comparing, interpreting and discussing data were concerned; following separate analyses, the qualitative and quantitative findings were systematically compared to identify patterns, similarities, and contradictions. A thematic comparison matrix was then created to align qualitative themes with corresponding quantitative domain scores, facilitating an integrated interpretation of the data. If a convergence between the two datasets was observed, it strengthened the validity of findings. For instance, if both the survey results and interview responses indicated dissatisfaction with the respectful and supportive care domain, this was interpreted as a consistent and reliable finding. If divergence was observed (e. g., high MPOC-56 scores in a domain where qualitative findings suggested dissatisfaction), potential reasons for the discrepancy were explored in the discussion, such as social desirability bias in survey responses or variations in individual experiences. Findings were interpreted within the broader context of FCEI literature and South African healthcare challenges.

RESULTS

Nine (n = 9) caregivers participated in the narrative interviews and their sociodemographic profile is summarized in Table 1.

The demographic and audiological profile of the children whose caregivers participated in the narrative interviews is summarized in Table 3.

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Survey participants' sociodemographic profile is summarized in Table 2.

Table 4 reflects the subscale scores for all the five domains of the modified MPOC-56.

The respectful and supportive care domain received the lowest sub-scale score indicating significant dissatisfaction among participants. Caregivers frequently reported that healthcare providers dismissed their concerns, suggesting a lack of acknowledgement and respect for their insights. Several participants described instances where early signs of hearing loss such as their child not reacting to loud sounds or exhibiting delayed speech and language milestones were overlooked by healthcare professionals, resulting in delayed diagnoses. This finding highlights a critical gap in healthcare provider training and suggests an over-reliance on clinical assessments, often at the expense of incorporating caregiver observations into the diagnostic process. The following statement exemplifies this concern:

Table 3: Demographic and audiological profile of children who are deaf or hard of hearing

Child	Race	Gender	Home language	Degree of hearing loss	Age at diagnosis (months)	Age at amplification (months)	Age at EI initiation (months)	Amplification device (s)	Key circumstances leading to diagnosis
Thabo*	Black	Male	English and SASL	Severe	18	19	22	Bilateral cochlear implants	Preschool teacher noticed lack of response; prompted mother to assess hearing
Lerato*	Black	Female	Sesotho	Severe	24	26	24	Hearing aid and cochlear implant	Mother noticed delayed speech compared to peers during immunization visits; employer urged hearing evaluation
Karabo*	Black	Male	Setswana	Moderately severe	4	5	4	Hearing aid and cochlear implant	Sister diagnosed with hearing loss; mother insisted on evaluation
Dimpho*	Black	Female	Setswana and SASL	Profound	20	24	27	Hearing aid and cochlear implant	Family noticed lack of reaction to thunder; initial concerns dismissed by nurses, eventually assessed at Hospital W
Sizwe*	Black	Male	Sepedi	Severe	18	18	18	Bilateral hearing aids	Pediatrician referred to OT for delayed milestones; OT referred to speech therapist, who then referred to audiologist
Andrew*	Indian	Male	English	Severe	27	27	27	Bilateral hearing aids	Teacher noticed difficulty following instructions; mother's concerns initially dismissed by pediatrician
Paige*	Indian	Female	English	Severe	6	6	6	Bilateral hearing aids	Brother diagnosed with hearing loss; parents insisted on assessment
Josh*	White	Male	Portuguese	Moderately severe	22	23	24	Bilateral cochlear implants	Mother raised concerns about inconsistent hearing; doctors dismissed concerns until one contacted an audiologist
Boikanyo*	Black	Female	Setswana	Profound	14	20	24	Hearing aid and cochlear implant	Mother concerned about the lack of speech and reaction to noise compared to twin sister; took her to an audiologist
Zack*	White	Male	Afrikaans	Profound	24	26	26	Bilateral cochlear implants	Mother suspected deafness due to lack of speech at 12 months; delayed appointment and acceptance of diagnosis
Mandla*	Black	Male	Sepedi	Moderately severe	30	36	36	Bilateral cochlear implants	Normal hearing screening at birth; later "not listening," biting, speech delay; referred to ENT and speech therapy, then audiologist

*$P < 0.05$. SASL: South African Sign Language, ENT: Ear, nose, and throat, OT: Occupational therapist, EI: Early intervention

Table 4: Modified measures of processes of care-56 domain scores

Domain	*n*	Mean	SD	Minimum	Median	Maximum
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, SD: Standard deviation

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"She [pediatrician] 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. The use of English as the primary language for EHDI services was reported as a significant barrier by six participants, whose home languages were African languages. 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)

Although caregivers appreciated the general information provided, some reported a lack of follow-up support or clear guidance on navigating the healthcare system, particularly regarding educational options and financial assistance.

The *coordinated and comprehensive care* domain received the second-highest sub-scale score. Participants were satisfied with the manner in which the care they received was coordinated 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)

While caregivers appreciated the comprehensiveness of the services provided, many described challenges related to fragmented care. For example, one caregiver stated, We were sent from one department to another without clear communication, which caused delays in accessing services' (CG1). Some participants stated: 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). Caregivers appreciated the specific information provided, such as genetic counseling and information on cochlear implants. However, the absence of fathers in counseling sessions emerged as a notable challenge. One participant noted, Her father was reluctant about having the cochlear implant fitted because he wasn't part of the counseling sessions (CG2). 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 the part of the second aim of the study, no statistically significant differences were identified between personal, family, and sociodemographic factors and caregivers' perceptions of the family-centeredness of EHDI services across all the domains. However, several *P* values approached statistical significance, indicating potential trends that may be clinically meaningful despite not reaching the conventional threshold of $P \leq 0.05$. Specifically, the *P* values for 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 suggest that these variables may play a role in shaping caregiver perceptions, though further research with a larger sample size is required

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to confirm these patterns. Although these findings were not statistically significant, they suggest systemic influences on caregiver experiences that align with qualitative reports. For instance, the near significant association between language used for EI and enabling partnership ($P = 0.12$) may reflect the linguistic barriers described by caregivers in narrative interviews, where many reported difficulties understanding service providers who did not speak their home language. Similarly, the trends observed in employment status and information access ($P = 0.09$–0.10) may highlight disparities in the ability to navigate EHDI services, as employed caregivers may have less time or fewer resources to engage with detailed informational counseling.

Given that P values nearing significance (e.g. language used for EI and specific information, $P = 0.06$) suggest potential relationships, future studies with larger sample sizes and more diverse populations should explore these associations further. Increasing the statistical power by recruiting a more representative caregiver sample may reveal underlying trends that were not detectable in the current study. In addition, future research could employ multivariate regression models to control for confounding variables and further investigate how sociodemographic factors influence caregiver perceptions of family-centered EHDI services.

DISCUSSION

This study provides a comprehensive evaluation of the family-centeredness of EHDI services in South Africa by examining caregiver perceptions and identifying systemic challenges. The findings demonstrate both strengths and critical areas for improvement in EHDI practices, particularly concerning linguistic and cultural responsiveness, caregiver engagement, and service coordination.

Current evidence supports the implementation of FCEI, yet it application remains in the early stages globally,[19] including in South Africa. To the best of our knowledge, this is the first study to use the MPOC-56 to evaluate the family-centeredness of EHDI services in South Africa. This study responds to the need for healthcare evaluations that consider not only outcomes but also service quality from the end-user's perspectives.[20] Findings suggest that while South African EHDI services are incorporating FCEI principles, their implementation varies across the five domains. The recognition that children and families should be supported within their cultural and social contexts aligns with the African philosophy of ubuntu, which values family and community over individualism.[26,27] However, significant gaps remain, particularly in respectful and supportive care and enabling and partnership, where systemic, linguistic, and cultural barriers hinder caregiver-provider collaboration and reduce the overall quality of care. These challenges, while not unique to South Africa, are worsened by socio-economic and linguistic diversity, emphasizing the need for tailored, context-specific solutions.

Across the five MPOC-56 domains, sub-scale scores ranged between 5.5 and 6.3, aligning with previous studies.[12,19,20] Narrative interviews provided further insights, particularly regarding the lack of respect for caregiver concerns. The respectful and supportive care domain received the lowest ratings, with many caregivers reporting dismissal of their early concerns about their child's hearing, leading to delayed diagnosis and intervention. One caregiver noted that their pediatrician dismissed concerns about speech delays, resulting in a diagnosis only after significant developmental setbacks. This highlights the need for improved training among HCPs to recognize and respect caregiver observations, as these often provide the first indicators of hearing loss. 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 can be expected.[30] Thus, current findings on 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. These findings highlight the need for improved training among HCPs to recognize and respect caregiver observations, which are often the first indicators of hearing loss.

Language barriers and caregiver engagement

The study found that language mismatches were a significant barrier to caregiver participation. Caregivers who spoke African languages such as IsiZulu and Setswana reported difficulty engaging with EHDI services conducted solely in English. One caregiver suggested that hospitals should have more multilingual therapists to improve communication and accessibility 'Maybe they should try to have 3–4 black therapists at each hospital so they can speak the same language as the patient' (CG3). Providing services in a language caregivers understand is critical for treatment adherence, informed decision-making, and positive health outcomes.[6,8,31] These findings highlight the need for culturally and linguistically congruent care, particularly in a multilingual country like South Africa. Such mismatches hinder caregivers' ability to engage fully

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with EHDI services and compromise their understanding of intervention processes, which can lead to suboptimal outcomes.

These findings highlight three critical implications: (1) recognizing caregivers as partners where HCPs must actively involve caregivers in decision-making and value their insights;[11,32,33] (2) *prioritizing early identification* where it is recognized that until universal NHS (UNHS) is widely available, HCPs must act on caregiver concerns to avoid delays in diagnosis;[29,34] and (3) *ensuring language accessibility* where EHDI services are provided in languages understood by caregivers and families, especially in a communication-based discipline.[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.[36-38]

EHDI programs emphasize that families should receive comprehensive information to make informed decisions.[39] Findings related to providing general information were encouraging, but gaps were noted in the follow-up support. Many caregivers expressed uncertainty about educational and financial decisions, highlighting the need for ongoing informational counseling beyond initial diagnosis. One caregiver noted that while genetic counseling was helpful, they felt unprepared for the long-term challenges of raising a child with hearing loss. These results suggest that EHDI services should adopt a more holistic, family-centered approach, ensuring caregivers receive continuous guidance throughout their child's development.[40-42]

Paternal involvement in early hearing detection and intervention services

The study also found a lack of informational counseling for fathers, mirroring previous findings on limited paternal participation in EI services.[43] Work commitments and traditional gender roles were identified as key barriers, with one caregiver reporting that their partner's reluctance to approve a cochlear implant was due to his absence from counseling sessions. Given that paternal involvement is linked to better language development, psychosocial well-being, and reduced behavioral challenges, strategies to engage fathers more actively – such as flexible scheduling, targeted information resources, and culturally sensitive interventions – are needed.[43,44]

Fragmentation in EHDI services

Ideally, EHDI services should be delivered through a coordinated, multidisciplinary team that ensures seamless care from screening to intervention.[45] A lack of cohesion has been shown to hamper effective implementation of EHDI services.[46,47] Findings suggest that South African EHDI services remain highly fragmented, reflecting broader healthcare inefficiencies.[48] One caregiver described how uncoordinated referrals resulted in multiple missed workdays, further burdening families. Addressing these issues requires a centralized, interdisciplinary model that prioritizes collaboration among HCPs.[29,49]

Sociodemographic influences on caregiver perceptions

Although no statistically significant associations were found between caregiver socio-demographic factors and perceptions of family-centeredness, trends suggest that language, employment status, and marital status may influence caregiver experiences. The *P* value for language used during EI and enabling partnership ($P = 0.12$) suggests that linguistic barriers may impact caregiver perceptions, even if statistical significance is not reached. These findings align with prior research showing that higher socio-economic status is sometimes linked to higher expectations from HCPs.[20] Given the diverse socio-economic and linguistic backgrounds of South African caregivers, future research should explore these relationships with larger, more representative samples.

These findings highlight the need for systemic reforms in EHDI practices to address linguistic mismatches, fragmented service delivery, and limited caregiver engagement. Implementing culturally and linguistically responsive care models, fostering interdisciplinary collaboration, and actively involving fathers are essential steps toward enhancing family-centeredness in South Africa's EHDI services.

This study has several limitations that should be considered when interpreting the findings. First, the limited number of participants, particularly in the quantitative strand, may have reduced statistical power. Near-significant *P* values suggest that a larger sample size could reveal stronger associations between caregiver characteristics and perceptions of family-centeredness. Future studies should recruit more diverse and representative samples to validate these findings. Second, all participants were recruited from EI preschools in Gauteng, introducing geographic constraints that limit the generalizability of the results to other provinces, particularly rural and under-resourced areas where access to EHDI services may differ significantly. Third, reliance on self-reported data is a limitation as both the survey and narrative interviews relied on caregiver recall, which may introduce recall bias. Some participants may have unintentionally underreported or overreported their experiences based on subjective

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interpretation rather than objective events. Lastly, this study focused solely on caregiver perceptions and did not include healthcare provider or policymaker viewpoints, thus excluding additional stakeholder perspectives. Including these perspectives in future research could provide a more comprehensive evaluation of family-centered EHDI services. Despite these limitations, the study provides valuable insights into the strengths and challenges of EHDI services in South Africa and lays the groundwork for future improvements in policy and practice.

CONCLUSION

This study evaluated the family-centeredness of EHDI services in South Africa, focusing on caregiver perceptions and the systemic, cultural, and linguistic challenges that affect service delivery. Findings reveal that while EHDI services in South Africa are increasingly adopting family-centered principles, significant gaps that compromise the overall effectiveness of family-centered care remain in areas such as respectful and supportive care, caregiver-provider partnerships, linguistic congruence, and service coordination. The lack of paternal involvement in EHDI processes and the absence of culturally responsive practices were also found. These challenges, compounded by the socio-economic and linguistic diversity of the South African context, highlight the need for systemic reforms and targeted interventions to improve the quality and accessibility of EHDI services. To address these challenges and to enhance the family-centeredness of EHDI services in South Africa, the following actionable recommendations are proposed: (1) improve training for healthcare providers where family-centered care principles, cultural competence, shared decision-making, and active listening skills are incorporated into healthcare provider training programs; (2) enhance linguistic and cultural responsiveness and integrate multilingual services where multilingual healthcare providers who can communicate effectively with caregivers in their home languages are recruited and trained; and where culturally appropriate communication tools, such as translated materials and visual aids are developed to support caregivers' understanding of the intervention process; (3) foster interdisciplinary collaboration and develop coordinated care models where centralized and interdisciplinary models of care are implemented to improve service coordination and reduce the burden on caregivers by minimizing service fragmentation and improving continuity of care-this includes streamlining referrals, consolidating appointments, and fostering collaboration among audiologists, speech therapists, educators, and other stakeholders; (4) promote paternal involvement where targeted interventions are designed to engage fathers, such as flexible appointment schedules, informational sessions tailored for fathers, and culturally sensitive messaging about the importance of paternal involvement; (5) expand access to rural and underserved areas through leveraging telehealth and mobile services where EHDI services are extended to rural and under-resourced areas through mobile clinics, telehealth solutions, and community-based initiatives-these efforts should address structural barriers, such as transportation and healthcare infrastructure, that limit access to care; (6) integrate ongoing informational counseling where continuous informational counseling that addresses caregivers' evolving needs (including guidance on educational options, financial assistance, and emotional support) throughout their child's developmental journey is provided; and (7) conduct further research where future studies adopting a multi-stakeholder approach, incorporating the perspectives of caregivers, healthcare providers, policymakers, and children themselves (where age-appropriate) are conducted.

By addressing these areas, South Africa's EHDI services can become more inclusive, responsive, and effective in meeting the needs of children who are DHH and their families.

Ethics approval and consent to participate

The current study adhered to the Helsinki Declaration of 1975, as revised in 2013. 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 EI preschool centers which cater for children who are DHH in Gauteng, South Africa, allowing the researchers access to the preschool records 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 before data collection.

Availability of data and material

The data sets used and/or analyzed during the current study are available from the corresponding author on a reasonable request.

Authors' contributions

NPM contributed to conceptualization, methodology, investigation, original draft preparation, reviewing and editing. KKS contributed to conceptualization, methodology,

supervision, original draft preparation, reviewing and editing. All authors read and approved the final manuscript.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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