Identifying Barriers to Follow-Up Compliance in Newborn Hearing Screening Program of AIISH

RUCHITHA P.

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ALL INDIA INSTITUTE OF SPEECH AND HEARING,

MANASAGANGOTHRI, MYSURU -570006

CERTIFICATE

This is to certify that this dissertation entitled **"Identifying Barriers to Follow-Up Compliance in Newborn Hearing Screening Program of AIISH"** is a bonafide work submitted as part of fulfilment of the degree of Master of Science Audiology of the student with Registration Number **P01IT23S023024.** This has been carried out under the guidance of a faculty of this institute and has not been submitted earlier to any other university for the award of any other Diploma or Degree.

M. Pushpavathi

Mysuru
8th June, 2026

Dr. M. Pushpavathi
Director
All India Institute of Speech and Hearing
Manasagangothri, Mysuru-570 006

CERTIFICATE

This is to certify that this dissertation entitled **"Identifying Barriers to Follow-Up Compliance in Newborn Hearing Screening Program of AIISH"** has been prepared under my supervision and guidance. It is also being certified that this dissertation has not been submitted earlier to any other university for the award of any other Diploma or Degree.

Mysuru
June, 2026

Dr. Sandeep M.
Guide
All India Institute of Speech and Hearing
Manasagangothri
Mysuru-570 006

DECLARATION

This is to certify that this dissertation entitled **"Identifying Barriers to Follow-Up Compliance in Newborn Hearing Screening Program of AIISH"** is the result of my own study under the guidance of Dr. Sandeep M., Professor of Audiology, All India Institute of Speech and Hearing, Mysuru and has not been submitted earlier to any other university for the award of any other Diploma or Degree.

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ABSTRACT

Newborn Hearing Screening plays a critical role in the early identification of hearing loss, enabling timely intervention to support speech, language, cognitive, and social development. However, the effectiveness of newborn hearing screening programmes depends on successful follow-up after referral, and loss to follow-up remains a major challenge in many screening programmes. This study aimed to identify barriers to follow-up compliance among infants referred through the Newborn Hearing Screening programme at the All India Institute of Speech and Hearing (AIISH), Mysuru, and to examine whether demographic, service-related, and clinical factors were associated with follow-up attendance.

A cross-sectional questionnaire based survey was conducted among a cohort of 595 infants referred following newborn hearing screening. Structured telephone interviews were completed with 202 parents or primary caregivers when the infants were between 5 and 15 months of age (mean age = 8.02 months, SD = 3.24). Information regarding demographic characteristics, parental awareness of hearing loss, perceived barriers to follow-up, and attendance status was collected. Programme records were reviewed to obtain data on gender, socioeconomic status, hospital type, locality, and presence of high risk indicators. Descriptive statistics and Chi-square tests of independence were used for analysis.

Of the referred infants, 202 families did not attend the recommended diagnostic follow-up. Analysis of questionnaire responses from this cohort indicated that the most commonly reported reason for non-attendance was the parental perception that their infant responded normally to sounds (96.0%). This was followed by distance and travel-related difficulties, which were reported by 40.6% of respondents. Other barriers, including lack of conviction regarding the need for testing, time and work constraints, waiting for the child to grow older, health-related concerns, and financial difficulties, were reported less frequently. Upon

analysing the 595 participants' data for factors associated with follow-up compliance, no significant association of follow-up compliance was found with either gender, income category, hospital type, locality, or HRR status.

Follow-up non-compliance was influenced primarily by parental perceptions rather than demographic, service-related, or clinical risk factors. The belief that the infant was hearing normally emerged as the predominant barrier to attendance, highlighting a gap between general awareness of hearing loss and perceived personal risk. The findings underscore the need for strengthened parent-centred counselling, clearer communication of screening results, improved tracking and follow-up systems, and strategies to reduce barriers to accessing diagnostic services. Such measures may improve follow-up compliance and enhance the effectiveness of newborn hearing screening programmes.

Key Words: *Universal Newborn Hearing Screening (UNHS); Follow-up Compliance; Hearing Loss; Parental Awareness; Barriers to Follow-up*

CHAPTER 1
INTRODUCTION

Hearing loss is one of the most common congenital conditions with the prevalence of approximately 1 to 3 per 1,000 live births worldwide (Morton & Nance, 2006; WHO, 2021). Untreated childhood hearing loss is also recognized as a significant contributor to disability-adjusted life years globally, emphasizing its importance as a major public health concern (Wilson et al., 2017). If congenital hearing loss remains undetected and unmanaged during infancy, it can lead to substantial delays in speech, language, cognitive development, literacy and academic achievement, ultimately affecting psychosocial well-being, social participation and future employment (Yoshinaga-Itano 1999; Meinzen-Derr et al., 2011)

Early auditory stimulation plays a critical role in the maturation of the central auditory nervous system and development of speech and language skills. The first few years of life represents a sensitive period of neural plasticity during which the auditory cortex is highly responsive to acoustic stimulation. Insufficient auditory input during this period disrupts normal auditory pathway development and cortical organization, resulting in long term deficit in speech perception, phonological processing, language acquisition, and cognition (Dobie & Van Hemel, 2004; Lieu et al., 2020). Beyond communication deficits, children with hearing impairment often experience psychosocial challenges including reduce classroom participation, social isolation, and emotional difficulties (Simkiss, 2013). These consequences highlight the critical importance of early identification and timely intervention.

Early hearing detection and intervention (EHDI) programs are intentionally recognised as the most effective strategy for minimizing the developmental impact of congenital hearing loss. The joint committee on infant hearing (JCIH, 2019) recommends the “1-3-6” benchmark, which includes hearing screening by one month of age, confirmation of diagnosis by 3 months,

and initiation of intervention by 6 months. More recently, “1-2-3” timeline has been advocated to maximize the benefits of early neural plasticity (Wilson et al.,2017). Research consistently demonstrates that children identified and provided intervention before 6 months of age achieve significantly better outcomes in language, literacy, and social functioning compared to those identified later (Yoshinaga-Itano, 2003; Ching et al., 2017).

Universal newborn hearing screening (UNHS) forms the foundation of EHDI programs by enabling the identification of hearing loss shortly after birth, before communication delays become apparent. UNHS is a systematic Public Health initiative design to screen all newborns using objective and non-invasive method such as otoacoustic emissions (OAEs) and automated auditory brain stem response (AABRs). Since, it is introduction in developed countries during the late 1990, UNHS program have demonstrated considerable success, with screening coverage exceeding 90% in country such as the United States, the United Kingdom, Germany, and Australia. Consequently, the average age of hearing loss diagnosis in these countries has significantly reduce to between 3 and 6 months (Neumann et al., 2006; Deng et al., 2020).

Despite these advancements, follow up compliance remains a major challenge worldwide. All the most newborns undergo initial screening, a significant proportion of infants referred for further testing fail to complete Diagnostic evaluation with in the recommended timeline op (Shulman et al., 2012; Deng et al., 2020). Factors contributing to loss to follow up include poor parental awareness, inadequate counselling, socio economic difficulties, transportation barriers, and poor coordination within healthcare systems (Elpers et al., 2016). Since early diagnosis depends not only on screening but also on timely confirmatory evaluation insurance effective follow-up compliance is essential for the success of any UNHS program.

In India, the burden of congenital hearing loss is particularly significant due to the countries high birth rate, with more than 27 million live births annually (UNICEF, n.d.). Prevalence estimates ranging from 1.59 to 8.8 per thousand live Births indicate that tens of thousands of newborns are affected each year (Verma et al., 2022). Although newborn hearing screening initiative were introduced in institution such as the All India Institute of speech and hearing (AIISH), Mysuru, and the postgraduate institute of medical education and research (PGIMER), Chandigarh, implementation remains limited largely to tertiary care centres (Nagapoornima et al., 2007)the Government of India later incorporated Newborn Hearing Screening Under The Rashtriya Bal Swasthya Karyakram (RBSK) as part of the national health mission (Ministry of Health and Family Welfare, 2016). However National screening coverage continues to remain below 1%, and the average age of hearing loss diagnosis in India is often beyond 3 years, considerably later than international recommendations (Ramkumar, 2017; Ravi & Sur, 2020).

Several Indian studies have highlighted poor follow-up compliance as one of the major barriers limiting the effectiveness of newborn hearing screening programs. Sinha et al., (2019) reported that only 35.4% of infants referred after initial screening return for confirmatory testing in a tertiary care setting in Northen India. Similarly, Sharma et al., (2015) reported follow-up compliance of 73% in a rural based screening program, which still falls short of the near-complete compliance expected for effective UNHS implementation in screening practices, loss to follow-up continues to compromise early identification and intervention.

The AIISH, Mysore, operates one of the largest structure newborn hearing screening programs in India under the POCD program. The program screens approximately 60,000 newborns annually through affiliated hospitals and outreach centres using the two-stage protocol involving OAEs and AABRs (Pazhayapisharath et al., 2024). Despite systematic

follow-up efforts including counselling, reminder phone calls, SMS notification, and coordination with healthcare professional, follow-up compliance at AIISH remains approximately 55%, indicating that multiple barriers continue to affect parental returns for diagnostic evaluation.

Existing literature suggest that poor follow-up compliance is influenced by several interrelated factors. Parent-related barriers include Poor awareness regarding hearing loss, denial of screening results, misconceptions about hearing impairment, and cultural stigma (Harrison et al., 2009; Pazhayapisharath & Maruthy, 2022). Socio economic challenges such as poverty, low literacy, and competing family priority further affect hearing help-seeking behavior (Varghese & Sur, 2020). Accessibility issues including long travel distance, lack of transportation, and shortage of audiology professionals also contribute significantly (Manchaiah et al., 2010). In addition, Healthcare system limitations such as in adequate counselling, weak referral pathways, poor record maintenance, and insufficient tracking mechanism reduce follow-up effectiveness (Merugumala et al., 2017). Pazhayapisharath and Maruthy (2022) summarized these determinants within the “3 As” framework: Awareness, Accessibility, and Affordability.

Given the substantial Burden of childhood hearing loss and the persistent problem of loss follow-up, understanding the factors influencing follow-up compliance is essential for strengthening newborn hearing screening programs in India. Although several studies have examined barriers to follow-up, these findings may not be universally applicable due to variations in healthcare access, social economic condition cultural beliefs, and regional health care infrastructure. Therefore, the presence study aims to identify the factors affecting follow-up compliance in newborn hearing screening programs, with particular emphasis on parent-related factors, social economic barriers, accessibility issues, and Healthcare system

challenges. Understanding these factors contribute to word developing effective Strategies for improving follow-up compliance, facilitating early diagnosis, and ensuring timely intervention of children with hearing loss.

1.1 Need for the Study

AIISH regularly conducts newborn hearing screening across affiliated hospitals, following the structure two-stage protocol involving OAEs is and AABRs. Separate screening pathways are implemented for infants with and without high-risk indicators, ensuring early detection and referral. Despite this systematic approach, follow-up compliance remains a critical challenge. Over the last two years, even with repeated reminders via SMS, follow-up calls and communication with pediatricians, the average follow-up rate has reached only about 55%.

Poor compliance with follow-up testing undermines the effectiveness of newborn hearing screening program. Multiple inter related barriers may contribute to this gap. Parental factor such as lack of awareness, misconceptions about speech and language development, stigma, and denial of screening results influence help-seeking behavior socio-economic constraints including poverty, low literacy, and competing priorities further limit hearing help seeking. Accessibility challenges related to distance, inadequate transport, and the difficulty of travelling with infants discourage families from returning for diagnostic testing. Affordability concern persists despite free screening, as indirect expenses (travel, accommodation, & wage loss) and costs of rehabilitation pose additional burdens. Finally, Healthcare system limitations such as the shortage of audiologists, weak referral pathways and poor tracking mechanism can also contribute to loss to follow-up.

Without addressing these barriers, a substantial number of infants with hearing loss may remain undiagnosed during the critical period for speech and language development. Therefore,

systematically identifying the factors contributing to poor follow-up compliance is essential for ensuring timely diagnosis and early intervention.

The present study aim to address this gap by using a purpose-developed questionnaire to investigate the barriers to follow-up in AIISH's NHS program. The findings are expected to provide actionable evidence to strengthen the newborn screening model, improve follow-up rates and reduce the burden of late-identified hearing loss. Ultimately, this research has the potential to bridge the gap between policy and practice, align outcomes with Global bench marks (JCIH,2019), and contribute to better developmental and outcomes and long-term economic savings for the Healthcare system.

1.2 Aim of the Study

To systematically identify the barriers to follow-up compliance in the newborn hearing screening program of AIISH and to delineate Strategies for improving adherence and program outcomes.

1.3 Objectives of the Study

1. To identify and analyze the common barriers to follow-up compliance among a cohort of 202 families who did not adhere to the recommended follow-up.
2. To identify the predictors of poor follow-up compliance, if any
3. To assess the association of follow-up compliance with the presence of High-risk indicators.

CHAPTER 2

REVIEW OF LITERATURE

Hearing is fundamental to the development of speech, language, communication, and social skills during early childhood. Congenital hearing loss is one of the most common sensory impairments present at birth and, if left unidentified, can adversely affect a child's linguistic, cognitive, educational, and psychosocial development. Universal Newborn Hearing Screening (UNHS) has been widely recommended as an effective strategy for the early detection of hearing loss, enabling timely diagnosis and intervention during critical periods of auditory and language development. However, the success of newborn hearing screening programs depends not only on the initial screening but also on the timely completion of diagnostic follow-up among infants who receive a referral result. Typically, in most screening programs, loss to follow-up remains a significant challenge worldwide, and one can expect more so in low- and middle-income countries such as India. This chapter reviews the literature related to childhood hearing loss, newborn hearing screening programs, follow-up compliance, barriers to follow-up attendance, and factors influencing parental decision-making following referral.

2.1 Prevalence and Impact of Hearing Loss in Children

Hearing loss is among the most prevalent sensory disabilities worldwide. One of the most common sensory disabilities in the world is hearing loss. The World Health Organization (WHO, 2021) estimate that there are about 430 million people in the world with disabling hearing loss, and could be as many as 700 million by 2050. The majority of people affected more than 80% are in low- and middle-income countries and across all age groups (WHO, 2021). In children, the burden is particularly significant, with 34 million children below 14 years accounting for approximately 7% of the total global population with hearing loss (WHO, 2021).

Congenital and prelingual hearing loss is a major contributor to paediatric hearing disability. The global prevalence of permanent congenital hearing loss is 1.33 per 1,000 live births (Morton & Nance, 2006), though this varies across regions. The Southeast Asian region, including India, bears a disproportionately higher burden (WHO, 2018), with prevalence ranging between 1.59 and 8.8 per 1,000 newborns in the general newborn population and 7 to 49.18 per 1,000 among high-risk newborns (Verma et al., 2022). Rawat et al. (2023) corroborated these findings, reporting incidence rates of 5.3 per 1,000 for well newborns and 18.3 per 1,000 for high-risk newborns through a pilot UNHS program in North India. The presence of high-risk indicators further increases the likelihood significantly: Wroblewska-Seniuk et al. (2017) and Zamani et al. (2004) reported that prevalence is 10–20 times higher among infants with risk factors such as genetic causes, TORCH infections, hyperbilirubinemia, asphyxia, and ototoxic medications. Approximately 1 to 3 per 1,000 newborns and 2 to 4% of NICU admissions are affected by permanent hearing loss (Dedhia et al., 2018; Erenberg et al., 1999; Parving et al., 2003). By 18 years of age, the prevalence rises to as high as 18% (Wang et al., 2019), reflecting the cumulative impact of acquired hearing loss through childhood.

Congenital and pre-lingual hearing loss can significantly affect child's educational, and psychosocial development due to reduced auditory input during critical periods of development (Davis et al., 1986; Borg et al., 2007; Shojaei et al., 2016). Studies have shown that children with hearing loss experience delays in working memory, and executive functioning, with more pronounced difficulties observed in those with greater degrees of hearing loss (Beer et al., 2011; Borg et al., 2007; Pisoni et al., 2011). These developmental issues can then impact upon poorer educational achievement, reduced social participation, behavioral difficulties, and limited future employment opportunities (Dobie & Van Hemel, 2004; Idstad & Engdahl, 2019; Lieu et al., 2020; Wong et al., 2017). Furthermore, children with congenital or pre-lingual hearing loss often demonstrate poorer long-term outcomes than those with post-lingual hearing

loss, highlighting the importance of early identification and intervention (Rotteveel et al., 2008).

Untreated hearing loss also has a substantial socioeconomic impact. Global expenditure on direct health costs, lost productivity, and special educational needs is estimated at 750–790 billion US dollars annually, with 73% borne by low- and middle-income countries (WHO, 2018). India ranks second globally in economic costs related to hearing health, education, and employment (WHO, 2018), with annual government expenditure attributable to unaddressed hearing loss estimated at approximately 6,336,233 thousand US dollars (WHO, 2017). These figures highlight the need for proactive, population-level strategies for early identification and intervention.

2.2 Effects of Hearing Loss on Speech & Language Development in Children and its Consequences

The most direct consequence of congenital hearing loss is its impact on speech, language, and communication development. The critical period for auditory development spans the first few years of life, during which adequate auditory input is essential for establishing normal speech and language pathways. Congenital and prelingual hearing loss, by depriving the developing auditory system of the necessary input, leads to delayed language, speech, and literacy skills (Borg et al., 2007; Davis et al., 1986; Dobie & Van Hemel, 2004; Shojaei et al., 2016).

Davis et al. (1986) examined the effects of hearing loss on speech, language, academic performance, and personality in 40 children with congenital hearing loss, finding that communicative abilities were impaired, with higher degrees of loss associated with greater impairment. Borg et al. (2007) similarly found that language development was primarily

delayed in children with sensorineural hearing loss, with word production and phoneme discrimination showing the greatest delays, and the magnitude of delay increasing with the degree of hearing loss.

Beyond communication, children with hearing loss face heightened risk for poorer cognitive development (Beer et al., 2011; Pisoni et al., 2011). Pisoni et al. (2011) found below-average verbal memory and rehearsal speed in 112 cochlear implant recipients tracked over eight years. Beer et al. (2011) reported poorer inhibitory control and working memory in 45 cochlear implantees aged 5.5 to 18 years, deficits associated with lower language ability and sentence recognition in noise.

These difficulties further affect academic attainment, social participation, and long-term employment (Dobie & Van Hemel, 2004; Idstad & Engdahl, 2019; Lieu et al., 2020; Teasdale & Sorensen, 2007; Wong et al., 2017). Data from England show that 63% of children with hearing loss fail to meet expected educational benchmarks, compared to 31% of children without special educational needs (Simkiss, 2013). Idstad and Engdahl (2019) found that people with hearing loss were approximately half as likely to achieve higher education. Wong et al. (2017) reported significantly more behavioral problems in children with greater degrees of hearing loss, with social skills strongly linked to language and cognitive ability. Haukedal et al. (2020) similarly found that hearing loss affects quality of life particularly in school and social domains. Rotteveel et al. (2008), studying 67 implanted children, found that those with prelingual hearing loss performed significantly worse than those with postlingual loss even after three to four years of cochlear implant use. The evidence consistently demonstrates that congenital hearing loss, if unidentified and untreated, carries consequences that extend across the lifespan, affecting the child, family, and society at large.

2.3 Importance of Early Identification of Hearing Loss in Children

Given the wide-ranging consequences of congenital hearing loss described above, the importance of early identification cannot be overstated. Early identification enables timely intervention, which is recognized as the most critical factor in minimizing the negative impact of hearing loss on a child's development and overall quality of life (WHO, 2021). The rationale for early identification rests on the neurobiological principle of the critical period: the auditory cortex exhibits maximal plasticity during the first few months and early years of life, and auditory stimulation during this window is essential for the normal organization of the central auditory pathways (Shojaei et al., 2016).

The landmark study by Yoshinaga-Itano et al. (1998) provided unequivocal evidence for the benefits of early identification. They compared the receptive and expressive language abilities of 72 children whose hearing losses were identified by six months of age with 78 children identified after six months of age. All children received early intervention services within an average of two months after identification. Children identified by six months of age showed significantly better language scores than those identified later. Critically, this language advantage was consistent across all test ages, communication modes, degrees of hearing loss, and socioeconomic levels, and was also independent of gender, minority status, and the presence or absence of additional disabilities. Yoshinaga-Itano (1999) further confirmed that children identified and intervened within the first six months of life had language development quotients within the normal range, while those identified later faced developmental delays. Even children with associated neurological and cognitive challenges, when identified within six months, demonstrated higher language development quotients than those identified after six months.

Meinzen-Derr et al. (2011), in a retrospective study on language development in 328 children enrolled in the Ohio early intervention program, demonstrated significantly higher language quotients in those intervened within six months of life. Meinzen-Derr et al. (2020) further showed that out of 385 children with hearing loss enrolled in kindergarten, those intervened before six months of age had kindergarten readiness assessment scores comparable to children without hearing loss, whereas children intervened later had poor scores. These findings underscore the irreplaceable role of the six-month intervention milestone in determining developmental outcomes.

Sajjad et al. (2008) reported that the cost of providing intervention and support is considerably lower when hearing loss is identified early, reducing the need for more extensive and costly future services such as special education and remedial support. Constantinescu-Sharpe et al. (2017) surveyed parents of children with hearing loss who underwent intervention using the listening and spoken language method at a mean age of 0.84 years, and found that these children were comparable to typically developing peers in education and social interaction. Collectively, these findings underscore that the benefits of early identification are not confined to language development but span the entire developmental trajectory.

Research on childhood hearing impairment also informs healthcare professionals, educators, and policymakers about best practices for supporting children with hearing loss effectively (Babtain et al., 2023). A better understanding of the prevalence, causes, and regional variations of hearing loss is essential to guide evidence-based interventions and ensure that scarce resources are directed most effectively. Based on the compelling body of evidence reviewed above, the WHO (2021) formally recognized that timely identification of hearing loss is crucial and recommended that successful implementation of universal newborn hearing screening (UNHS) initiatives is a necessary precondition for it.

2.4 Universal Newborn Hearing Screening: Rationale, Objectives, and Cost-Effectiveness

UNHS emerged from the recognition that targeted screening based on risk factors alone was insufficient, as nearly 50% of infants with permanent hearing loss do not present with identifiable risk indicators at birth. Consequently, many affected infants remained undetected until significant delays in speech and language development became apparent. The limitations of risk-based screening and behavioral surveillance led to the adoption of a universal approach, in which all newborns are screened irrespective of risk status. The concept was formally endorsed by the Joint Committee on Infant Hearing (JCIH) in 1994 and later refined into the widely accepted 1-3-6 guideline, recommending screening by one month, diagnosis by three months, and intervention by six months of age. Since then, UNHS has been recognized internationally as the standard of care for early detection and management of childhood hearing loss.

2.4.1 Why 'Universal'? The Rationale for Universal Screening

Newborn hearing screening programs may follow two broad philosophies: targeted hearing screening (THS), which restricts screening to infants with identifiable risk factors, UNHS, which aims to screen all newborns regardless of risk status. The debate between these approaches has largely been resolved in favor of universality on both epidemiological and clinical grounds.

The primary argument for universal screening over targeted screening lies in the epidemiology of hearing loss itself. Approximately 50% of infants born with permanent hearing loss have no identifiable risk factors at birth (Ohl et al., 2009; Wroblewska-Seniuk et al., 2017). Targeted screening, by definition, would fail to identify this large proportion of affected infants. Over decades of clinical practice, it has been well established that clinical behavioral observation the traditional method of parental and clinician surveillance is incapable

of reliably identifying hearing loss in infants before six months of age (Thompson & Weber, 1974). In the absence of systematic physiological screening of all newborns, the average age of diagnosis in unscreened populations is 1–2 years for moderate to severe hearing loss, and the identification frequently occurs just before school entry in cases of mild to moderate hearing loss (Chary et al., 2012; Martínez-Pacheco et al., 2016).

Neumann et al. (2020), in their global NHS survey, reported that children who underwent NHS were diagnosed at an average age of 4.6 months, compared to 34.9 months in unscreened children a difference of over 30 months. This dramatic difference in the age of identification has profound implications for developmental outcomes, as reviewed in Section 2.2 and 2.3. With universal screening, the ownus of risk identification lies with the NBS programme rather than requiring the parents or clinicians to first suspect a problem, effectively shifting the locus of responsibility from reactive help-seeking to proactive system-level action.

Furthermore, evidence from high-income countries that have implemented UNHS demonstrates that the average coverage achieved through universal approaches exceeds 90% (Wilson et al., 2017). In the United States, the Early Hearing Detection and Intervention (EHDI) programmes achieved screening of 98% of babies born in 2017 (CDC, 2017). Countries with established UNHS programmes, including the United Kingdom, the USA, Australia, New Zealand, and several European nations, have reported average ages of identification of 4.2 months (USA) and 3.1 months (Germany), compared to pre-UNHS averages of 26 months in Britain, approximately 30 months in the USA, 35 months in New Zealand, 17.8 months in Germany, and 15.2 months in Iran (Aurelio & Tochetto, 2010; Dalzell et al., 2000; Yoshinaga-Itano, 2004). These data provide robust evidence that UNHS rather than targeted screening alone is the only approach capable of achieving the desired age of identification consistent with the JCIH benchmarks.

2.4.2 Objectives of UNHS

The primary objective of UNHS is to detect permanent hearing loss in all infants at the earliest possible age, enabling timely diagnosis and intervention within the critical developmental window. The Joint Committee on Infant Hearing (JCIH, 2019) has articulated evidence-based guidelines the 1-3-6 framework as the standard for paediatric hearing healthcare. According to these guidelines, all infants should undergo hearing screening using a physiological measure within one month of age; infants who do not pass the initial screening should receive comprehensive diagnostic audiological evaluation to confirm hearing status by three months of age; and appropriate intervention including fitting of hearing aids, cochlear implants, bone-anchored hearing aids, or other assistive devices, followed by therapeutic intervention should be initiated no later than six months of age (JCIH, 2019). For countries that have already achieved these milestones, the JCIH recommends an even more ambitious target of screening by one month, diagnosis by two months, and intervention by three months of age.

The JCIH recommends the use of objective physiological measures for newborn hearing screening. OAEs which reflect the integrity of outer hair cell function and AABRs which assess neural integrity from the cochlea through the brainstem are the two widely endorsed tools. OAEs are reported to have a sensitivity of 78.7% and specificity of 88.8%, while AABR demonstrates sensitivity of 91.7% and specificity of 92.1%, sometimes exceeding 95% (Ibrahim et al., 2022; Khaimook et al., 2019). Importantly, AABR is necessary for the detection of neural hearing loss, such as auditory neuropathy spectrum disorder, which OAEs alone would miss. Globally, OAEs are used in 57% of countries for NHS, AABR in 11%, and a two-step OAE-AABR protocol in 30% of countries (Neumann et al., 2020).

Beyond the primary objective of early detection, UNHS also aims to: ensure equitable access to hearing healthcare regardless of the presence or absence of risk factors; create a

surveillance infrastructure for tracking outcomes and refining programme protocols; strengthen the referral chain from screening to diagnosis to intervention; reduce the societal burden of hearing disability through timely rehabilitation; and generate population-level data to inform health policy and resource allocation.

2.4.3 Cost-Effectiveness of UNHS

The cost-effectiveness of UNHS has been examined in multiple studies, consistently demonstrating that the investment in early screening yields substantial returns in terms of reduced long-term costs of special education, rehabilitation, and reduced productivity loss. Sajjad et al. (2008) reported that early identification of hearing loss significantly reduces the need for more extensive and costly future services, such as special education and remedial support. Elango et al. (2015) further reported that children who receive early intervention are more likely to achieve better educational outcomes and long-term employment prospects, contributing positively to the economy.

Grosse and Ross (2006) compared the costs and benefits of universal versus targeted newborn hearing screening and concluded that UNHS is cost-effective, with costs per quality-adjusted life year gained being well within the accepted threshold for healthcare interventions. Studies from the United Kingdom, the Netherlands, Germany, and the United States have consistently demonstrated that UNHS generates cost savings by reducing expenditure on special education, communication rehabilitation, and social support for individuals who would otherwise be identified late (Mohr et al., 2000; Gaffney et al., 2010). In a systematic review, Keren et al. (2002) and subsequent analyses confirmed that UNHS programs are not only clinically beneficial but are also economically justified when lifetime costs and quality of life gains are accounted for.

In the Indian context, WHO (2017) estimated that India's expenditure due to unaddressed hearing loss in direct health costs and loss of productivity is approximately 6,336,233 thousand US dollars annually. This figure reflects the enormous economic burden of delayed identification and intervention. Given that India witnesses approximately 67,000 births every day (UNICEF, n.d.), and that the prevalence of congenital hearing loss ranges from 1.59 to 8.8 per 1,000 live births (Verma et al., 2022), an estimated 38,883 to 215,204 babies are born with hearing loss in India every year. The implementation of UNHS by enabling early identification and intervention has the potential to prevent a significant proportion of this economic burden, in addition to the immeasurable benefit of improving the quality of life of affected children and their families.

2.5 Best Time for Newborn Hearing Screening

The timing of hearing screening is a critical determinant of its effectiveness. Evidence from developmental neuroscience, clinical audiology, and outcomes research converges on a single key principle: the earlier the identification, the better the developmental outcomes. The JCIH (2019), building on decades of research, has articulated the 1-3-6 framework as the operational benchmark for peadiatric hearing healthcare.

Neumann et al. (2020) documented that in countries with established UNHS programs, the average age at which congenital hearing loss is identified in screened children is 4.6 months, while the average age at the start of intervention is 6.9 months figures that approach, though do not yet uniformly achieve, the JCIH benchmark. In the United States, the average age of identification is 4.2 months, and in Germany, 3.1 months (Harrison et al., 2003; Neumann et al., 2006). In stark contrast, children not exposed to NHS are diagnosed at an average age of 34.9 months and begin intervention at 35.2 months (Neumann et al., 2020) a delay of over two years that results in the loss of the most critical window for language development.

From a practical standpoint, the birth hospitalization provides a uniquely efficient opportunity for NHS, as it represents a time when essentially all newborns in institutional delivery settings are accessible to the healthcare system. The JCIH (2019) and the American Academy of Pediatrics both endorse in-hospital screening as the preferred model for achieving the one-month milestone. Screening at birth is facilitated by the maturity of OAE technology which can be reliably applied in the neonatal period and AABR equipment that is portable and suitable for bedside use. A two-step protocol involving OAE screening followed by AABR for those who do not pass the first screen is the most commonly recommended approach, as it minimizes refer rates while maintaining high sensitivity for all forms of permanent hearing loss.

In India, the timing of screening is complicated by the low proportion of institutional deliveries, the geographic dispersal of the population, and the limited availability of audiological infrastructure. However, the opportunity provided by the routine immunization schedule particularly the immunization visits at birth, six weeks, and subsequently offers a potential catch-point for at-birth or early post-discharge screening. The National Programme for Prevention and Control of Deafness (NPPCD) and the Rashtriya Bal Swasthya Karyakram (RBSK) have identified immunization visits as opportunities for hearing surveillance (Ramkumar, 2017). Sirur and Rangasayee (2011) conducted a time-series analysis showing that from 1989 to 2008, the average age of identification in Mumbai reduced by 9.59 months, though it had not yet reached the one-year mark let alone the three-month JCIH benchmark by 2008. The study by Pazhayapisharath and Maruthy (2024) found the mean age of suspicion of hearing loss to be 18.6 months, the mean age of diagnosis to be 25.0 months, and the mean age of intervention to be 30.6 months, consistent with earlier findings (Rout & Singh, 2010; Varshney, 2016), highlighting the substantial gap between current practice and best practice.

2.6 Newborn Hearing Screening Programs in India

India, the world's most populous country, records approximately 67,000 births per day, resulting in an estimated 38,000–215,000 infants born with congenital hearing loss annually (UNICEF, n.d.; Verma et al., 2022; Pazhayapisharath & Maruthy, 2023). The proportion of institutional deliveries has increased substantially from 38.7% in 2005–06 to 88.6% in 2019–21, creating a significant opportunity for hospital-based UNHS programmes (NFHS-5, 2021). However, despite this favourable healthcare infrastructure, hearing screening coverage remains extremely low, with less than 1% of Indian newborns undergoing screening (Neumann et al., 2020).

National initiatives such as the NPPCD and the RBSK have emphasized early identification and intervention for hearing loss; however, comprehensive nationwide UNHS coverage has not yet been achieved. A survey by Kumar and Mohapatra (2011) indicated that most newborn hearing screening programmes in India are conducted by speech and hearing institutes or medical colleges. Considerable variation exists in screening protocols across programmes, with differences in personnel involved, screening technologies used, and the number of screening stages employed (Nagapoornima et al., 2007; Paul, 2016; Rai & Thakur, 2013; Vignesh et al., 2015). Referral and follow-up rates also vary substantially across programmes (Ramkumar, 2017).

Some large-scale programmes have demonstrated successful implementation. The Child Care Center programme in Kochi screened more than 120,000 newborns through a hospital consortium model and reported follow-up rates exceeding 90% (Paul, 2016). The AIISH, Mysuru, is one of the more established institutional newborn hearing screening initiatives in India. The programme operates screening facilities across 11 hospitals in Mysuru, 3 newborn screening centres nationwide, and 16 primary healthcare centre outreach sites, with

an additional 14 hospitals across the country offering newborn screening services under the AIISH network (AIISH, n.d.). Screening is conducted using OAE and AABR protocols, achieving referral rates within internationally recommended thresholds (Vinod et al., 2023). These initiatives demonstrate the feasibility of large-scale newborn hearing screening in India while highlighting the need for greater standardisation and nationwide coverage.

2.6.1 Overview of NHS Programs in India: Protocols, Referral and Follow-up Rates

A survey of NHS practices in India by Kumar and Mohapatra (2011) revealed that approximately 38% of medical colleges have an NHS programme, and that most initiatives are based in speech and hearing institutes or medical colleges with an audiologist. The country lacks a uniform national protocol for NHS, with existing programmes differing widely in the tools used, the levels of screening, the professionals involved, and the referral and follow-up rates. Chandrasekar and Selvarajan (2021) documented similar heterogeneity in Tamil Nadu, where 67.1% of sites employ targeted screening, and the preferred tool is transient evoked otoacoustic emissions (TEOAE).

A comprehensive review of published NHS programmes in India (Pazhayapisharath & Maruthy, 2023; Ramkumar, 2017) reveals the following experience: In Western India, Vaid et al. (2009) reported outcomes from a hospital-based programme (2005–2007) that screened 2,621 babies using a two-step OAE protocol (screening within three days of birth and at one month). Referral rates were 19.2% after the first screen and 8.4% after the second screen. Follow-up rates for rescreening were 43%, with a diagnostic follow-up rate of 94%. ABR was used for diagnostics.

Several hospital-based newborn hearing screening programmes across India have demonstrated the feasibility of using OAE- and AABR-based screening protocols. Studies from

different regions reported referral rates ranging from approximately 0.5% to 6% after rescreening and diagnostic follow-up rates ranging from 69% to 100% (John et al., 2009; Nagapoornima et al., 2007; Rai & Thakur, 2013; Sharma et al., 2015). Among these, the centralized programme in Kerala, operating through a consortium of private hospitals, achieved particularly high follow-up rates, with 99% of infants completing rescreening and 94% undergoing diagnostic evaluation (Paul, 2011, 2016). These findings demonstrate that effective newborn hearing screening programmes can be implemented in India, although follow-up outcomes vary considerably across settings.

2.6.2 NHS Programs at AIISH and Their Outcomes

The AIISH, Mysuru, a premier institute under the Government of India and located in Karnataka, has established one of the most comprehensive NHS programmes in the country. AIISH provides hearing healthcare services free of cost to persons in the low-income group and at nominal costs for others. The NHS programme at AIISH currently caters to approximately 60,000 newborns annually, drawn from 30 outreach service centres across the country and 13 hospitals in Mysuru, Karnataka (Pazhayapisharath & Maruthy, 2023). The programme employs a combined OAE and AABR-based screening protocol and has achieved a referral rate of less than 2% a figure that reflects both the high specificity of the combined protocol and the quality of programme implementation (Vinod et al., 2023).

The introduction of AABR into the AIISH NHS protocol has been particularly significant. AABR has better sensitivity and specificity than OAE alone (Ibrahim et al., 2022; Khaimook et al., 2019), and its inclusion enables the detection of neural hearing loss including auditory neuropathy spectrum disorder which would be missed by an OAE-only protocol. Vinod et al. (2023) reported the outcomes of including AABR in the AIISH NHS programme

at the KSB ISHACON, demonstrating improved programme outcomes through reduced referrals with the combined approach.

The AIISH programme thus represents a model for NHS implementation in India: a well-established, high-volume, outreach-based programme with a scientifically validated protocol, a low referral rate, and a commitment to follow-up and diagnostic services. Karnataka hosts the largest number of speech and hearing institutes in India, and the concentration of these resources, combined with the AIISH programme, has contributed to higher rates of NHS coverage in the state compared to the national average (Pazhayapisharath & Maruthy, 2023). The AIISH NHS programme, along with the centralized programme in Kerala (Paul, 2016), can serve as replicable models for expanding NHS across the country in both the government and private sectors.

2.7 Follow-up Rates in Newborn Hearing Screening Programmes: Global and Indian Evidence

Follow-up is a critical component of newborn hearing screening programmes, as it ensures that infants who do not pass the initial screen receive timely diagnostic evaluation and intervention. Effective follow-up enables early identification and management of hearing loss, leading to improved speech, language, and communication outcomes (Yoshinaga-Itano et al., 1998; Ching et al., 2019). Countries with well-established screening programmes, such as the United Kingdom, have reported diagnostic follow-up rates exceeding 95%, contributing to earlier identification and intervention (Kennedy & McCann, 2004; Wood et al., 2015).

Despite high screening coverage in many countries, loss to follow-up remains a major challenge. Neumann et al. (2020) reported that 17.2% of referred infants worldwide were lost to follow-up. Common barriers include distance from referral centres, financial constraints, inadequate counselling, poor parental awareness regarding the significance of referral, and the

absence of effective tracking systems (Bush et al., 2014; Elpers et al., 2016; Neumann et al., 2020).

In India, follow-up rates vary enormously between programme. The best-performing programmes in India have demonstrated follow-up rates that are competitive with developed-country benchmarks. Paul (2016) reported a follow-up rate of 99% for rescreening and 94% for diagnostic ABR in the centralized Kerala programme among the highest reported anywhere in the world. John et al. (2009) from Southern India achieved 100% follow-up rates for both rescreening and diagnostics in a three-step protocol. However, these are exceptional programmes.

Most programmes in India report substantially lower follow-up rates: Augustine et al. (2014) found that only 28% of referred infants completed diagnostic follow-up within three months; Rai and Thakur (2013) from Northern India achieved 69% diagnostic follow-up; Sharma et al. (2015) from Western India reported 73% follow-up for diagnostics; and Vaid et al. (2009) reported 43% follow-up for rescreening. The wide variation in follow-up rates across programmes reflects differences in programme design, location (urban versus rural), availability of trained personnel, parental awareness, and accessibility of follow-up services.

Kanji (2022), studying NHS at primary healthcare clinics designated as National Health Insurance pilot sites in South Africa, highlighted that community-based NHS models when well-designed can achieve satisfactory follow-up rates even in resource-limited settings. This finding is particularly relevant for India, where community-based NHS through the RBSK represents a potential avenue for expanding coverage and improving follow-up.

2.8 Follow-Up Compliance in Newborn Hearing Screening

Successful newborn hearing screening depends not only on the completion of initial screening but also on timely attendance for diagnostic follow-up among infants who receive a referral result. However, loss to follow-up remains a significant challenge worldwide. Studies have identified several factors contributing to poor follow-up compliance, including geographical distance from referral centres, transportation difficulties, financial constraints, inadequate counselling, poor parental awareness regarding the significance of screening results, and the absence of effective tracking systems (Bush et al., 2014; Elpers et al., 2016; Neumann et al., 2020). In low- and middle-income countries, these barriers are often compounded by limited access to specialised audiological services and fragmented healthcare systems (Neumann et al., 2020; Ramkumar, 2017). Indian studies have similarly reported poor follow-up compliance due to logistical difficulties, lack of parental awareness, and inadequate follow-up mechanisms (Augustine et al., 2014; Rai & Thakur, 2013; Sharma et al., 2015).

Parental perceptions and beliefs have emerged as particularly important determinants of follow-up behaviour. Several studies have reported that parents often rely on their infant's apparent responses to environmental sounds and may conclude that hearing is normal despite a referral result (Bush et al., 2014; Elpers et al., 2016). Misunderstanding the purpose of newborn hearing screening and the need for confirmatory diagnostic testing has been identified as a major contributor to loss to follow-up. Furthermore, insufficient counselling at the time of referral may result in parents underestimating the importance of further evaluation (Neumann et al., 2020; Ramkumar, 2017).

Research has examined various demographic and service-related factors that may influence follow-up attendance after newborn hearing screening. Previous studies have reported associations between poor follow-up compliance and rural residence, lower

socioeconomic status, lower parental education, greater travel distance, and limited healthcare accessibility (Marcus et al., 2010; Bush et al., 2014; Elpers et al., 2016). Families from underserved communities are often disproportionately represented among those lost to follow-up. However, findings across studies have not always been consistent, suggesting that follow-up behaviour is influenced by a complex interaction of socioeconomic, healthcare, and parental factors (Neumann et al., 2020).

The presence of high-risk indicators for hearing loss has also been investigated as a potential factor influencing follow-up attendance. Although infants with recognised risk indicators require closer monitoring, previous research suggests that the presence of risk factors alone does not necessarily improve compliance with follow-up recommendations (JCIH, 2019; Neumann et al., 2020). Parents may place greater emphasis on observable hearing behaviour than on clinically identified risk indicators, thereby reducing the perceived need for further evaluation.

Parental awareness plays a critical role in determining whether families pursue recommended healthcare services. However, awareness alone may not always translate into appropriate health-seeking behaviour. Research has shown that many parents are aware of childhood hearing loss and its consequences but may still fail to attend follow-up appointments when they perceive their own child to be unaffected (Bush et al., 2014; Elpers et al., 2016). This discrepancy can be understood through the Health Belief Model, which proposes that health-related actions are influenced not only by knowledge but also by perceived susceptibility and perceived severity of the condition (Rosenstock, 1974). Parents who believe that their infant responds normally to sounds may not perceive a personal risk of hearing loss, reducing motivation to seek further evaluation.

Studies have therefore emphasized the importance of parent-centred counselling, clear communication of referral results, and education regarding the limitations of behavioural observations in detecting hearing loss during infancy. Structured counselling, reminder systems, integration of follow-up with immunization visits, and culturally sensitive educational interventions have been recommended to improve follow-up compliance (Neumann et al., 2020; Paul, 2016; Ramkumar, 2017).

Although several studies have investigated newborn hearing screening programmes and follow-up outcomes, limited evidence is available regarding the specific barriers influencing follow-up compliance among referred infants in India. Existing literature has largely focused on screening coverage, referral rates, and programme implementation, while relatively few studies have explored the role of parental perceptions, demographic characteristics, and High-Risk Register status in influencing follow-up attendance. Therefore, there is a direct need to identify barriers to follow-up compliance and examine factors associated with follow-up attendance among infants referred through the AIISH NBS programme, Mysuru.

CHAPTER 3

METHODS

3.1 Study Design

The present study employed a qualitative, questionnaire-based survey design to investigate the factors influencing parental compliance with follow-up recommendations after newborn hearing screening. Specifically, the study aimed to identify the barriers affecting follow-up compliance among parents or primary caregivers of infants referred for diagnostic audiological evaluation following newborn hearing screening conducted under the POCD department of AIISH, Mysuru. Although newborn hearing screening programs play a crucial role in the early identification of hearing loss, loss to follow-up remains a significant challenge that can delay diagnosis and intervention. Therefore, the study focused on exploring demographic, awareness-related, accessibility-related, and practical factors that may influence families' decisions regarding follow-up attendance. This chapter outlines the methodology adopted to achieve the study objectives.

3.2 Participants

The participants in the present study were parents or primary caregivers of infants who had been referred for diagnostic audiological evaluation following a 'Refer' result on bedside newborn hearing screening conducted under the AIISH newborn hearing screening program. To facilitate a comparison of factors associated with follow-up compliance, the study included those who did not comply with the follow-up recommendation.

A list of referred infants was obtained from the newborn hearing screening database maintained by the department of POCD, AIISH, Mysuru. The database contained screening

records and contact details of infants referred for diagnostic audiological evaluation. The study considered referrals made between January 2025 and November 2025.

Two datasets were used in the present study. Data obtained through structured telephone interviews with 202 parents/caregivers were used to examine barriers affecting follow-up compliance, parental awareness, and follow-up-related outcomes. In addition, retrospective records of 394 infants from the POCD database were analysed separately. Together, these datasets comprised information from 596 participants and were used to examine the association of demographic variables and High-Risk Register (HRR) status with follow-up compliance.

A total of 295 families were identified from the database as having been referred for diagnostic evaluation, with no documented confirmation of follow-up attendance at AIISH. Of these, successful telephone contact was established with 202 families. Families for whom valid contact could not be established after three attempts were excluded from the study. Families who reported that their child had already received a confirmed diagnosis at another institution prior to contact were also excluded.

Among the 231 participants contacted, 29 (12.6%) reported having attended the recommended diagnostic audiological evaluation at AIISH following the newborn hearing screening referral and were classified as the Follow-up group. The remaining 202 participants (87.4%) had not attended a diagnostic evaluation at the time of data collection and were classified as the Non-follow-up group.

Of the 231 respondents, 219 (94.8%) were the infant's parents, comprising either the mother or father, while the remaining 12 participants (5.2%) were other primary caregivers, such as grandparents or other family members responsible for the infant's care. Among the parent respondents, 142 (61.5% of the total sample) were mothers and 77 (33.3%) were fathers. Regarding the infants, 117 (50.6%) were female and 114 (49.4%) were male. All participants

were contacted telephonically, and data collection was initiated only after obtaining their informed consent.

The age of the infant at the time of telephone contact ranged from 5 to 15 months, with a mean of 8.02 months (SD = 3.24) and a median of 8 months. Among infants in the follow-up group, the mean age was 8.38 months (SD = 2.96), and among those in the non-follow-up group, the mean age was 7.97 months (SD = 3.28).

Socioeconomic status was classified as Below Poverty Line (BPL) or Above Poverty Line (APL) based on the family's BPL card status. Of the 231 families, 172 (74.5%) were BPL and 59 (25.5%) were APL. In the follow-up group, 23 families (79.3%) were BPL and 6 (20.7%) were APL. In the non-follow-up group, 149 families (73.8%) were BPL and 53 (26.2%) were APL.

All 231 infants had their newborn hearing screening done at the delivery centre itself. Among them, 173 infants (74.9%) were delivered in government hospitals and 58 (25.1%) in private hospitals. The largest single delivery centre was KRH Chaluvamba Hospital, a government facility, from which 170 infants (73.6%) were referred 169 through the main unit and 1 from an associated unit. Other government hospitals included Jayanagar Hospital (n = 4), Gopal Gowda Hospital (n = 1), and SMTDH Mohan Das/Tulsi Das Hospital (n = 7). Among private hospitals, Kamakshi Hospital contributed the largest share (n = 36), followed by Ashwini Nursing Home (n = 5), Mahadeshwara Nursing Home (n = 4), Sigma Hospital (n = 2), and Lakshmi Devamma Hospital (n = 2).

Families delivering at KRH Chaluvamba Hospital and the other government hospitals in Mysuru city were predominantly from urban or semi-urban areas within Mysuru district. A smaller proportion came from rural areas in surrounding taluks such as Nanjangudu, Hunsuru, Periyapatna, and T. Narasipur, based on address records available in the POCD database. An

estimated 60–65% of participants were from urban or semi-urban areas within Mysuru city, while approximately 35–40% were from rural or semi-rural areas surrounding Mysuru district.

3.3 Questionnaire for Data Collection

Data were collected using a structured questionnaire developed at the department of POCD, AIISH, Mysuru. No modifications were made to it. The questionnaire is designed to capture information on the demographic background of the participant and to identify the specific barriers that had prevented or influenced families in their decision about attending follow-up diagnostic evaluation.

The questionnaire was developed based on a systematic review of existing literature on barriers to follow-up compliance in newborn hearing screening programs, combined with the clinical experience of faculty and professionals in the POCD Department who have been running the AIISH hearing screening program for more than two decades. Items were framed to cover the three major domains of barriers commonly reported in the literature, namely awareness-related barriers, accessibility-related barriers, and affordability-related barriers. In addition, barriers specific to the Indian cultural and healthcare context were included, such as traditional postnatal care practices (locally referred to as Banantana, which restricts the movement of the mother and newborn for a period after delivery) and the influence of family members on health decision-making.

The questionnaire was first written in English. Content validity was obtained by expert review. The questionnaire was pre-tested by a committee of faculty members from the department of POCD, AIISH, who critically analysed each item with respect to its clarity, relevance to the research objectives and overall comprehensiveness. The wording of some

items was changed, based on their comments, to make some wording clearer, and to make each question easy for participants of different education levels to understand.

The questionnaire was validated and then translated into Kannada, the major language spoken by the majority of the participants from Mysuru and the other nearby districts. Translation was undertaken to ensure that language was not a barrier to participation and ensure that the response was that of the participant and not constrained by their understanding of English. This Kannada version was then translated back into English by a native Kannada speaker familiar with English language.

The questionnaire consisted of two main sections. Section I collected general demographic and background information about the referred infant and the family. This included the child's date of birth, current age in months, gender, socioeconomic status, the name and type of the delivery hospital, whether newborn hearing screening had been done, and whether the family had been referred for follow-up diagnostic evaluation and if so, whether they had attended. Section II consisted of 12 pre-defined barrier items presented in a Yes or No response format. Each item asked whether a particular factor had affected the family's decision regarding attending the follow-up evaluation.

The 12 barrier items were selected based on barriers that were most commonly reported in the newborn hearing screening literature and were reviewed and finalised by the expert audiologists of the department of POCD. The items covered the following perceptual barriers such as the baby appearing to hear normally in daily life, logistical barriers such as the testing centre being too far to travel to; informational barriers such as not being told that the baby needed further testing, financial barriers, time and work-related constraints, the family waiting for the child to grow older before testing, health-related reasons involving the mother or the baby; cultural practices that restrict postnatal travel, advice from family members or friends

against testing, and lack of support from the family to bring the child for testing. A thirteenth item asked about unfavourable weather as a barrier. An open-ended question was also included to allow participants to mention any other reason that was not covered in the pre-defined list.

At the end of the questionnaire, two awareness questions and one decision-making question were included. Participants were asked whether they were aware that hearing loss can occur in children from birth, and whether they were aware that untreated hearing loss affects a child's ability to speak normally. Those who had not attended follow-up were additionally asked whether they believed they had made the correct decision by not bringing the child for testing. A copy of the questionnaire used is shown in Table 3.1

Questionnaire for Parents Who Did Not Attend Detailed Hearing Evaluation after Referral

1) Name: ……..
2) D. O. B: ……
3) Male/ Female: ……..
4) Current age of the child: ……..
5) Respondent: Father/ Mother/others (specify): ……
6) Socio-economic status/income: ……..
7) Hospital in which the baby was delivered: …….
8) Was hearing screening done for child?

   If yes, the location: AIISH/Delivery center/other (specify) ……

   If no, were you informed about hearing screening for the newborn? Yes/No
9) Was the child referred for detailed evaluation after hearing screening? If yes, did you get the child hearing tested? Yes/No.

   If yes, where? ……

If no, please specify the reason why? ……...

Instructions: Please answer YES/NO to the following as applicable. We did not get the child's hearing tested because:

Sl No	Questions	Yes	No
01.	We're not informed that the child needed detailed hearing testing		
02.	We're not convinced about the need for more hearing testing.		
03.	Waiting for the baby to be a little older, to bring for testing.		
04.	The testing center is too far/ difficult to access. Have to travel long distance to get the testing done.		
05.	Could not come due to the rules of post- natal care (Banantana)		
06.	Baby is responding to sounds very well.		
07.	A friend/family member suggested that the testing is unnecessary.		
08.	There is no support/help from the family to get the child to the testing center.		
09.	The baby's or the mother's health was poor.		
10.	There are financial constraints to get the child tested at present.		
11.	There are other commitments /time constraints.		
12.	The climate (weather) was not conducive for the baby/mother to travel.		
13.	Do you think you made the right decision by not bringing the child for detailed testing?		
14.	Are you aware that children can be born with hearing loss?		
15.	Are you aware that children with hearing loss if not treated early will not be able to speak normally?		
Any other reason (please specify)			

3.4 Procedure

Data collection was carried out by the investigator (Author of this dissertation), through telephone interviews. At the beginning of each call, the investigator introduced herself by name and designation, explained the purpose and nature of the study in simple terms, and informed the participant that their involvement was completely voluntary and that all responses would be kept confidential. Verbal informed consent was obtained from the participant before proceeding with the questionnaire. Participants were also informed that their responses would not affect the services they were receiving or would receive at AIISH.

Each interview took approximately five to eight minutes to complete. The language of administration was selected based on the preference of the respondent. Kannada was used in the majority of interviews, as most participants were from Kannada-speaking families in and around Mysuru. English was used in a smaller number of cases where the respondent indicated a preference for it. All responses were recorded on a google form based questionnaire form during the telephone call by the investigator and were subsequently entered into a computer-based spreadsheet for data management. To ensure data accuracy and reliability, the responses recorded by the investigator during the interviews were independently cross-verified by the mentor against the corresponding audio recordings.

Calls were made during daytime hours on working days to maximise the likelihood of reaching the respondent. A maximum of three contact attempts were made for each family. These three attempts were made on different days and at different times of day so as not to miss families who may have been unavailable at particular times. If contact could not be established after three attempts, the family was excluded from the study and noted as a non-contactable case.

3.5 Ethical Considerations

The study was conducted as part of the Master's dissertation program at AIISH. The study involved minimal risk to participants as it did not involve any clinical procedures, physical examination, or collection of personal identifying information beyond what was already available in the POCD database. Verbal informed consent was obtained from each participant at the beginning of the telephone call. Participants were informed of their right to withdraw from the study at any time without any consequence. All data collected were kept confidential and used only for the purposes of this research. No names or identifying details of participants are reported in this dissertation.

3.6 Data Analysis

The data collected through the structured telephone interviews were entered into a Microsoft Excel spreadsheet and subsequently imported into SPSS Version 25 for statistical analysis. The following statistical procedures were used:

- Descriptive statistics were used to summarise all major variables. For categorical variables such as gender, socioeconomic status, and hospital type, frequency counts and percentages were calculated.
- For categorical variables, Pearson's chi-square test of independence was used to examine whether there was a statistically significant association between each variable and follow-up compliance.
- Data obtained through structured telephone interviews with 202 parents/caregivers were analysed to describe demographic characteristics, follow-up status, parental awareness, and barriers affecting follow-up compliance. In addition, retrospective records of 394 infants extracted from a larger POCD database of 596 referred infants

were analysed separately to examine demographic characteristics and High-Risk Register (HRR) status in relation to follow-up compliance. Frequency counts and percentages were calculated for categorical variables.

- Effect size for the chi-square test was calculated using Cramér's V.
- A significance level of $p < .05$ was considered statistically significant for all analyses.

CHAPTER 4

RESULTS

The results obtained in the study are presented under the following headings:

1. Common barriers to follow-up compliance among families who did not adhere to the recommended follow-up
2. Association of demographic and service-related variables with the follow-up compliance
3. Association of presence of High-risk indicators with the follow-up compliance.

4.1 Common Barriers to Follow-up Compliance among Families Who Did Not Adhere to the Recommended Follow-up.

Among the cohort of the present study, 202 participants had not adhered to the follow-up recommendations. The target questionnaire was administered only to these 202 participants, to identify the barriers to follow-up compliance in them. The outcomes of the questionnaire-based survey (frequency of barriers) among these participants are represented in the Figure 4.1. The most frequently reported barrier was the 'perception that the baby was responding well to sounds' (N = 194, 96.0%). 'Distance and travel difficulties' were the second most commonly reported barrier (N = 82, 40.6%). Other barriers were reported less than 10% and included 'lack of conviction regarding the need for testing', 'time or work constraints', 'waiting for the child to grow older', 'health-related issues involving the mother or infant', and 'financial constraints. Less than 1% of participants reported 'not being informed about the need for testing', 'advice from family or friends against follow-up', 'lack of family support', and 'cultural practices' (Banantana - postpartum care) as the barriers. No participants reported 'unfavorable weather' as a barrier to follow-up attendance.

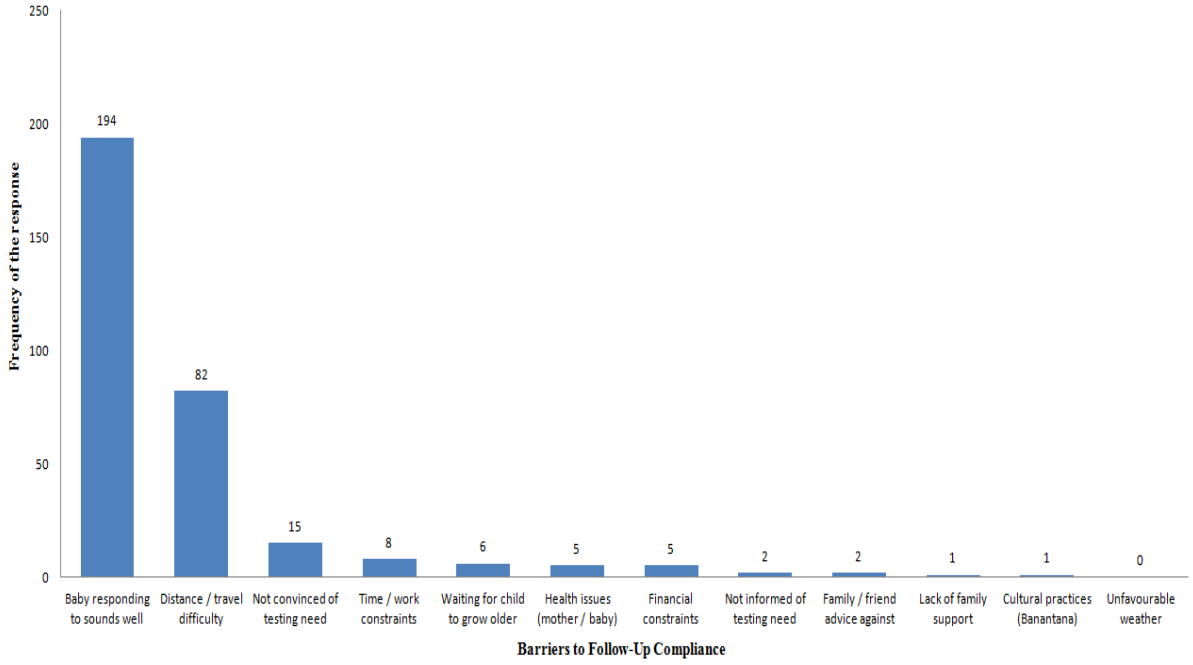

Figure 4.1: Distribution of Reported Barriers to Follow-Up Compliance among Non-Attendees (N = 202). The same figure is shown in the landscape layout in Appendix 1.

4.2 Association of Demographic and Service-Related Variables with Follow-Up Compliance

Table 4.1 presents the results of the association analysis examining the relationship of demographic and service-related variables with the follow-up compliance among the referred infants. Chi-square tests of independence revealed no significant associations between follow-up compliance and gender ($\chi^2 = 0.250$, $p = .617$), income category ($\chi^2 = 0.827$, $p = .363$), hospital type ($\chi^2 = 2.948$, $p = .086$), or locality ($\chi^2 = 0.237$, $p = .626$). These findings indicate that follow-up compliance did not differ significantly across gender, income categories, or hospital type in the study cohort.

Table 4.1: Results of Chi-square test showing the association of demographic and service-related variables (Gender, Income Category, and Hospital Type) with the follow-up Compliance (N = 595)

Variables	**Category**	**Follow-up Compliance**		**χ^2**	***p***
		Attended	**Not Attended**		
Gender	Male	236	102	0.250	.617
	Female	185	73		
Income	BPL	419	173	0.827	.363
	APL	2	2		
Hospital type	Government	335	128	2.948	.086
	Private	86	47		
Locality	Rural	133	59	0.237	.626
	Urban	287	116		

As none of the examined variables showed a statistically significant association with follow-up compliance, regression analysis was not pursued to assess for their ability to predict poor follow-up compliance.

4.3 Association between High-Risk Register Status and Follow-Up Compliance

Table 4.2 presents the results of Chi-square test showing the association between High-Risk Register (HRR) status and follow-up compliance among referred infants. The results revealed no significant association between HRR status and follow-up compliance [χ^2 (1, N = 595) = 0.930, p = .335], indicating that follow-up attendance did not differ significantly between infants with and without HRR indicators.

Table 4.2: Results of Chi-square test showing association between High-risk register (HRR) status and follow-up compliance (N = 595)

Variables	**Category**	**Follow-up Compliance**		χ^2	***p***
		Attended	**Not Attended**		
High Risk Register	With	19	26	0.930	.335
	Without	02	9		

4.4 Parental Awareness and Decision-Making

Participants were asked questions regarding their awareness of childhood hearing loss and its impact on speech and language development. In addition, parents who did not attend the recommended follow-up were asked whether they believed their decision was correct.

As shown in Table 4.3, almost all participants were reportedly well aware of possibility of occurrence of childhood hearing loss, as well as its potential consequences for speech-language development. Similarly, almost all parents who did not attend the recommended follow-up believed that their decision not to attend was correct. Only one participant across the study sample responded negatively to all three items.

Table 4.3: Parental awareness about childhood hearing loss, its consequences on speech-language development, and parents' conviction regarding follow-up decision-making (N = 202)

Item	Yes N (%)	No N (%)
Aware that hearing loss can occur in children	202 (100%)	0 (0%)
Aware that untreated hearing loss affects speech development	202 (100%)	0 (0%)
Believed decision not to attend follow-up was correct[a]	202 (100%)	0 (0%)

Note. Percentages are based on N = 231 for awareness items. [a] This item was asked specifically to participants who did not attend follow-up (n = 202). One participant across the full sample responded 'No' to all three items.

CHAPTER 5

DISCUSSION

The present study examined barriers to follow-up compliance among infants referred through the UNHS programme and explored whether demographic factors, service-related variables, or HRR status were associated with follow-up attendance. The findings revealed that the most commonly reported reason for non-attendance was the parental perception that the child was responding well to sounds, while no significant associations were observed between follow-up compliance and gender, income category, hospital type, locality, or HRR status.

5.1 Barriers to Follow-Up Compliance

The most frequently reported barrier to follow-up attendance in the present study was the parental belief that the infant was responding normally to sounds. This finding is consistent with previous studies that have identified parental perception of normal hearing as a major contributor to loss to follow-up following newborn hearing screening referrals (Muñoz et al., 2016; Ravi et al., 2016; Shulman et al., 2010). In routine daily interactions, parents commonly assess their child's hearing by observing responses to voices, environmental sounds, music, and other auditory stimuli. When such responses are present, parents may conclude that their child's hearing is normal and perceive further diagnostic evaluation as unnecessary. Consequently, confidence in their own observations may reduce the perceived importance of attending follow-up appointments. However, behavioural responses alone cannot reliably identify mild, unilateral, progressive, or frequency-specific hearing losses.

Future studies could contact infants who were lost to follow-up and conduct comprehensive hearing assessments to determine the extent to which parental observations accurately reflect the child's hearing status. Such investigations would provide valuable insight

into the reliability of parental perceptions as indicators of normal hearing and help inform strategies to improve follow-up compliance.

Distance and travel difficulties were the second most commonly reported barrier. This finding reflects broader challenges within the Indian hearing healthcare system, where specialized audiological services are often concentrated in tertiary care centres and urban locations. India continues to face a shortage of hearing healthcare professionals, with an estimated audiologist-to-population ratio of approximately 1:950,000 (Manchaiah et al., 2010). Long travel distances, transportation challenges, and the need to take time away from work or family responsibilities may therefore discourage families from attending follow-up appointments.

The low follow-up rate observed in the present programme reflects a challenge that continues to affect newborn hearing screening systems globally. Even in well-structured screening programs, studies consistently report attrition arising from barriers such as limited access to diagnostic centres, financial constraints, travel distance, and competing family priorities (Akinpelu et al., 2014). These barriers often intersect with broader socioeconomic realities, creating practical difficulties for families attempting to return for follow-up. Such observations align with longstanding evidence that families facing structural disadvantages are more likely to experience disruptions in continuity of care, particularly when screening services and diagnostic facilities are geographically or financially inaccessible.

In addition to structural barriers, previous literature has emphasized the importance of parental understanding and the quality of counselling provided at the time of screening. Parents who receive limited explanation regarding the implications of a "refer" result may underestimate the need for timely diagnostic evaluation. This was reflected in the present study, where many caregivers relied on everyday behavioral responses as evidence of normal hearing,

and 7.4% of non-attenders reported not being convinced of the need for further testing. Such findings suggest a limited understanding of the two-stage screening process, in which newborn hearing screening identifies infants requiring further evaluation, while diagnostic assessment confirms or rules out hearing loss. Similar misconceptions have been reported previously and have been identified as important contributors to loss to follow-up (Dodd-Murphy & Murphy, 2001; Muñoz et al., 2011; Ravi et al., 2016). Low levels of health literacy, particularly limited awareness of childhood hearing loss and its long-term consequences, may further compound this issue (Prieto-Tato et al., 2023). These findings highlight the need for clear, structured counselling and culturally appropriate educational materials at the point of referral to improve parental understanding and follow-up compliance (White et al., 2010).

Several practical barriers were reported by smaller proportions of non-attenders, including time and work constraints (4.0%), waiting for the child to grow older (3.0%), health issues affecting the mother or infant (2.5%), and financial constraints (2.5%). Although none of these factors reached statistical significance individually, they reflect the cumulative burden of everyday circumstances that can interfere with healthcare attendance. In a population where the majority of families belonged to below-poverty-line households and accessed services through government hospitals, competing priorities may reduce the likelihood that a follow-up appointment is perceived as urgent.

The belief that waiting for the child to grow older would resolve uncertainty regarding hearing status has been reported in other South Asian healthcare contexts (Olusanya et al., 2014). Parents may expect hearing difficulties to become apparent only when the child begins babbling, speaking, or responding consistently to their name. Such expectations can delay diagnostic evaluation beyond the critical early period recognized as essential for optimal

speech and language development (Yoshinaga-Itano et al., 1998; Joint Committee on Infant Hearing, 2019).

Social and cultural barriers were reported by only a small number of participants. These included advice from family members or friends against follow-up (1.0%), cultural practices such as Banantana (0.5%), and lack of family support (0.5%). Although infrequent, these findings illustrate how local beliefs, cultural traditions, and family influences may contribute to delayed follow-up in certain families and should be considered when designing culturally sensitive counselling and follow-up strategies.

Collectively, these findings highlight the importance of strengthening parental counselling and communication at the screening stage to improve follow-up adherence. Across these diverse influences, a unifying theme emerges: parental awareness, comprehension, and perception of risk form the cornerstone of successful follow-up behavior. This underscores the importance of strengthening counselling immediately following initial screening. Clear, supportive, and family-centred communication has been shown to enhance follow-up adherence, particularly when parents understand that normal behavioral responses do not reliably exclude hearing loss. Quality-improvement studies further demonstrate that structured parental education and explicit guidance at discharge can significantly improve compliance (Sanchez et al., 2016). Enhancing help-seeking behavior therefore requires not only accurate information, but also empathetic and context-sensitive counselling that empowers families to pursue timely diagnostic evaluation.

Beyond individual parent–provider interactions, community-level awareness strategies and broader family-centred educational initiatives play a vital role. When caregivers understand the developmental implications of delayed identification, particularly for speech, language, and social outcomes, they are more likely to prioritize follow-up visits. Integrating

such education within community health platforms may therefore contribute meaningfully to reducing follow up absence. Ultimately, a combination of strengthened counselling, accessible services, and proactive community education forms the foundation of a more equitable and responsive newborn hearing screening pathway, ensuring that infants at risk of hearing loss receive timely diagnosis and early intervention.

5.2 Influence of Demographic Variables on Follow-Up Compliance

An important finding of the present study was the absence of significant associations between follow-up compliance and the demographic or service-related variables examined. Neither gender, income status, hospital type, nor locality appeared to influence attendance at follow-up appointments. This suggests that poor follow-up compliance may be a widespread phenomenon that cuts across socioeconomic and demographic categories rather than being confined to specific population groups.

Although socioeconomic disadvantage has been consistently associated with reduced healthcare utilization in the broader literature (Braveman & Gottlieb, 2014; Nieman et al., 2014), such a relationship was not evident in the present study. One possible explanation is that the follow-up attendance may be influenced more strongly by parental beliefs and understanding of the screening process than by demographic or service-related variables. When parents believe that their child hears normally or do not fully appreciate the importance of diagnostic confirmation, the motivation to attend follow-up appointments may decrease regardless of socioeconomic background, locality, or healthcare setting. These findings suggest that improving parental awareness and counselling may be as important as addressing structural barriers in efforts to enhance follow-up compliance.

5.3 Influence of the Presence of High-Risk Indicator/s on Follow-Up Compliance

No significant association was observed between HRR status and follow-up compliance, indicating that infants with recognized risk indicators for hearing loss were no more likely to attend follow-up appointments than infants without such indicators. This finding is consistent with previous reports suggesting that the presence of risk indicators alone does not ensure follow-up attendance (Ravi et al., 2016). One possible explanation is that, although HRR status is clinically important, parents may not fully understand the implications of these risk indicators for their child's hearing. Instead, they may place greater emphasis on the infant's apparent behavioral responses to sound when deciding whether further evaluation is necessary. This interpretation is supported by the finding that the vast majority of non-attenders believed their child responded normally to sounds. Consequently, the perceived absence of hearing difficulties may outweigh the significance of identified risk factors. These findings highlight the importance of providing clear, risk-specific counselling that explains both the relevance of HRR indicators and the limitations of relying solely on observable responses to sound. Enhanced follow-up communication and targeted educational materials for families of HRR-positive infants may help improve compliance with diagnostic evaluation (Gaffney et al., 2010; Holte et al., 2012).

5.4 Parental Awareness, and the Gap Between Knowledge and Action

Another notable finding of the present study was the coexistence of high parental awareness regarding childhood hearing loss with poor follow-up compliance. Nearly all participants were aware that hearing loss can occur in children and that untreated hearing loss can adversely affect speech and language development. Despite this, almost all non-attenders believed that their decision not to pursue follow-up was correct. This apparent discrepancy suggests that general awareness of hearing loss does not necessarily translate into an

understanding of newborn hearing screening outcomes or the need for confirmatory diagnostic testing. Parents may recognize the consequences of hearing loss in general while perceiving their own child to be unaffected because of observed responses to sound. This interpretation is consistent with the Health Belief Model, which proposes that health-related action depends not only on knowledge but also on perceived personal risk (Rosenstock, 1974; Janz & Becker, 1984). When parents do not believe that their own child is at risk of hearing loss, awareness alone may be insufficient to motivate follow-up attendance. These findings highlight the importance of counselling strategies that address parental perceptions of risk and clarify the limitations of relying solely on behavioral responses as indicators of normal hearing.

This finding has direct importance for how referral counselling is delivered. Increasing public awareness about childhood hearing loss, while useful at a population level, is not sufficient to drive follow-up attendance at the individual level. What is needed is a shift from general information to individually focused counselling at the point of referral, one that specifically addresses the parent's belief that their child is hearing normally and explains why a child can respond to sounds and still have a clinically important hearing loss.

Taken together, the findings suggest that improving follow-up compliance within newborn hearing screening programmes may require greater emphasis on parent-centred counselling. Counselling should focus not only on communicating screening results but also on explaining why behavioral responses to sound cannot reliably rule out hearing loss during infancy. Educational efforts should specifically address common misconceptions, reinforce the importance of diagnostic confirmation, and emphasize that hearing loss can be present even in children who appear to respond normally to environmental sounds. Such strategies may be particularly important in the Indian context, where family observations often play a central role in health-related decision-making.

5.5 Limitations of the Study

Some limitations of the present study should be noted. First, data on barriers were collected through telephone interviews, which introduces the possibility of recall error and social desirability, as parents may have reported reasons for non-attendance that were easier to articulate or more socially acceptable. Second, responses given over the telephone could not be independently verified, which may have affected the accuracy. Third, the study was conducted at a few specialized referral hospitals, which limits how widely the findings can be applied to other programme settings or regions. Fourth, the cross-sectional design does not allow causal conclusions: the identified barriers are associated with non-attendance but do not establish a direct cause-and-effect relationship

CHAPTER 6

SUMMARY AND CONCLUSIONS

Newborn Hearing Screening plays a critical role in the early identification of hearing loss, enabling timely intervention to support speech, language, cognitive, and social development. However, the effectiveness of newborn hearing screening programmes depends on successful follow-up after referral, and loss to follow-up remains a major challenge in many screening programmes. This study aimed to identify barriers to follow-up compliance among infants referred through the Newborn Hearing Screening programme at the All India Institute of Speech and Hearing (AIISH), Mysuru, and to examine whether demographic, service-related, and clinical factors were associated with follow-up attendance.

A cross-sectional questionnaire based survey was conducted among a cohort of 595 infants referred following newborn hearing screening. Structured telephone interviews were completed with 202 parents or primary caregivers when the infants were between 5 and 15 months of age (mean age = 8.02 months, SD = 3.24). Information regarding demographic characteristics, parental awareness of hearing loss, perceived barriers to follow-up, and attendance status was collected. Programme records were reviewed to obtain data on gender, socioeconomic status, hospital type, locality, and presence of high risk indicators. Descriptive statistics and Chi-square tests of independence were used for analysis.

Of the referred infants, 202 families did not attend the recommended diagnostic follow-up. Analysis of questionnaire responses from this cohort indicated that the most commonly reported reason for non-attendance was the parental perception that their infant responded normally to sounds (96.0%). This was followed by distance and travel-related difficulties, which were reported by 40.6% of respondents. Other barriers, including lack of conviction regarding the need for testing, time and work constraints, waiting for the child to grow older,

health-related concerns, and financial difficulties, were reported less frequently. Awareness of childhood hearing loss and its impact on speech and language development was very high (99.6%). Despite this, almost all parents who did not attend follow-up believed that their decision was correct. Upon analysing the 595 participants' data for factors associated with follow-up compliance, no significant association of follow-up compliance was found with either gender, income category, hospital type, locality, or HRR status.

Follow-up non-compliance was influenced primarily by parental perceptions rather than demographic, service-related, or clinical risk factors. The belief that the infant was hearing normally emerged as the predominant barrier to attendance, highlighting a gap between general awareness of hearing loss and perceived personal risk. The findings underscore the need for strengthened parent-centred counselling, clearer communication of screening results, improved tracking and follow-up systems, and strategies to reduce barriers to accessing diagnostic services. Such measures may improve follow-up compliance and enhance the effectiveness of newborn hearing screening programs.

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APPENDIX 1

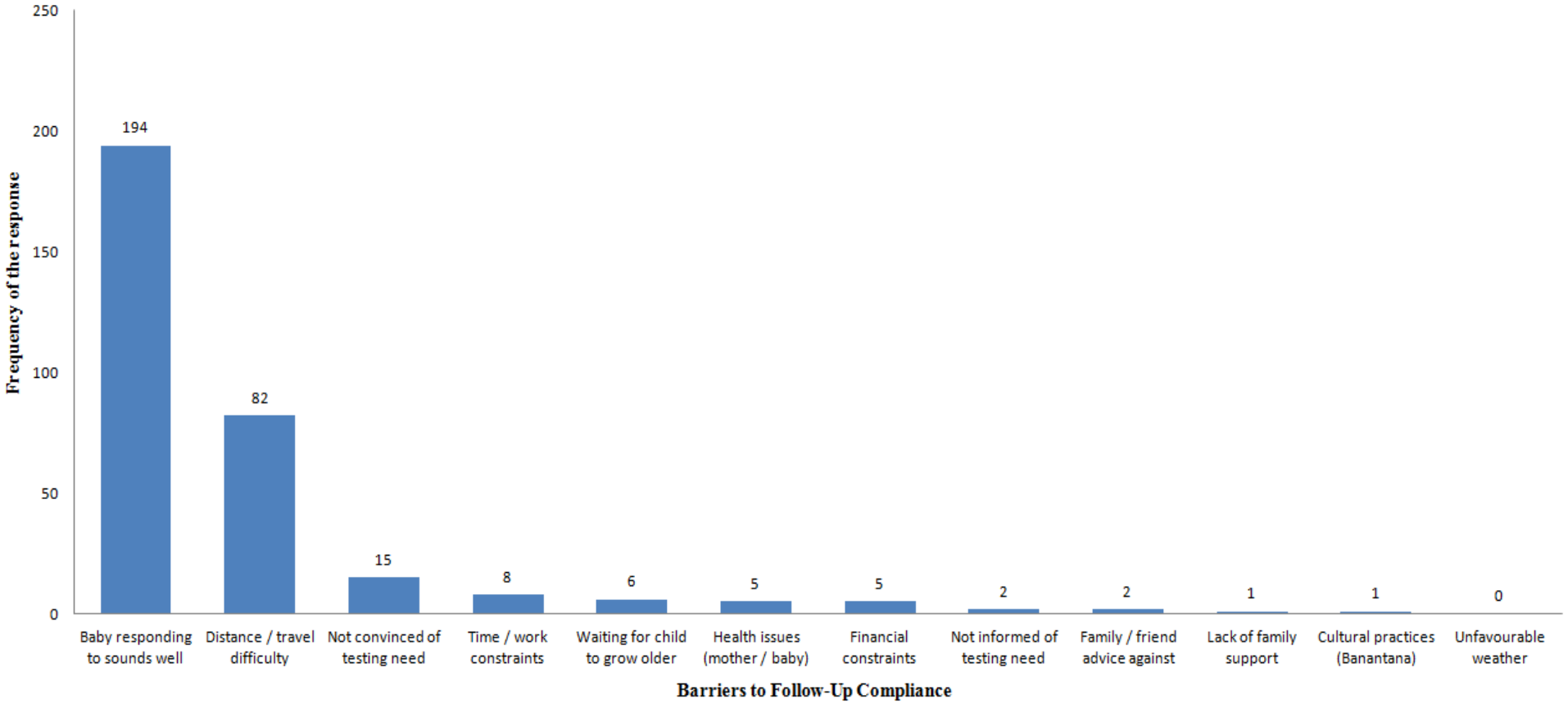

Figure 4.1: Distribution of Reported Barriers to Follow-Up Compliance among Non-Attendees (N = 202).