

Non-compliance With Neonatal Hearing Screening Follow-up in Rural Western India

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Objective: The reasons of failure to follow-up for the Universal Neonatal Hearing Screening (UNHS) program were delineated. **Methods:** Review of case records for data related to follow-up of neonates who underwent the UNHS between February 2012 - January 2015. **Results:** 2534 neonates underwent primary screening with Distortion Product Oto-acoustic Emission (DPOAE). 14 (26.9%) were lost to follow-up between the first and second DPOAE screenings. 275 neonates (including high-risk cases) were to undergo confirmatory Brain Evoked Response Audiometry testing out of which 201 (73.4%) came for follow-up. Out of 74 who failed to follow-up (including those lost between first and second DOPAE screenings), unwillingness and non-compliance was the commonest reason. **Conclusion:** Increasing awareness and counseling of the caretaker are important interventions for ensuring good follow-up in hearing screening programs.

Keywords: Deafness, Follow up, Outcome.

The incidence of hearing impairment in India is 1-6 per thousand newborns screened [1]. The World Health Organization advises that optimal vocational and functional outcomes in infants and children with hearing loss can be achieved by early identification and prompt management, which is achieved by infant hearing screening programs [2]. In India, various pilot studies have shown that universal hearing screening is feasible and cost-effective [3]. Studies in developed nations suggest that low-income, rural, African-American, minority infants, and poor access to health care are at risk for loss to follow up [4,5]. Using a good data management system has been suggested as a solution to handle loss to follow-up [6]. There is sparse literature on factors that cause loss to follow-up in India.

This study focuses on the factors related to loss to follow-up in UNHS, and interventions to minimize the loss to follow-up.

METHODS

Our center conducted a Universal Neonatal Hearing Screening (UNHS) Program from February 2012 to January 2015 for all neonates admitted in the hospital [7]. All neonates born or admitted during study period in Shree Krishna Hospital, Karamsad (Anand), underwent hearing assessment using Distortion Product Otoacoustic Emission (DPOAE) as the first level of

hearing screening. Neonates who failed the first screening were subjected to a second level of hearing screening after 10 days by performing second DPOAE test. Neonates who failed second DPOAE test underwent confirmatory Brain Evoked Response Audiometry at the age of three months.

For this study, the records of all the neonates were retrieved and information including demographics, social status, perinatal and prenatal information were collected. Various methods were made to communicate with parents to prevent loss to follow-up cases. Protocol involved telephonic reminders for follow up visits (at least three times by social worker). If no follow up occurred, home visits were also conducted by the health worker to persuade them to come for follow-up testing, specifically in high risk cases. Reasons for loss to follow up were discussed by health workers during telephonic or in person interviews. It was done within 4 weeks' time or when the test was scheduled. In case of hesitation for follow up due to financial reasons, financial assistance in deserving cases (such as Below poverty line) was offered by a separate department managed by social workers. The attendants were informed about the ways of arranging the financial assistance. Descriptive statistical analysis was performed.

RESULTS

Majority of the neonates (1824, 71.9%) came from families

WHAT THIS STUDY ADDS?

- Loss to follow-up in Universal Newborn Hearing Screening program is primarily due to parental unwillingness; better counselling in perinatal period may improve follow-up rates.

residing in the nearby areas, with most of them (2103, 82.9 %) falling in the low socio-economic strata. The highest education level of the caregivers was high school graduates. Sixty-seven neonates missed the first screening test (21 refused to give consent while 46 were discharged on a holiday); 60 high-risk neonates who had passed the first screening test were lost to follow-up and did not have a BERA done. The second screening by DPOAE was missed by 14 neonates who were classified as 'Refer' in the first.

Reasons for failure to follow-up were analyzed in 74 babies who failed to undergo BERA or DOPAE test. The most common cause for failure to follow-up was not willing for any testing (32, 43.24%); 19 (25.7%) other were due to large distance between house and hospital. Change of address was observed in 18 cases (24.3%); financial constraints and foregoing of daily wages of parents (5, 6.7%) was given as a reason, especially by the extreme poor persons surviving on daily wages. There was no difference in loss to follow-up with respect to gender ($P < 0.05$).

DISCUSSION

Screening coverage in the current UNHS program was better than the recommended benchmark of >95% [8]. The follow-up rate after first DPOAE screening was 73.1%, which is poor, while follow-up rate after second DPOAE for confirmatory diagnostic BERA, as well as referred cases, was 100%.

Not willing for any testing was the single largest cause for loss to follow-up. Some parents believed that their child responded to sound and hence ignored the advice. A large proportion of cases (39, 52.7%) underwent delivery at our center but followed up later at primary care centers in their native villages, and hence did not follow-up for screening. In a study on very low birth weight infants done in Africa, a follow-up rate was only 31.4% [9]. In this study the distance away from the hospital was of less significance while lack of prescreening education in antenatal period was important. Another study in Nigeria had a follow-up rate of 51.9% in spite of relying on the caregivers' compliance by a simple appointment slip [10]. Our follow-up rates were probably higher due to counselling by community health workers and home visits in select high risk cases. Another study in Nigeria showed better follow-

up compliance of 89.8% for BERA but 84.1% loss to follow-up on the BERA referred infants. Compliance varied by religion and also by high-risk neonates being involved [11]. In the US there was improvement in follow-up data after increasing collaborative efforts made by health professionals, health workers, audiologists, families of babies and administrators [12]. They noted lower follow-up rates amongst migrants from India, which points towards the socio-cultural background, which restricts maximum health benefits.

Follow-up rates are the key indicator of the efficacy of any UNHS program. A recent study in Europe has emphasized on the first information given to parents after their child is diagnosed with hearing loss, and they have noted that the manner in which the parents are counselled is crucial in their compliance to further treatment interventions [13]. The current scenario of UNHS in developing countries has been studied by Olusanya, *et al.* [14] in South Africa, which showed a dismal follow-up rate with only Oman and Saudi Arabia fulfilling the benchmark of 95% [8,14]. The study has also reported that the caregivers' perception to hearing screening in India is uncertain whereas in all other countries it is positive, which is a cause for worry for us. This is in consonance with our study.

Our study is limited by the fact that we have not evaluated the demographics in relation to follow-up such as economic status, distance of house from hospital, and details such as how many patients came after a single phone call or two phone calls, and how many required a follow-up at home.

A method we adopted to ensure good follow up was to include the hearing screening follow-up schedule with the immunization clinic, which has shown good results by other researchers as well [15]. National immunization program is well embedded in the minds of the population and so they are bound to bring the child for vaccination. The authors believe at the very least, counsellors need to be involved in antenatal and postnatal care to improve follow-up rates. If UNHS is envisaged on a national scale in India, implementation research would be needed to ensure good follow-up. The current study and other similar studies can form the framework of the implementation program.

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