

Why parents refuse newborn hearing screening and default on follow-up rescreening—A South African perspective

Lucia Jane Scheepers^a, De Wet Swanepoel^{a,b,c,*}, Talita le Roux^a

^a Department of Speech-Language Pathology and Audiology, University of Pretoria, South Africa

^b Ear Sciences Centre, School of Surgery, University of Western Australia, Nedlands, Australia

^c Ear Science Institute Australia, Subiaco, Australia

* Corresponding author at: Department of Speech-Language Pathology and Audiology, University of Pretoria, c/o Lynnwood and University Road Hatfield Gauteng 0002, South Africa. Tel.: +27 12 420 4280; fax: +27 12 420 3517. E-mail address: dewet.swanepoel@up.ac.za (D.W. Swanepoel).

ABSTRACT

Objectives: This study describes screen refusal and follow-up default characteristics together with caregiver reasons for screen refusal and follow-up default in twfigo South African universal newborn hearing screening programs.

Methods: A retrospective record review of universal newborn hearing screening conducted at two hospitals (Hospital A $n = 954$ infants; Hospital B $n = 2135$) over a 31 to 33 month period. Otoacoustic emission screening was conducted with rescreen recommended within six weeks for a uni- or bilateral refer. Program efficacy was described according to coverage, referral and follow-up rates. A prospective telephonic interview with caregivers who declined the initial screen ($n = 25$) and who defaulted on follow-up ($n = 25$) constituted the next study component. Caregivers were randomly selected from the screening programs for a survey related to reasons for newborn hearing screening refusal and follow-up default.

Results: Screening coverage (89.3% Hospital A; 57.4% Hospital B), initial referral rates (11.6% Hospital A; 21.2% Hospital B) and follow-up return rates (56.1% Hospital A; 35.8% Hospital B) differed significantly between hospitals and were below benchmarks. The most frequent reasons for screen refusal were related to costs (72%), caregiver knowledge of newborn hearing screening (64%) and health care professional knowledge and team collaboration (16%). Almost all caregivers (96%) indicated that if costs had been included in the birthing package or covered by medical insurance they would have agreed to newborn hearing screening. Reasons for follow-up default were most commonly related to caregiver knowledge of newborn hearing screening (32%) and costs (28%). One in four caregivers (24%) defaulted on follow-up because they forgot to bring their infant for a rescreen. Only half of caregivers (48%) who defaulted on follow-up reported being aware of initial screen results while 60% reported being aware of the recommended follow-up rescreen.

Conclusion: Caregivers most commonly refused screening due to associated costs and mostly defaulted on follow-up due to an apparent lack of knowledge regarding initial screen outcome and recommendations made for follow-up. Including NHS as a mandated birthing service is essential if coverage is to be increased, while reducing follow-up defaults requires proactive reminders and improved communication with caregivers.

Keywords: Universal newborn hearing screening; Early hearing detection and intervention; Distortion product otoacoustic emissions; Coverage; Screen refusal; Follow-up default

Abbreviations: NHS, newborn hearing screening; EHDI, early hearing detection and intervention.

INTRODUCTION

Despite the demonstrated advantages of newborn hearing screening (NHS) for optimal outcomes in infants with hearing loss [1-3], it is still not legislated or mandated in South Africa. The absence of legislation together with a lack of awareness of the importance of NHS in South Africa means that initial detection of hearing loss is typically delayed, with average ages of first diagnosis ranging from 23 to 42 months of age [4-7].

The South African health care system consists of a state run and taxpayer-funded public health care sector and a private sector, which caters for those individuals covered by private medical insurance or those who pay for care themselves. It is estimated that 16% to 45% of the population access private health care and between 55% and 84% use public health care facilities [8]. Only 27% and 53% of hospitals in the public and private health care sectors respectively offer NHS services [5, 9], with universal NHS being offered by only 14% of hospitals in the private health sector [9].

The shortage of NHS services in the private health sector and their unsystematic nature have been attributed to several factors: the omission of NHS services from hospital birthing packages, health care institutional policy and the lack of reimbursement to individuals by medical insurance [9,10]. These obstacles are compounded by a lack of awareness of the importance of NHS among other health care professionals [10]. In the public health care sector, the situation is exacerbated by inadequate equipment and training and staff shortages [5]. As a result, it is estimated that more than 90% of infants born in South Africa will not have access to NHS [5].

In the private health sector, NHS is mostly dependent on individual initiatives by private audiologists. The service remains unstructured, unsystematic and available only in certain hospitals [4]. Since NHS becomes an additional service that is often an out-of-pocket expense, concerns regarding costs may influence screen refusal and poor uptake of services [11]. Screen refusal and coverage are also influenced by caregiver knowledge and attitudes towards NHS [12], both of which could be improved through support of NHS by medical professionals involved in the newborn's care [13].

Together with the lack of NHS coverage and caregiver screen refusal, the failure of caregivers to bring their infants for follow-up rescreen after an initial NHS refer result also contributes to delayed identification and intervention of hearing loss. To date, NHS follow-up return rates in both the private and public health care sectors of South Africa have failed to meet the recommended minimum of more than 70% [14]. A minority (28%) of existing hospital-based NHS programs in the private health care sector meet national and international benchmarks ($\geq 70\%$) for follow-up [9, 14, 15].

Globally, poor follow-up return rates among infants who have failed NHS also remain a major challenge to existing programs [16]. Reports from Nigeria have indicated inadequate follow-up returns rates for second stage screening at both clinic (48.1%) and hospital-based (16%) levels [17-19]. Further afield in the USA, a national review of early hearing detection and intervention (EHDI) programs revealed that although national coverage is reported to be $>95\%$, almost half of those with initial referrals (46.1%) are lost to follow-up [20]. The lack of timely follow-up contributes to delays in diagnosis and intervention of hearing loss and may have a detrimental impact on childhood development and later academic achievement [17].

Since screen refusal and follow-up default are major barriers to the success of NHS programs [21] in South Africa, this study investigated caregiver reasons for screen refusal and follow-up default in two private health care hospital-based universal newborn hearing screening programs.

METHOD

Institutional review board approval was obtained before any data collection commenced. The investigation consisted of three components: a retrospective record review of two NHS programs (Study I), a prospective survey of reasons for screen refusal (Study II) and follow-up default (Study III).

Research context

This study was conducted at two private health care hospitals in different areas of the Western Cape Province, South Africa. The hospitals fall under the same municipality of the Western Cape region, however, according to the most recent census, the demographics of these hospitals differ considerably [22, 23]. Hospital A serves an area of 110.8 km² and a community with a population of 33 448 people, of whom 76% are white, 12.1% black African and 8.4% colored [22, 23]. English is the most commonly spoken language (68.4%), followed by Afrikaans (19.8%) [22]. Hospital B serves an area of 20.5 km² and a community with a population of 43 288 people, 65.2% of whom are colored, 18.1% black African and 14.8% white [22, 23]. Afrikaans is the most commonly spoken language (67.6%), followed by English (24.2%) [22].

NHS retrospective record review – Study I

Study population

Files of infants enrolled over a 31 to 33 month period were reviewed and processed electronically. Results of the NHS program at Hospital A were reported from May 2007 until December 2009, and from July 2007 until December 2009 at Hospital B. Hospital A included 954 infants over this period while Hospital B included 2135 infants.

Protocol and methods

Audiologists employed by the private practice situated at each hospital conducted the screening daily, except on Sundays. Automated Distortion product otoacoustic emissions were used for screening (Biologic AuDx) as recommended by the Health Professions Council of South Africa Year 2007 position statement on EHDI for South Africa [14]. The choice of screening technology was context driven and OAE screening was employed as all the infants included in the study were from a well baby nursery [14]. Screening parameters included the evaluation of the frequencies from 2, 3, 4 and 5 kHz using a 65/55dB SPL stimulus level (L1/L2). Three of the four frequencies were required for the infant to pass, with a minimum distortion product amplitude of -8dB and a minimum signal-to-noise ratio of 6dB for an overall pass result.

Caregivers were approached one to three days after the birth of the infant, prior to discharge. NHS was explained to the caregiver and subsequently offered as a fee-based service. If caregivers were discharged before being offered the hearing screening they were contacted telephonically and informed of the NHS service. Only infants from the well-baby nurseries were included in this study. Written consent was required from caregivers before hearing

screening could proceed. Record was kept of every infant enrolled in the NHS program, whether the respective caregiver had declined or agreed to the hearing screening. This hard copy record form included demographic information and hearing screening results if hearing screening had been conducted.

At both hospitals, infants were screened in the nursery, at the caregiver's bedside or in the audiology private practice situated inside the hospital building and in a room with acceptably low noise levels. The NHS program protocol was based on the guidelines provided by the Health Professions Council of South Africa Year 2007 position statement on EHDI for South Africa [14]. If the hearing screening yielded a unilateral or bilateral refer, a rescreen within six weeks of the first screen was recommended. Caregivers were required to arrange a convenient appointment date and to bring the infant to the audiology private practice for this rescreen. It was suggested that caregivers arrange the rescreen to coincide with the routine six week follow-up appointment with their pediatrician. An information leaflet was provided to all caregivers, providing general information on NHS and the contact details of the audiology practice. A sticker was placed in the infant's clinic card and hospital file indicating the practice's contact details and whether NHS had been declined, passed or a rescreen recommended. When NHS was conducted a report containing both initial and rescreen NHS results was sent to the pediatrician concerned in order to encourage caregiver follow-up compliance and to facilitate a collaborative approach to NHS. If another unilateral or bilateral refer was recorded at the rescreen, immittance measures, including high frequency tympanometry, were conducted immediately. If abnormal immittance measures were obtained, referral to an otolaryngologist and/or pediatrician was recommended, followed by a rescreen after medical management. A diagnostic audiological evaluation was scheduled as

soon as possible if normal immittance measures in conjunction with a refer result were obtained in one or both ears during the rescreen.

Data management and analysis

Information from the participants' record forms was captured in an electronic database and subsequently analyzed using a statistical package (SPSS versions 19.0 and 20.0). The retrospective data was analyzed using descriptive and inferential statistics, including the independent samples t-test with a 1% level of significance. Frequency distributions and other descriptive measures such as the mean, median and standard deviation were used to describe the results. The efficacy of the NHS programs at the two hospitals are described according to the screening and follow-up characteristics, coverage and referral rates.

Surveys of screen refusal (Study II) and follow-up default (Study III)

The second and third components of this study comprised a prospective telephonic interview with caregivers who had declined the initial hospital screen (Study II) and who defaulted on follow-up (Study III). Twenty-five caregivers who declined hearing screening for their infants and twenty-five who did not bring their infants for a follow-up rescreen at or before six weeks of age were selected out of a combined group of 363 caregivers, using a non-probability quota sampling method. Information was elicited from participants through a partially open-ended interview schedule. Only participants from Hospital B were included in these two surveys as more participants were recorded at this hospital and there was a higher rate of screen decline and follow-up default than at Hospital A.

Study population

Participants were mothers with an average age of 29.8 years (± 5.7 SD) in the screen refusal group and 29.3 years (± 5.6 SD) in the follow-up default group. Almost all (96%) ($n = 48$) participants had private medical insurance and 4% ($n = 2$) had none. Infant birth dates ranged from June 2008 to December 2009 and interviews were conducted between November 2011 and June 2012.

Protocol and methods

Telephone numbers of caregivers were obtained from the infant record forms. Participants were contacted telephonically on weekdays between 17:30 and 18:30. Informed consent was obtained verbally from the caregivers before the interview commenced.

The interview survey for screen refusal consisted of four sections (demographic information, caregiver knowledge of NHS, initial test and follow-up rescreen), containing in total 12 partially open-ended questions. The interview survey for follow-up default also comprised four sections (demographic information, caregiver knowledge of NHS, initial and follow-up rescreen and one year follow-up), composed of a total of 11 partially open-ended questions. The researcher and a trained research assistant conducted the interviews, which lasted on average between 12 and 15 minutes.

Data management and analysis

Responses were recorded on data collection forms and transferred to an electronic database before being analyzed using the statistical package SPSS (versions 19.0 and 20.0).

Descriptive statistical analysis was employed to determine frequency distributions, means

and standard deviations. The Fisher's Exact and Chi-Squared tests were conducted to determine statistically significant relationships between variables.

RESULTS

NHS retrospective record review – Study I

There were 954 infants from Hospital A and 2135 from Hospital B. The mean age of the infants from Hospital A was 3.1 days (± 11.3 SD), and 1.8 days (± 1.0 SD) at Hospital B. Almost all the caregivers of the infants concerned had private medical insurance (99.8% (952/954) for Hospital A and 98% (2093/2135) for Hospital B).

Very few (10.5% 11%; $n = 100$) caregivers from Hospital A who were offered NHS declined the service, while at Hospital B just under half (42.5%; $n = 907$) declined NHS. The initial referral rate for Hospital A was 11.6% and for Hospital B, 21.2% (figure 1). Follow-up default rates were 43.9% ($n = 43$) for Hospital A and 64.2% ($n = 167$) for Hospital B (figure 1).

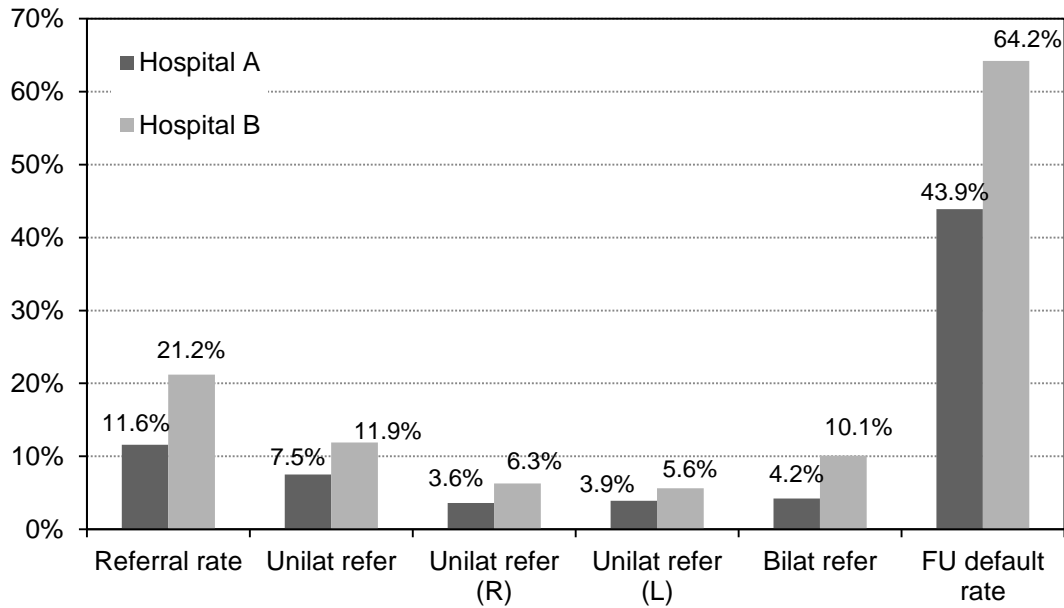


Figure 1. Newborn hearing screening referral rate and follow-up return rate *Unilat = Unilateral; Bilat = Bilateral; R = Right; L = Left; FU = Follow-up*

There was a statistically significant difference (Fisher’s Exact test; $p < 0.0001$) between the age of infants who failed the initial screen (1.7 days; 1.3 SD; $n = 91$) and those who passed (3.5 days; 12.4 SD; $n = 690$) at Hospital A (figure 2). Results for Hospital B also revealed a

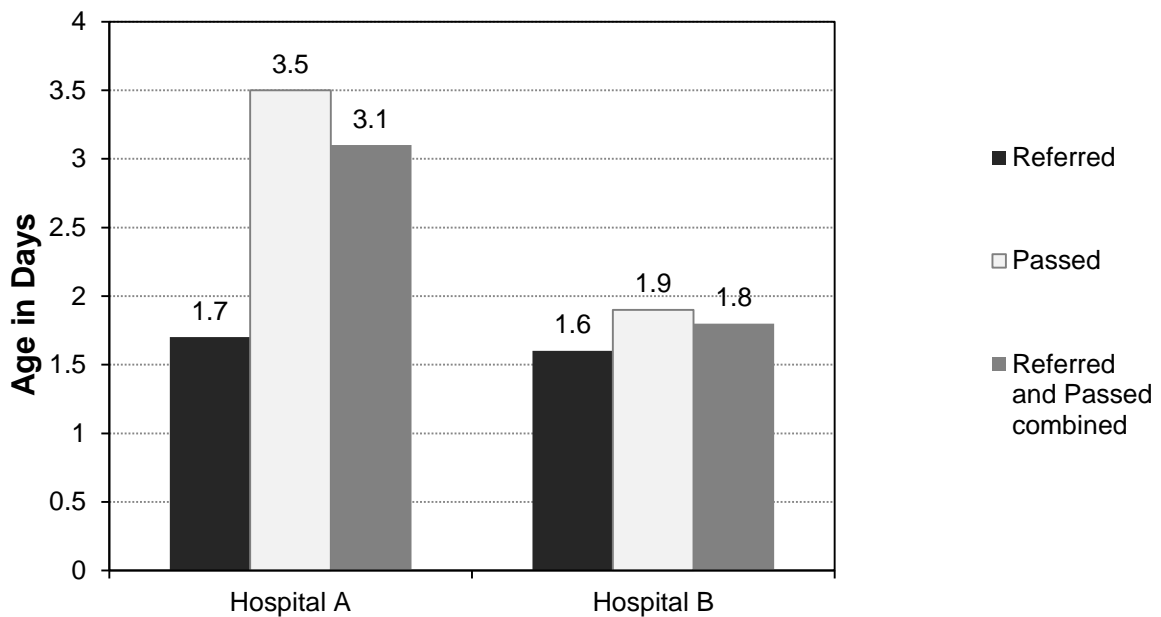


Figure 2. Average age of infants who passed or referred newborn hearing screening

significant difference (Fisher’s Exact test; $p < 0.0001$) between the age of infants who failed the screen (1.6 days; 0.6 SD; $n = 252$) and those who passed (1.9 day; 1.3 SD; $n = 925$). There was no statistically significant effect of the duration of program existence (Chi-squared test; $p > 0.05$) or birth weight (Fisher’s Exact test; $p < 0.0001$) on the referral rate.

Screen refusal survey – Study II

The reason most commonly given by caregivers for screen refusal was the failure of medical insurance to cover the costs (52%; $n = 13$), followed by the perception that such screening was unnecessary (32%; $n = 8$) (table 1).

Table 1. Caregivers’ reasons for declining the NHS screen ($n = 25$)

Reason for screen refusal	Frequency
Medical insurance does not cover cost	52% ($n = 13$)
Not necessary	32% ($n = 8$)
Not enough information received prior to the birth	24% ($n = 6$)
Not included in the hospital birthing package	20% ($n = 5$)
Not recommended by the pediatrician	16% ($n = 4$)
Unsure	8% ($n = 2$)
Consult with family first	4% ($n = 1$)
Caregiver forgot	4%

Just over a third of caregivers (36%; $n = 9$) who were surveyed indicated prior knowledge of the fact that a baby’s hearing can be tested soon after birth. Of this group, 20% ($n = 5$) had received information on NHS at the time of the birth of an earlier child, while 16% ($n = 4$)

received information from a pediatrician. Only 40% ($n = 10$) of respondents thought that NHS was reliable, with the majority (60%; $n = 15$) unsure.

Almost all caregivers (88%; $n = 22$) reported that NHS was important (figure 3). Although 20% ($n = 5$) of caregivers indicated that they did not think effective treatment or intervention was available for infants identified with permanent hearing loss, and half (48%; $n = 12$) were unsure about this, almost all (96%; $n = 24$) caregivers indicated that they would have agreed to hearing screening if it had been included in the cost of the birthing package or if their private medical insurance covered the costs.

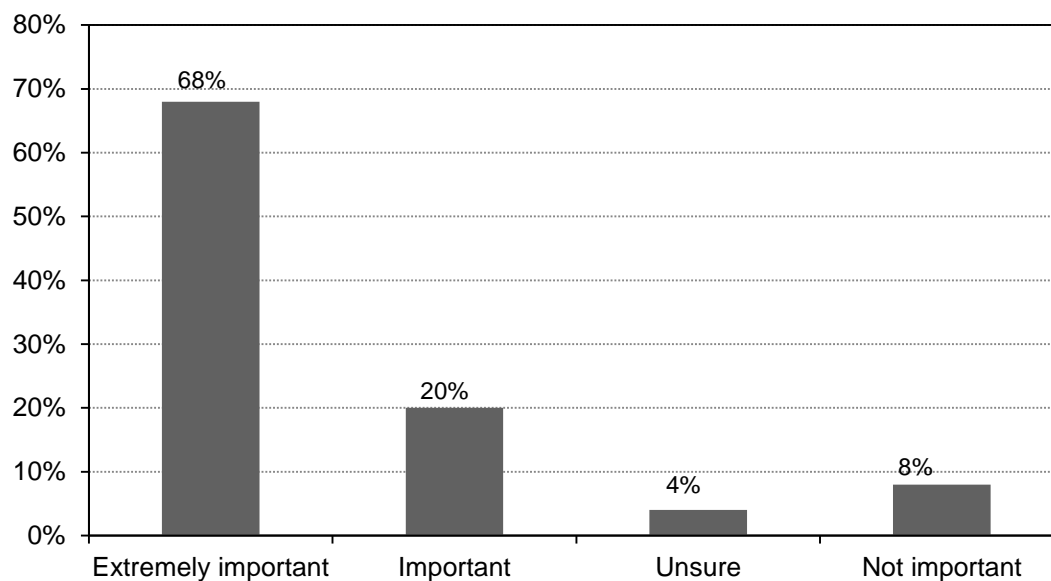


Figure 3. NHS importance as perceived by caregivers who refused hearing screening ($n=25$)

Just over a third of caregivers (36%; $n = 9$) reported having received written information regarding NHS when the screen was offered to them. Of the caregivers who received this information, the majority (77.8%; $n = 7$) reported that NHS was extremely important although most of this group (77.8%; $n = 7$) were uncertain of its reliability. One third (33.3%; $n = 3$) of

this group believed that there was effective treatment available for infants born with a permanent hearing loss. Almost half (44.4%; $n = 4$) of the caregivers who received written information regarding NHS indicated that an audiologist was the person responsible for NHS, whilst 44.4% ($n = 4$) indicated that the responsible professional was the pediatrician. The remainder (11.1%; $n = 2$) believed that the caregiver was primarily responsible for NHS. There was no statistically significant effect of maternal age on the rate of screen refusal (Fisher's Exact test; $p < 0.0001$).

Follow-up default survey – Study III

The reasons given most frequently for follow-up default were caregivers' perceptions that follow-up was unnecessary (32%; $n = 8$), and the fact that they had forgotten about the follow-up (24%; $n = 6$) (table 2).

Table 2. Caregivers' reasons for defaulting on the follow-up appointment ($n=25$)

Reason for follow-up default	Frequency
Not necessary	32% ($n = 8$)
Caregiver forgot	24% ($n = 6$)
Unaware re-test costs were included in initial cost	20% ($n = 5$)
Re-test not recommended by pediatrician	12% ($n = 3$)
Medical insurance did not cover cost of initial test	8% ($n = 2$)
Caregiver unable to bring infant owing to work commitments	8% ($n = 2$)
No transport	4% ($n = 2$)

Almost all caregivers (96%; $n = 24$) reported having received information regarding NHS while they were still in hospital after the birth of their infant. The majority (80%; $n = 20$)

received this information from an audiologist or from nurses (8%; $n = 2$), from pediatricians (4%; $n = 1$), gynecologists (4%; $n = 1$) or others (4%; $n = 1$). Most (80%; $n = 20$) of the caregivers reported having received an information pamphlet on NHS, outlining its importance and providing the audiology practice's contact details.

Despite almost all caregivers (96%; $n = 24$) indicating that they believed that early detection of hearing loss was extremely important, only 56% ($n = 14$) believed that there was effective treatment and intervention for infants born with a permanent hearing loss. Only 8% ($n = 2$) thought that no treatments are available while 36% ($n = 9$) were unsure.

Almost half of the caregivers (48%; $n = 12$) reported being aware of the hearing screening outcome, while 48% ($n = 12$) were apparently unaware of this, and 4% ($n = 1$) were unsure. The majority (60%; $n = 15$) of caregivers reported being aware of the recommendation to bring their child back for a follow-up re-test after six weeks, but 36% ($n = 9$) were apparently unaware of this (4%; $n = 1$ were unsure). Of those who indicated being aware of the six week follow-up recommendation, most (44%; $n = 11$) attributed this to a discussion with the audiologist, while others (36%; $n = 9$) attributed it to the sticker placed in the infant's clinic card by the audiologist, recommending the follow-up. No caregivers reported being informed of the follow-up recommendation by the pediatrician or a nurse.

Just over half of caregivers (56%; $n = 14$) reportedly felt NHS was reliable, while 24% ($n = 6$) indicated that it was unreliable and 20% ($n = 5$) were unsure. Half of the caregivers (48%; $n = 12$) indicated that they would like to bring their child for a follow-up rescreen, while 44% ($n = 11$) reported that they would not want to bring their child for a rescreen as they felt it was unnecessary (84.6%; $n = 11$), or because their medical insurance did not cover the initial test

cost (7.7%; $n = 1$). A small group of caregivers (7.7%; $n = 1$) was unsure whether they wished to bring their child for a follow-up rescreen or not.

The majority of caregivers (80%; $n = 20$) reported receiving written information regarding NHS. Almost all (95%; $n = 19$) of those who had received written information indicated that NHS was extremely important and over half (60%; $n = 12$) felt that NHS was reliable. Half (50%; $n = 10$) felt that effective treatment of a permanent hearing loss was available, while 40% ($n = 8$) were unsure and 10% ($n = 2$) believed that no treatment was available. The majority of caregivers (85%; $n = 17$) who received written information about NHS felt that an audiologist was the person responsible for NHS, 10% ($n = 2$) believed it was the role of the nurse and 5% ($n = 1$) were unsure.

DISCUSSION

NHS retrospective record review — Study I

Screening coverage differed between hospitals (89.3% Hospital A; 57.4% Hospital B) and was below recommended national and international ($\geq 95\%$) benchmarks [14, 15]. Different demographic characteristics, including socio-economic conditions and educational levels in the two areas in which the hospitals are situated, may partly explain differences in screen coverage and rate of screen decline. Hospital A serves a more affluent and educated, predominantly white, (76%) community while Hospital B serves a relatively socially deprived colored (65.2%) community with lower levels of education [23]. Higher levels of caregiver education have previously been associated with earlier diagnosis of hearing loss and initiation of intervention [24]. While almost all (99.8% Hospital A; 98% Hospital B) caregivers had medical insurance, some schemes covered only the birthing and hospitalization costs, leaving caregivers to cover the NHS costs out of their own pockets. In a

private hospital in Gauteng, South Africa [11], poor coverage rates were attributed to the exclusion of NHS from the birthing package. When NHS costs were included in the birthing package the coverage rate increased from 20% to 75% [11].

Initial referral rates of both Hospital A and Hospital B (11.6% and 21.2% respectively) were two to four times higher than the recommended referral rate of 5% [14, 15], with rates at Hospital B twice as high as those at Hospital A, despite similar protocols and quality control measures. This discrepancy may be partly attributable to the higher annual birth rate at Hospital B (2135 compared to 954 infants at Hospital A). A heavier caseload increases the pressure to test infants earlier in order to ensure all infants are tested before being discharged. This was confirmed by the lower average screen age for Hospital B, where infants tested were, on average, only half the age (1.8 days; 1.0 SD) of those tested at Hospital A (3.1 days; 11.3 SD). Testing younger newborns, predisposed as they are to residual vernix in the ear canal and amniotic fluid in the middle ear, makes them less likely to pass the NHS than older infants [25, 26]. Referral rates that are too high place an added burden on NHS program resources and influence successful tracking and follow-up of referred infants [27]. An increased caseload may influence time spent with caregivers and for motivating for NHS and for counseling following NHS.

Follow-up return rates at both hospitals (56.1% Hospital A; 35.8% Hospital B) were below recommended national benchmarks ($\geq 70\%$) [14, 15]. Screening programs in this study relied heavily on caregivers complying with the requirement to return for follow-up rescreening; there was little or no tracking by NHS program staff. This failure to remind and encourage caregivers to comply with the recommended follow-up re-test may have affected follow-up rates adversely [18]. Lack of quality control and inefficient tracking of caregivers following

discharge [9,11], as well as inadequate support from other health care professionals are reasons which have been offered for the poor follow-up rates in studies conducted in the private health sector in South Africa [9, 11]. Satisfactory follow-up return rates have recently been reported at public health clinic and tertiary hospital level (85.1% and 91.8% respectively) [28], however, where this success was attributed to the employment of a dedicated screening coordinator to monitor the NHS program through a system of telephone calls, home visits, training of staff and visual reminders to track participants and ensure follow-up compliance [28]. In the United States, satisfactory follow-up rates (94.4%; 93.6%) have been recorded in states that actively follow up on caregivers [20]. Furthermore, follow-up rates could be improved by addressing caregiver attitudes towards the necessity and reliability of NHS [29, 30].

Internationally, high referral rates and sub-par follow-up return rates were also reported for hospital-based (32.3% and 16% respectively) and immunization clinic-based (14.3% and 48.1% respectively) NHS programs in Nigeria [17, 18]. A review of the average coverage and follow-up return rates across a combination of 46 developed and developing countries indicated that regional coverage (66% for high income and 1% for low income countries) falls significantly below proposed benchmarks ($\geq 95\%$) [15], with only the high income countries achieving follow-up rates above these benchmarks ($\geq 70\%$) [15, 21].

Reported NHS coverage, referral and follow-up return rates across South Africa have been poor and to date the reasons for caregiver screen refusal and follow-up default have not been surveyed. The second part of this study investigated these reasons.

NHS prospective surveys - Study II and Study III

Reasons for screen refusal

The most frequently occurring reasons (72%) that caregivers gave for screen refusal were cost related (52% medical insurance does not cover cost; 20% cost not included in the hospital birthing package). Almost all (96%) caregivers indicated that they would have agreed to NHS had the cost been included in the birthing package and/or covered by medical insurance. These findings support the inclusion of NHS costs in hospital birthing packages and medical insurance [31] with centralized data management and quality control monitoring [9] to improve coverage.

Other reasons given included those associated with caregiver knowledge (64%) of NHS (32% NHS not necessary; 24% not enough information given prior to the birth; 8% unsure). In a survey of maternal views of EHDI, 99% of mothers expressed the need for more information [30] with clear and easily understandable written information detailing the hearing evaluation results and diagnosis [7]. Findings from this study revealed that caregivers who received written information were more likely to report that NHS was extremely important (77.8%), that effective treatment was available for permanent congenital hearing loss (33.3%) and that an audiologist was the professional responsible for NHS (44.4%), than those caregivers who did not receive written information. Caregiver awareness and education about NHS are vital for its successful implementation [30]. The degree of understanding among caregivers of the importance of NHS is directly related to the level of caregiver participation [32]. Public awareness campaigns focusing on NHS at appropriate levels, such as at antenatal visits [17, 33, 31], with a particular emphasis on underserved communities are therefore essential to successful NHS programs in South Africa [24].

A number of caregivers (16%) declined NHS because their pediatrician did not recommend it. More than half (52%) of caregivers refusing NHS believed that the pediatrician was the professional responsible for NHS (figure 4). For these caregivers, this may have influenced screen compliance negatively as NHS was offered by the audiologist and not the pediatrician. This emphasizes the importance of physician support for NHS. The majority of caregivers (68%) who agreed to NHS believed that the audiologist was the professional responsible for NHS (figure 4). A survey of NHS in the private health sector of South Africa revealed that limited awareness of the importance of NHS among health care professionals often undermines its successful implementation [10]. Strengthening the medical community's knowledge and involvement, from screening to intervention, can better advocate and support NHS [32]. In this study, the cost of NHS, caregiver knowledge of NHS and the level of support from health care professionals involved in infant care were most influential in parental refusal of NHS.

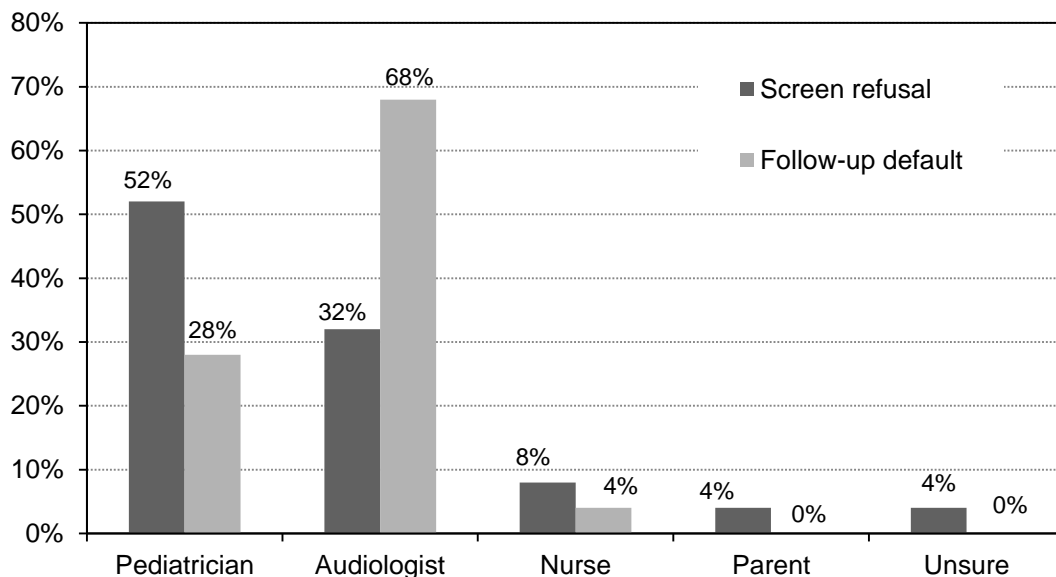


Figure 4. Person perceived responsible for NHS as reported by caregivers who refused NHS (n=25) and who defaulted on follow-up retest (n=25)

Reasons for follow-up default

The reason caregivers gave most frequently for follow-up default was associated with caregiver knowledge of NHS, with 32% indicating that they regarded follow-up rescreen as unnecessary. Only half of caregivers (48%) who defaulted on follow-up indicated that they were aware of the screen results while only 60% indicated that they were aware of the recommended follow-up rescreen. This implies that follow-up default may have occurred in part because caregivers were unaware of or did not comprehend the screen outcome and follow-up rescreen recommendations, despite most (80%) indicating that they had received written information regarding NHS at the initial screen. These findings emphasize the importance of effective communication with the caregiver and explanation of screen results and recommendations to this individual by the screener, accompanied by written information explaining NHS, the meaning of the screen results and the follow-up process [24]. The breakdown in clear communication of NHS results and the importance of follow-up interaction with the caregiver can have a negative effect on follow-up compliance [17, 33]. Although screening results and recommendations from these screening programs were conveyed to caregivers both verbally and in writing, follow-up compliance may have been enhanced had a follow-up appointment been confirmed immediately after the screen refer. Effective screener-caregiver communication must be supported by the education of caregivers regarding NHS at pre-birth opportunities [34].

A number of caregivers failed to return for follow-up as they were not aware that the rescreen cost was included in the initial screen cost (20%), while others (8%) failed to return because their medical insurance did not cover the initial screen cost. NHS cost is therefore an important concern for caregivers and influences screen refusal as well as follow-up compliance. These findings highlight the need for NHS to be made mandatory and part of

national policy in both the private and public health care sectors of South Africa. NHS costs should be included in hospitalization birthing packages and covered by medical insurance in South Africa in order to ensure effective identification and subsequent management of permanent congenital and early-onset infant hearing loss [31].

One in four caregivers (24%) defaulted on follow-up because they forgot to bring their infant for a rescreen. Caregivers were not reminded, either telephonically or in writing, with screening programs in this study relying exclusively on caregivers' own initiative in arranging a follow-up appointment based on screen outcome. The administration of efficient data management systems and tracking protocols [35] by dedicated personnel through the use of telephone calls and visual reminders such as text messages and emails to inform caregivers of the need to follow up [28] would facilitate and improve follow-up rescreen compliance. The immediate confirmation of a follow-up appointment date in writing following NHS would support follow-up compliance.

In a small number of cases (12%), caregivers failed to bring their infants for follow-up as the pediatrician concerned did not recommend the rescreen. This emphasizes the importance of team collaboration and increased awareness of NHS and continuing professional education amongst health care professionals involved in infant care [31]. A team approach is essential in facilitating the follow-up process and in reducing delays in early intervention [24].

Multiple parties who are involved in the infant's care and who encourage NHS and motivate caregivers to comply with follow-up re-test recommendations will improve program outcomes. Lastly, logistical issues (8% unable to bring infant because of work commitments; 4% no transport) were cited by caregivers as reasons for defaulting on their follow-up appointments. These same logistical reasons for follow-up default were reported by some

caregivers in a study in Nigeria [17] and could be addressed by scheduling a follow-up rescreen appointment immediately, to coincide with compulsory pediatric check-ups or hospital visits.

The large time frame between the birth of the infant and the caregiver interview is a limitation of this study along with sampling from only one of the two hospitals. Future studies investigations of reasons for screen refusal and follow-up default from should sample communities with various demographic profiles and contexts..

CONCLUSION

Issues of cost were the most common factors related to screen refusal, followed by lack of awareness of the importance and reliability of NHS among caregivers and the health care professionals involved in their infants' care. In terms of factors related to follow-up default, caregivers' lack of knowledge of screen outcome and follow-up recommendations, as well as inadequate knowledge of NHS and the NHS process were most commonly related to follow-up default. Findings from this study indicate that caregivers who received written information about NHS were more likely to have an accurate understanding of and positive associations with NHS. Support and education of health care professionals may best be facilitated if NHS becomes mandated hospital or birthing facility practice so that individual preferences do not overrule best practice. Centralized data management and quality control monitoring systems that include accurate tracking of referred infants through the use of text message, email and telephonic reminders by dedicated personnel are also essential to improve follow-up compliance. Screen refusal and follow-up default rates must drop if the development of age-appropriate speech and language through early identification and intervention of infants born with a hearing loss is to be facilitated.

ACKNOWLEDGMENTS

The authors acknowledge the valued assistance of Dr Mike van der Linde, Department of Statistics, University of Pretoria, and thank the audiologists and caregivers who participated in this study.

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