

Factors Affecting Neonatal Hearing Screening Follow-up in Developing Countries: One Institution Prospective Pilot Study

Gelişmekte Olan Ülkelerde Yenidoğan İşitme Taraması Takibini Etkileyen Faktörler: Bir Kurumda Prospektif Pilot Çalışması

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ABSTRACT

Objective: To detect factors related with loss to follow-up (LTF) in neonatal hearing screening (NHS) program of one institution in a developing country.

Methods: A prospective study was planned based on the data collected in a pilot study conducted a year before in the same institution. In this pilot study, hearing screening was performed before hospital discharge for every infant (1217 newborns) in six months period. Total referral rate was 19.1% (223/1217). Loss to follow-up (LTF) was 38.1% (85/223). Telephonic interviews were done with 50 parents who had not come with their child to the second hearing test. For these telephonic interviews the questionnaire with four sections (socio-demographic information; information about pregnancy, birth, and present health condition of the child; caregiver knowledge of neonatal hearing screening, and reasons for default on follow-up) was created.

Results: The mothers participated in this study were 29.1 years (± 5.2 SD) of age in average. Place of residence was mostly rural (64%; $n=32$) with 39.4 Km (± 24.8 SD) away from the rescreen referral center. Their knowledge on neonatal hearing screening, hearing impairment incidence or treatment opportunities was at a very low level. Caregivers' perceptions that follow-up was unnecessary (50%; $n=25$), was most frequently given reason for follow-up default, followed by newborns bad health condition (12%; $n=6$) and forgetting about the follow-up visits (8%; $n=6$).

Conclusion: The main reason for default in follow-up in our study was caregiver's poor knowledge about this topic.

Keywords: Neonatal screening, follow-up, developing countries, early detection, otoacoustic emissions

ÖZ

Amaç: Gelişmekte olan bir ülkede hastane tabanlı bir yenidoğan işitme taraması (NHS) programında takip kaybı (LTF) ile ilişkili anne ve bebek faktörlerini belirlemektir.

Yöntem: Aynı kurumda bir yıl önce yapılan pilot çalışma verileriyle ileriye dönük bir çalışma planlanmıştır. Bu pilot çalışmada, altı aylık dönemde her bebeğe (1217 yenidoğan) hastaneden taburcu edilmeden önce işitme taraması yapılmıştır. Toplam sevk oranı %19,1 (223/1217) idi. Takip kaybı (LTF) %38,1 (85/223) idi. İkinci işitme testine çocuklarıyla gelmeyen 50 ebeveyn ile telefon görüşmesi yapılmıştır. Bu telefon görüşmeleri için dört bölümlü (sosyo-demografik bilgiler; hamilelik, doğum ve mevcut sağlık durumu hakkında bilgiler; bakım verenin yenidoğan işitme taraması bilgisi ve takipte gecikme nedenlerinden oluşan) bir anket hazırlanmıştır.

Bulgular: Katılımcılar yaş ortalaması 29,1 ($\pm 5,2$ SD) olan annelerdir. İkamet yeri çoğunlukla kırsaldır (%64; $n=32$) ve yeniden tarama sevk merkezine ortalama 39,4 km ($\pm 24,8$ SD) uzaklıktadır. Yenidoğan işitme taraması, işitme bozukluğu insidansı veya tedavi fırsatları hakkındaki bilgilerinin çok düşük olduğu bulunmuştur. Takip kaybı için en sık ifade edilen nedenler, bakım verenlerin takibin gereksiz olduğu yönündeki algıları (%50; $n=25$), çocuğun sağlık durumunun kötü olduğu gerekçesi (%12; $n=6$) ve takibin unutulmasıdır (%8; $n=6$).

Sonuç: Çalışmamızda takipte kayıplar oluşmasının ana nedeni bakım verenin bu konudaki yetersiz bilgisi olarak ortaya çıkmıştır.

Anahtar kelimeler: Yenidoğan taraması, takip, gelişmekte olan ülkeler, erken teşhis, otoakustik emisyonlar

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INTRODUCTION

In comparison with other congenital malformation for which treatment can be provided, hearing impairment has the highest incidence of at least 1/1000 and in some studies 6/1000⁴ or even 8/1000⁵ newborns with high degree hearing impairment or deafness¹⁻³. Deafness or bad hearing can lead to poor cognitive and language development, behavioral and social adjustment, and academic success^{6,7}. The chance of optimizing a child's potential in speech and language development increases if hearing loss is detected and intervention is done in very early age^{2,8}. In Joint Committee in Infant Hearing and The first European Consensus Development Conference on Neonatal Hearing Screening, screening of all infants prior to one month of age was recommended^{9,10}. The Centers for Disease Control and Prevention (CDC) in the USA and Early Hearing Detection and Intervention (EHDI) program published universal goals for early detection and intervention of hearing loss. The first three goals were later popularized as a 1-3-6 plan. It was planned to screen all newborns by one month of age, to have diagnosis by three months, and to start with therapy/intervention at the age of six months for all diagnosed infants¹¹. States that achieve the 1-3-6 goal should try to meet a 1-2-3-month timeline¹⁰. The effectiveness of universal neonatal hearing screening (UNHS) has been proven by the reduction in age of diagnosis and age of hearing aid fitting since UNHS was first implemented¹²⁻¹⁴.

Along with the lack of NHS coverage, the failure of parents to bring their children for following hearing control examination after first NHS referral results also contributes to delayed detection and intervention of hearing impairment¹⁵. Active parental support for UNHS and early identification and intervention programs are crucial for successful developmental outcome for the affected children¹⁶. It was found that follow-up is the most difficult part of a NHS program, especially in early

years of program implementation¹⁷ in which many programs break down¹⁸. Although problematic follow-up of newborns in NHS programs are more frequently seen in developing countries, developed countries are also struggling with the same problem¹⁵.

In implementation process of two stage UNHS in our institution with main goal to achieve 1-3-6 plan of hearing impairment detection and intervention, we already did some pilot studies. During those pilot studies, we noticed higher rates of loss to follow-up (LTF) and we decided to do research to find main reasons for that.

METHODS

Institutional Ethics Committee approval for this study was obtained on January 26, 2016 (No 20/1-2-491/2-2), before any data collection commenced. One of our pilot studies was done between February and August 2016. In this six months, we screened for hearing impairment every infant born in our institution with Transient Evoked Otoacoustic Emission (TEOAE) tests. A brand new interacoustic device "Titan" (Interacoustics A/S, Denmark) was used for screening of all infants. Total of 1217 infants (2434 ears) were screened. In Well-baby Nursery (WBN) 76.4% (930/1217) and in Neonatal Intensive Care Unit (NICU) 23.6% 287 (Total referral was 19.1% (223/1217 infants), in NICU 21.9% (63/287) and in WBN 17.2% (160/930)¹⁹. All of those 223 newborns were referred to a next hearing examination (rescreening) in two to four weeks. Eleven months after this pilot study had been completed, the review of data was done and it was found that 38.1% (85/223) infants were lost to follow-up (LTF), 27.1% (23/85) in NICU and 72.9% (62/85) in WBN (Table 1).

A prospective telephonic interview with parents who defaulted a follow-up (did not bring their children to follow-up hearing test) was done. We interviewed with the parents (mothers) that we

managed to get on the phone. Telephone numbers were taken from the infant records. All interviews were done from the official hospital phone number on weekdays between 16:30 and 19:30. Before the interview was commenced, informed consent was obtained verbally from caregivers. For this telephonic interview, the questionnaire with four sections (socio-demographic information; information about pregnancy, birth and present health condition of the child; caregiver knowledge of NHS, and reasons for default on follow-up) composed of 20 questions in total was created. The researcher conducted all interviews, which lasted seven minutes on average (± 1.7 SD) with a range of four minutes minimally to a maximum of 11.5 minutes. Telephonic interviews were done with 58.8% (50/85) caregivers. Another three caregivers (3.53%) that we had got on the telephone refused to be interviewed. We could not get on the telephone with the remaining 37.6% (32/85) of the caregivers. Among participating caregivers, 28% (14/50) were parents of the children who were in NICU because of different indications (Table 2) and remaining 72% (36/50) were parents of healthy children from

WBN and without risk factors for hearing impairment. All infants were born and screened in this six-month period (February-August 2016) during above-described pilot study. All telephonic interviews were performed between 21st of June and 5th July 2017.

Data Management and Analysis

Responses were recorded on data collection forms and transferred to electronic Microsoft Excel database before being analyzed using the statistical package IBM-SPSS version 20.0. Standard descriptive methods of statistics were used. Percentage and chi square calculations, and binomial tests were employed for data analysis. For all analyses, a p-value of <0.05 was accepted as statistically significant.

RESULTS

Demographics

Participants were mothers with a mean age of 29.1 years (± 5.2 SD). A statistically significantly greater number of respondents were mothers whose children were placed in the Well-baby Nursery (WBN) after birth (WBN group), compared to surveyed mothers whose children were placed in the Intensive Care Unit (NICU) after birth (NICU group) (binomial test $p=0.003$). We did not attribute much importance to this intergroup difference when we considered the comparable percentages of children who were lost to follow-up in both groups (38.75% for WBN and 36.12% for NICU). Indeed, we managed to survey almost the same percentage of parents from both groups (36/62 or 58.1% for WBN and 14/23 or 60.9% for NICU) (Table 1).

Surveyed families were living in rural (64%; $n=32$), and urban (36%; $n=18$) areas. A borderline statistically significant difference was noted between the number of respondents who were living in rural areas compared with those living in the city (binomial test $p=0.066$). No statistically significant difference was found in the number of

Table 1. Overview of the study participants.

	Total N (%)	Referred N (%)	LTF N (%)	Interviewed of LTF N (%)
WBN	930 (76.40)	160 (17.20)	62 (38.75)	36 (58.10)
NICU	287 (23.60)	63 (21.90)	23 (36.51)	14 (60.90)
Total	1217 (100)	223 (18.32)	85 (38.12)	50 (58.82)

WBN: Well-Baby Nursery, NICU: Neonatal Intensive Care Unit, LTF: Lost to Follow-up

Table 2. Indications for referrals to the neonatal intensive care unit (NICU).

Indications	N	%
Low birth weight	5	35.8
Asphyxia	5	35.8
Prematurity	1	7.1
Vacuum delivery	1	7.1
Mother's health condition	1	7.1
Unknown	1	7.1
Total	14	100

respondents with respect to their places of residence (rural or urban) between WBN and NICU groups was found (chi-square test $p=0.495$).

Average distance from the rescreen referral center was 39.4 km (± 24.8 SD) (range: 10 to 90 km). Only 25% of the respondents lived at a distance of more than 51.25 km from the referral center for a hearing check-up. While 50% of the respondents lived at a distance of 43 km from the referral center.

Education levels were elementary school, high school, and university in 14% ($n=7$); 58% ($n=29$); 28% ($n=14$) of the participating mothers, respectively. Statistically significantly greater number of surveyed mothers had completed high school, when compared with those that completed only primary school or university (chi-square test $p=0.001$). There was no statistically significant difference regarding the level of education of the surveyed mothers between groups of WBN, and NICU (chi-square test $p=0.586$).

Both parents were employed in 34% ($n=17$), only father was employed in 58% ($n=29$) of interviewed families, and in 8% ($n=4$) of the families both parents were unemployed. There was no family in which only the mother was employed. Therefore, a statistically significant difference among the surveyed families, was noted depending on the employment status of the parents (chi-square test $p<0.001$). When the groups of WBN and NICU were compared no significant difference in the employment status of the parents was found (chi-square test $p=0.367$).

Participants estimated their total monthly household income as low, average, and high in 16% ($n=8$), 76% ($n=36$), and 8% ($n=4$) of the families respectively. Compared to the surveyed families that rated their monthly income as low or high, most of the families statistically significantly more often rated their monthly income as average (chi-square test $p<0.001$). There was no statistically

significant difference groups of WBN and NICU (chi-square test $p=0.400$).

Pregnancy, Birth, and Present Health Condition of the Child

It was the first child of 42% ($n=21$), and second, third or fourth child in 46% ($n=23$), 8% ($n=4$) and 4% ($n=2$) of the participants, respectively. Surveyed parents had mostly their first or second child rather than their third or fourth child with a statistically significantly proven difference among groups (chi-square test $p<0.001$). Any statistically significant difference was not observed between groups of WBN, and NICU (chi-square test $p=0.413$).

Prematurity was reported in 8% ($n=4$) of the cases. There were many more term births than preterm infants (binomial test $p<0.001$). All preterm infants were from NICU group and there was no preterm infants in WBN group (chi-square test $p=0.001$).

Natural birth occurred in 72% ($n=36$) of the mothers, and C-section was performed in 28% ($n=14$) of the cases. Significantly more surveyed mothers had natural childbirth in total sample (binomial test $p=0.003$). In NICU group, significantly greater number of surveyed mothers underwent cesarean section compared to WBN group (chi-square test $p=0.004$).

Complications during pregnancy were reported in 14% ($n=7$) of interviewed mothers (high blood pressure, cardiac arrhythmia in the mother, suspected Down Syndrome, etc.). A significantly higher number of surveyed mothers did not have any problems in pregnancy (binomial test $p<0.001$). The difference in complications during pregnancy between WBN and NICU groups had a borderline significance (chi-square test $p=0.064$).

There were complications in delivery reported in 10% ($n=5$) of the cases (rupture of the uterus, birth by vacuum, and fracture of the clavicle of the

baby). Complications during childbirth were reported by only a few surveyed mothers with a statistically significantly proven intergroup difference (binomial test $p < 0.001$). Childbirth complications were not significantly more common in any of the groups compared (NICU and WBN) (chi-square test $p = 0.093$).

Referrals for both ears were noted in 22% ($n = 11$) and for one ear in 78% ($n = 39$) of the children (right 24% or $n = 12$; left 54% or $n = 27$). One ear was retested more frequently than both ears (chi-square test $p = 0.008$).

At the time of interview, the children were 13.9 months old in average (± 1.9 SD). The youngest was 11 and the oldest 18 months of age. All mothers had estimated good hearing and no other serious health problems in their children.

Caregiver's Knowledge about the Topic

Knowledge of the participants about NHS, incidence of hearing impairment or treatment opportunities were at a very low level (Table 3). There was no significant difference in the number of surveyed mothers who did and did not know what NHS was (binomial test $p = 0.322$). All of them who knew what NHS means told us that they first heard about the NHS from us when their baby was screened. No statistically significant difference in NHS knowledge was observed between both groups (WBN and NICU) (chi square test $p = 0.574$).

Table 3. Knowledge of the participants about NHS, incidence of hearing impairment or treatment opportunities.

Questions	Yes N (%)	No N (%)
Do you know what NHS is?	21 (42)	29 (58)
Do you know the incidence of hearing impairment?	2 (4)	48 (96)
Do you know if any treatment can help children with hearing loss?	30 (60)	20 (40)
Do you know what cochlear implant is?	14 (28)	36 (72)
Do you support NHS?	50 (100)	0 (0)

NHS: Newborn Hearing Screening

A small number of surveyed mothers knew the incidence of deafness in newborn babies (binomial test $p < 0.001$) without any statistically significant difference between the groups of NICU and WBN (chi square test $p = 0.368$).

All caregivers (100%; $n = 50$) indicated that they supported hearing screening, but only 34% of them ($n = 17$) believed that there were effective treatments and interventions for infants born with a permanent hearing loss. Remaining 60% ($n = 30$) thought that no treatment was available while 6% ($n = 3$) were unsure. A significant difference between the surveyed mothers in terms of knowledge of therapeutic options for deaf children was noted (chi square test $p < 0.001$). The surveyed mothers in NICU group showed a significantly higher level of knowledge about therapeutic options for deaf children compared to the surveyed mothers in WBN group (chi square test $p = 0.013$).

Only 28% ($n = 14$) knew what cochlear implant (CI) was. Significantly more surveyed mothers did not know what a cochlear implant was (binomial test $p = 0.003$). Any statistically significant difference was not detected between the groups of NICU, and WBN as for being knowledgeable about cochlear implants (chi square test $p = 0.519$).

Reasons for Default in Follow-up

Most frequently given reasons for follow-up default were caregivers' perceptions that follow-

Table 4. The reasons given for follow-up default.

Reasons	N	%
We thought it was not necessary	25	50
We forgot	4	8
Control was not recommended	4	8
We could not come because of work and other obligations	3	6
Too far from the hospital	2	4
We had no transportation means	1	2
We did not have any money for transportation	1	2
The child was sick	6	12
Something else	4	8
Total	50	100

up was unnecessary (50%, n=25), their child was in serious health condition (12%, n=6), and the fact that they had forgotten about the follow-up (8%, n=6) (chi square test $p < 0.001$) (Table 4).

Despite their follow-up default, majority of the participating mothers (60%, n=30) reported that they were very disturbed in the moment we told them to bring their newborn to hearing control (rescreening). No statistically significant difference in the total sample was found (binomial test $p = 0.203$). In terms of concerns among the surveyed mothers, we did not find statistically significant difference between NICU and WBN groups (chi square test $p = 0.797$).

DISCUSSION

Despite all proven advantages of Universal Neonatal Hearing Screening (UNHS) for best treatments of children with hearing impairment^{8,20,21}, UNHS is still not implemented in hospitals in our country. Also, NHS is still not mandated or legislated. The lack of legislation along with absence of awareness of the significance of NHS typically delays initial detection of hearing loss with average ages of first diagnosis ranging from 23 to 42 months of age^{22,23}. As a developing country, our country has no data about NHS coverage or percent of newborns participating in NHS. There is also no unique NHS protocol for all birth centers in the country. Screening all newborns is performed in some centers, some of them perform screening tests for hearing only for newborns with risk factors for developing hearing impairment and some centers have no NHS protocol at all.

Total “referral” result at the first hearing test in this study was 19.1% which was much higher than 5% recommended in the literature²⁴. The reason for such a result may be an early discharge of newborns from the hospital which is forcing us to make the first hearing test of NHS too early²⁵. It is known that OAE method is very sensitive to

barriers in the middle ear (amniotic fluid) and external ear (vernix). If hearing tests have been done too early, likelihood of getting false-positive results (referral) would be higher due to these barriers in the ear canal or middle ear of the newborn with intact hearing in reality²⁶. In all cases of “referral” results of the first hearing test, we are obliged to refer the newborn to a control auditory examination which imposes additional financial burden on the parents attending NHS program and its complete and efficient implementation becomes difficult. Subsequently, increased number of newborns will not be taken to the hearing check. In this study, majority of the referred children had to be retested only on one ear and it was noted as statistically significant. It is possible that the parents did not consider the situation to be serious and therefore, they decided not to bring the child for a control hearing test. The effectiveness of NHS program, whose primary goal is to find newborn babies with high hearing threshold in time for timely intervention, is reduced in this way²⁰.

In this study, 38.1% of the newborns for whom control hearing test were recommended were not tested because of their absenteeism. Some reports from other developing countries have indicated inadequate attendance to follow-up visits²⁷. LTF rate of 43% in Malaysia and 66% in Pakistan were reported in UNHS pilot study after the first stage of screening^{28,29}. Most common causes of LTF at rescreening are low socioeconomic status, social risk factors, accessibility to follow-up facilities, having multiple children and having no babysitter/family member to care for the children left at home, having no time off from work, financial burdens imposed by travel on the facilities, lack of understanding about importance of rescreening, and mothers’ level of education^{18,30,31}. In the USA, almost 94% of newborns who needed hearing control came to control testing, and only 6-7% of newborns were lost to follow-up in the United States³². A response rate of 85% or LTF rate of 15% in the literature is

considered satisfactory³³. The results of previous study cannot be considered satisfactory with 38.1% of newborns who were lost to follow-up. As an extremely important issue, this study attempted to understand the reasons for default of newborn children on the second hearing test. The intention was to identify the reasons for newborns' failure to attend the second hearing test and to try to find solutions which would decrease LTF rates. Any reduction in the number of newborns that are lost to follow-up increases the quality and efficiency of NHS program. In this way, the costs of NHS program itself would also be reduced.

The most common reasons for parental decisions not to bring their newborn to a second hearing test scheduled in the survey were lack of information and knowledge of parents/guardians about the importance of NHS for their children. The parents' knowledge about NHS, and the incidence of hearing loss in newborns and the possibilities of rehabilitation/habilitation in this study were at a very low level. Even 50% of the surveyed parents considered that a hearing control for their newborn was not needed. Awareness of the parents/guardians and their knowledge about NHS are very important for successful implementation of NHS in our institution. In one study that looked at the problem from the perspective of parents, 99% of mothers said they needed more information about the NHS. Only parents aware of the issues dealt with by NHS were well cooperated³⁴.

In 12% of the cases poor health of the child was stated as the reason for the absence of a newborn on second hearing test in the survey. This factor cannot be influenced, but the parent with proper knowledge of NHS would bring his child to a hearing check as soon as their child's health condition allowed it. It is clear that parents' NHS education programs, at least during the pregnancy, would greatly improve the situation regarding the attendance to hearing controls.

Socioeconomic and demographic results of this study showed that most of the surveyed parents were from rural areas (64%) with low monthly income. Distance from home to the place of control of hearing test was 39.4 km on average which imposed additional financial burden on parents. The distance from the test site and transportation problems in 8% of the cases in this study were cited as a reason for LTF and another 8% of the surveyed mothers reported that they forgot to bring their child to hearing control. In the literature, good data management and introduction of a monitoring system for mothers and children after discharge from the hospital are recommended. In this way, hearing test appointments of newborn babies can be reminded to the parents. There are many opportunities for reminding parents of appointments. Phone calls, short message services (SMS), and e-mails are some of the suggested options. For a good response of parents to hearing control and for achieving low LTF, the key factor is dedicated staff involved in NHS program³³.

It seems that prematurity and the way of delivery (natural delivery or C-section), which in our study proven to be significantly different between the examined groups (NICU and WBN), were at the same time the reason why children were placed in NICU. Due to the fact that their child was placed in NICU, degree of concerns of the parents, in our study may be related to the significantly better knowledge about the treatment of children with hearing impairment. However, the amount of parental knowledge in both groups on other issues (about NHS, incidence of hearing loss in children, and CI) did not differ significantly in our study. Also, this study did not show that parents from any of the compared groups were more concerned about their child's hearing. Although certain differences between groups (NICU and WBN) were noted in this study, the fact that a child is placed in NICU after birth requires greater parental responsibility cannot be argued with certainty.

Table 5. Table of recommendations.

- Implementation of unique UNHS in all hospitals in the country with separate protocols for WBN (healthy newborns) and NICU.
- Continuing education of staff involved in execution of NHS procedures which should reduce the number of false positive (refer) results of the first hearing test.
- Continuing education of young couples and future parents about NHS, therapeutic possibilities for the children with hearing impairment and its benefits should reduce the number of children that would be lost to follow-up.
- Development of good data management and introduction of a monitoring system for mothers and children after discharge from the hospital.
- Development of some of protocols for reminding the parents on appointments for the hearing control tests (e-mails, phone calls, short message services - SMS etc.) to be.

UNHS: Universal Newborn Hearing Screening, WBN: Well-baby Nursery, NICU: Neonatal Intensive Care Unit, NHS: Newborn Hearing Screening

CONCLUSION

UNHS should be implemented and performed with unique protocols in whole country. The main reason for default in follow-up in our study was caregiver's poor knowledge about this topic. With the intention of introducing the highest quality NHS, we conducted several studies from which the following recommendations emerged as described in Table 5. Further studies should be conducted in order to prepare, and implement UNHS in our country.

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