

**EARLY DETECTION OF INFANT HEARING LOSS IN THE PRIVATE HEALTH
CARE SECTOR OF SOUTH AFRICA**

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ABSTRACT

Objective: A national survey of early hearing detection services was undertaken to describe the demographics, protocols and performance of early hearing detection, referral, follow-up and data management practices in the private health care sector of South Africa.

Methods: All private hospitals with obstetric units (n=166) in South Africa were surveyed telephonically. This data was incorporated with data collected from self-administered questionnaires subsequently distributed nationally to audiology private practices providing hearing screening at the respective hospitals reporting hearing screening services (n=87). Data was analyzed descriptively to yield national percentages and frequency distributions and possible statistical associations between variables were explored.

Results: Newborn hearing screening was available in 53% of private health care obstetric units in South Africa of which only 14% provided universal screening. Most (81%) of the healthy baby screening programs used only otoacoustic emission screening. Auditory brainstem response screening was employed by 24% of neonatal intensive care unit screening programs with only 16% repeating auditory brainstem response screening during the follow-up screen. Consequently 84% of neonatal intensive care unit hearing screening programs will not identify auditory neuropathy. A referral rate of less than 5% for diagnostic assessments was reported by 80% of universal programs. Follow-up return rates were reported to exceed 70% by only 28% of programs. Using multiple methods of reminding parents did not significantly increase reported follow-up return rates. Data management was mainly paper based with only 10% of programs using an electronic database primarily to manage screening data.

Conclusions: A shortage of programs and suboptimal and variable protocols for early hearing detection, follow-up and data management in existing programs mean the majority of babies with hearing loss in the South African private health care sector will not be identified early. Newborn hearing screening must be integrated with hospital-based birthing services, ideally with centralized data management and quality control.

KEYWORDS

Newborn hearing screening; infant hearing loss; auditory brainstem response; otoacoustic emissions; auditory neuropathy; follow-up

Introduction

All children have the basic human right to have access to human communication, regardless of where they are born, their race, their nationality, their family's income, or the level of education of their parents [1]. Every year more than 800 000 infants globally are estimated to be born with, or acquire permanent bilateral hearing loss (>40dBHL) within the first few weeks of life [2-3]. This estimate is even higher if unilateral, fluctuating and/or minimal hearing losses are also included [2-3]. More than 90% of these infants reside in developing countries such as South Africa, where a scarcity of quality data describing the epidemiology of hearing impairment exists as a result of limited systematic or routine screening programs [3-6].

The South African health care system is divided into the public and private sectors. The majority of South Africans rely on the public health care sector for health services [7-8]. Recent South African reports evidence some progress in the initiation of pilot early hearing detection and intervention (EHDI) programs in public and private health care settings, but no mandated systematic hearing screening programs are available [6-7]. At present the prevalence of infant hearing loss has been estimated at 6/1000 live births in the public health care sector and 3/1000 live births in the private health care sector [6]. These infants can only be detected early enough for optimal intervention outcomes through widespread newborn and infant hearing screening programs using objective screening technologies such as otoacoustic emission and auditory brainstem response screeners [6, 9-13].

Late detection of hearing loss impedes language, psychosocial, emotional and cognitive development in early childhood, which in turn undermines later educational and vocational attainment [1, 3, 9-14]. The negative effects of hearing loss are exacerbated by the poor socio-economic conditions and burdened health care system in South Africa [14]. The longer the hearing impairment goes undetected, the poorer the language and speech outcomes are likely to be with higher associated costs [1, 9-11, 14]. In South Africa, various studies report average age of diagnosis to be well over 18 months due to the absence of a systematic effort to screen infants [5-6]. This can be attributed to the poor status of current EHDI services in South Africa. In the public health care sector, which serves approximately 85% of the population, only 7.5% of hospitals provide some form of neonatal and infant hearing screening and virtually no (<1%)

universal screening is provided [7]. As a result more than 90% of babies born in South Africa are left without the prospect of early detection of hearing loss [7].

Although the principles of EHDI programs are supported by the Integrated National Disability Strategy White Paper [15] and the Position Statement produced by the Health Professions Council of South Africa [12] it is not mandated by hospital management or universally included as part of maternal birthing services [6]. Consequently, efforts to implement EHDI programs remain mostly unsystematic and only available in certain hospitals with the exact status unknown [6]. National surveys on current screening services and available resources (including financial, equipment, facilities and trained personnel resources) have been recommended as an important priority to establish the current status and capacity of EHDI programs [6,12]. In response, a survey of newborn screening services in the public health care sector was completed in 2008 [7].

Until recently, however, there has been no survey of EHDI services in the private health care sector. The current study is part of the first national survey on early hearing detection services in the private health care sector where approximately 150 000 babies are born annually [16]. Screening, referral, follow-up, and data management protocols in early detection services across the private health care sector of South Africa are reported in this study.

METHOD

The national survey was conducted in South Africa's private health care sector and institutional ethics committee approval was obtained before data collection was initiated.

Study Population

The total population included all private health care institutions that offer obstetric services and the private practice audiologists (registered with the Health Professions Council of South Africa) who provide infant hearing screening services at these units. Every private health care (non government funded) sector institution in South Africa was contacted telephonically by the first author to determine whether the respective institution rendered obstetric services. A total of 304

private health care sector institutions, including hospitals, clinics or private practices listed on a national registry (www.medpages.co.za) [17] were identified for potential inclusion in the sample. After removing duplicate listings, the remaining 298 hospitals were contacted. Eight of these hospitals were not eligible for the current study since they were partly government funded whilst four others no longer exist. Of the remaining 286 eligible private health care institutions, 120 (42%) did not render obstetric services. Ward matrons at the remaining 166 institutions with obstetric units were subsequently surveyed regarding newborn hearing services.

Procedures

Data on the existence of and type of newborn hearing screening program were collected from matrons at private hospital maternity wards by means of a telephonic survey along with information on the responsible audiologist. Subsequently questionnaires were distributed nationally to audiologists providing hearing screening at the respective private sector institutions who reported hearing screening services (n=87). Questionnaires were sent out in July 2010 and all data was collected by the end of August 2010. Participants who rendered services at more than one private institution were asked to complete separate questionnaires for each institution to ensure that data was representative of the respective hospitals or clinics. The self-administered questionnaire was distributed by email or fax and consisted of sections including biographical information, work context and hearing screening practices. Subsequent sections covered information on data management and quality control, diagnostic protocols and intervention practices. A high return rate of 89% (77/87) was obtained for the questionnaires across all nine provinces of South Africa, providing data of early detection programs in the private health care sector nationally.

This study reports on the following aspects of the private health care sector survey: 1) early hearing detection program demographics and protocols used; 2) performance and protocols related to referral and follow-up; 3) data management practices.

Data management and analysis

Data collected from a telephonic survey made to private hospital maternity wards were incorporated with data from the questionnaires completed by audiologists at the respective private

health care institutions. The data were analyzed descriptively to yield percentages and frequency distributions nationally. In addition, Chi-Squared and, where appropriate, Fisher’s Exact tests were used to investigate a possible statistically significant association between variables.

RESULTS

Early hearing detection program demographics and protocols

Of the 166 private health care institutions nationally with obstetric units, only 53% (87/166) reported some form of newborn hearing screening service. Of the 87 units reporting hearing screening, 77 (89%) returned the questionnaires. Universal hearing screening was only reported by 14% of institutions with obstetric units and a further 18% reporting universal screening on most days but not 7 days a week. The remaining units indicated using a risk-based newborn hearing screening approach (3%) and offering screening on request from parents or other health care providers (18%). All audiologist respondents indicated that they work in towns and cities and none in rural contexts.

Table 1: Screening tests used for the initial and follow-up hearing screening (n=77)

SCREENING TESTS USED	INITIAL SCREENING		FOLLOW-UP SCREENING
	Healthy baby wards	NICU	
AABR only	1%	8%	0%
AOAE only	81%	47%	17%
AOAE and AABR	1%	16%	10%
AOAE and HF tympanometry	9%	9%	10%
AOAE and Diagnostic OAE	0%	4%	5%
Diagnostic OAE and Diagnostic ABR	4%	4%	5%
Diagnostic OAE only	1%	1%	3%
Diagnostic ABR only	0%	3%	0%
Diagnostic ABR and AOAE	0%	1%	0%
AOAE, HF tympanometry and diagnostic OAE	0%	0%	8%
AOAE and HF tympanometry and diagnostic OAE and behavioral observation audiometry	0%	0%	8%
AOAE and behavioral observation audiometry	0%	0%	4%
AABR and AOAE and HF tympanometry	0%	0%	4%
Other combination or no testing	3%	7%	26%

Table 1 represents the combinations of screening tests used for the initial hearing screening regardless of the screening program employed. In the healthy baby ward, the vast majority of programs (91%; 70/77) used automated otoacoustic emission (AOAE) screening as a single test or in combination with other procedures as part of their protocol, whilst only 2 programs (3%) employed automated auditory brainstem response (AABR) testing (Table 1). Most (81%; 62/77) of the screening programs used only AOAE screening for healthy babies, and a single screening program reported utilizing AOAE in conjunction with AABR. In the neonatal intensive care unit (NICU) the majority (47%; 36/77) of programs employed only AOAE testing on NICU babies for initial screening and 16% (12/77) utilized two-stage screening with AOAE and AABR. A small number (9%; 7/77) of screening programs reported using AOAE testing in conjunction with high frequency tympanometry on NICU babies (Table 1).

Almost all (97%; 75/77) screening programs conducted the initial screen within the healthy baby or NICU wards. Of the remaining two programs (3%), one conducted screening in a separate room in the unit and another one performed screening in the audiology department. In the event of noise levels being too high in the ward, alternative test environments were reportedly sourced by 39% (29/75) of programs. Twenty two per cent (17/75) of programs reported using a room in the audiology department, 12% (9/75) reported using a sound-treated room and 4% (3/75)

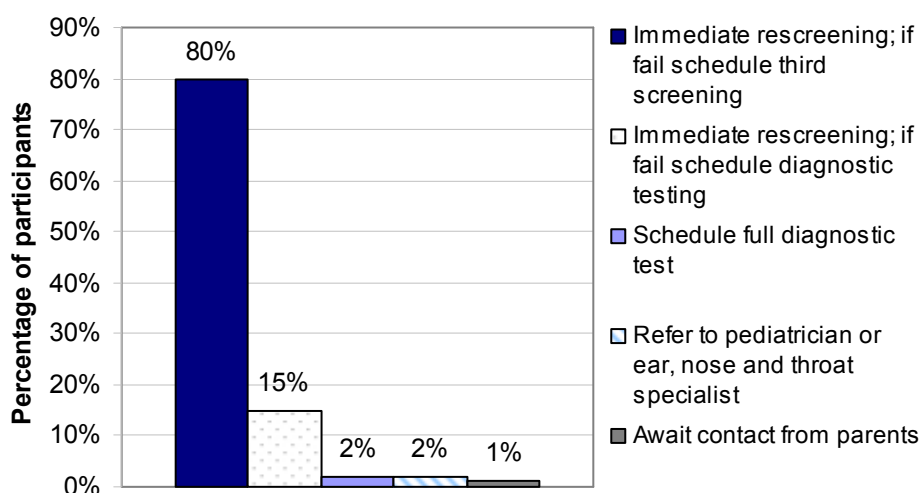


Figure 1: Protocol following first screening fail result (n= 77)

reported screening in the out-patient department as an alternative location when screening could not be performed in the healthy baby or NICU ward due to excessive noise levels.

All programs indicated that a bilateral pass criterion was employed for an overall pass result. However, if a baby failed the first screen, programs proceeded differently in terms of referral pathways and follow-up protocols as summarized in Figure 1.

Referral and follow-up performance and protocols

Figure 2 illustrates the distribution of first screen refer rates. Parents of babies who presented with fail results on the first screening often did not return for follow-up testing appointments. Twenty-eight per cent of programs indicated that less than 20% of babies scheduled for follow-up testing returned. Follow-up return rates of between 21% and 69% were reported by almost half (44%) of programs and only 28% reported follow-up return rates of 70% and higher.

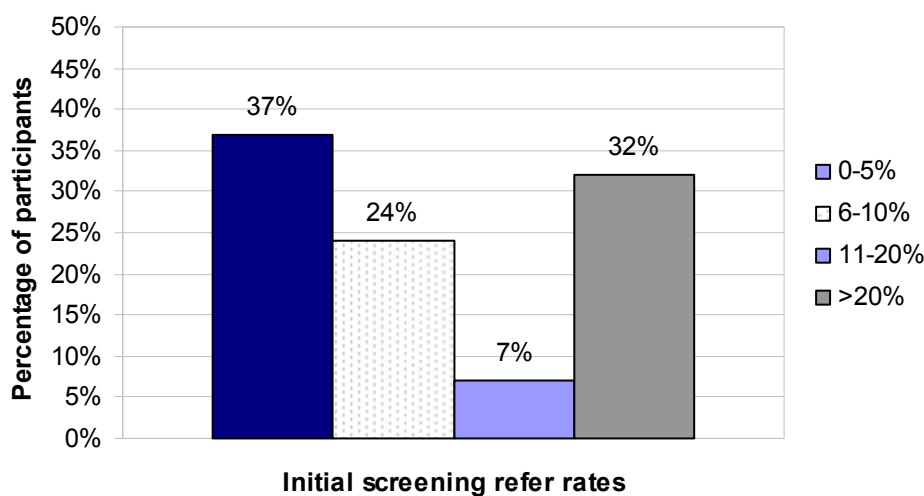


Figure 2: Distribution of reported initial screening failure rates (n=68)

In the event of an initial fail result, caregivers were reminded about the follow-up screening appointment in various ways. More than half (38/71) of the programs utilized a single method to remind parents of the follow-up appointment. One in four programs (18/71) contacted parents telephonically, 23% (16/71) sent reports or letters and 6% (4/71) sent text message reminders. Twenty-seven programs used a combination of two methods to remind parents to return for the follow-up screening appointment. These combinations included a mailed letter and phone call for

17% (12/71); a phone call and text message for 16% (11/71); a mailed letter and text message for 4% (3/71); and one program (1%, 1/71) sent an email and text message reminder. The remaining six participants used combinations of three different methods to remind parents to return for follow-up screening. No significant association was found between number of methods used to remind parents and the reported follow-up return rate (Chi-Square and Fisher's Exact tests; $p > 0.05$).

Similar to methods used for initial screening, the most commonly used (80%; 61/76) screening approach for follow-up screening was AOAE testing for both healthy and NICU baby graduates (Table 1). Babies who returned for the follow-up testing and subsequently failed the screening were referred for diagnostic testing. The vast majority (80%) of universal screening programs reported that less than 5% of babies screened had to be referred for diagnostic testing whilst the remaining 20% reported diagnostic referral for between 5% and 10% of babies.

Data management practices

Most (90%; 69/77) programs relied primarily on paper database systems to keep track of patient and screening data. The remaining 10% (8/77) utilized an electronic database for patient and screening data. All programs indicated that recorded results were stored in more than one location. Of the programs relying primarily on a paper database, 62% (43/69) additionally document screening results on the baby's "Road to Health" card which is kept by caregivers, 59% (41/69) indicated results in the hospital file, 28% (19/69) stored results on the equipment database and 22% (15/69) stored results on a separate electronic database. The majority (88%; 7/8) of programs that primarily recorded results on an electronic database also documented the screening results on the baby's "Road to Health" card with 25% (2/8) also documenting results in the hospital file.

DISCUSSION

Early hearing detection program demographics and protocols

The present study is part of a national survey of newborn hearing screening and early hearing detection protocols in the private health care sector of South Africa [16], which serves

approximately 15% of the population [8]. Despite serving a minority, the private health care sector utilizes most of the financial and human resources devoted to health care in the country and is funded by individuals, government departments and companies as opposed to the public health care sector for which the main source of funding is general taxation [18]. The current study describes screening and follow-up protocols together with referral and data management characteristics. Nationally just more than 53% of private health care sector birthing units in South Africa offer some form of hearing screening service. Only 14% however provide true universal newborn hearing screening[16] which means a small minority of private health care birthing units provide recommended best practice in neonatal care [10-11,13].

Universal screening is provided by 14% of birthing units in the private health care sector that provides services to 15% of the population .[16] These services are rendered by less than 1% of birthing units in the public health care sector which serves 85% of the population [7-8]. By combining these figures it is estimated that less than 3% (2,95%) of birthing units in South Africa offer universal newborn hearing screening programmes.

All screening programs (n=77) in the private health care sector who responded included objective screening technologies in their protocols. These test measures, including AOAE and AABR, were employed separately or in combination, depending on different cost and effectiveness considerations [14]. Only one (1/77) program utilized a two-stage screening protocol in the healthy baby nursery, including AOAE and AABR testing. This two-stage protocol has previously demonstrated to have the most favorable combination of specificity, sensitivity and acceptability for the healthy baby population [14, 19]. The combination of AOAE and AABR screening in the healthy baby nursery requires AABR to be offered to those who failed an initial screen with AOAE [14]. This is a preferred protocol recommended in many developed countries including England and the USA [10, 12-13, 20].

Seven per cent (5/76) of programs reported not being allowed to conduct screening in the NICU populations even though screening was allowed in the healthy baby nurseries. AABR screening was employed by 24% (18/76) of NICU program protocols, 8% utilized only AABR screening and 16% employed AABR and AOAE technologies. The majority (47%; 36/76) of NICU

screening protocols used only AOA as an indication of hearing status whilst 22% (17/76) utilized combinations of technologies which excluded AABR. The prevalence of hearing loss, both sensorineural and auditory neuropathy, in NICU populations is significantly higher than in the healthy baby nursery due to the perinatal risk factors associated with this population [1, 13, 21]. Auditory neuropathy is a condition where OAEs are mostly present whilst ABRs are absent or grossly abnormal [22]. It has been reported to comprise approximately 10% of newborn hearing loss in well-babies and up to 40% of newborn hearing loss in NICU graduates [22-25].

Despite being the measure of choice for NICU screening to identify auditory neuropathy and reduce referrals related to transient middle ear effusion [21], AABR screening was uncommon in the private health care sector NICU programs, with only one in every four (18/76) utilizing this technology. As a result the majority of programs will not identify auditory neuropathy. The poor availability of AABR screening in NICU's may partly be attributed to the increased equipment and disposable costs usually associated with AABR screening [26]. Screening equipment utilized is entirely dependent on the devices acquired by private practice audiologists, resulting in significant variability in screening protocols.

Initial screenings usually occur in the well baby or NICU wards and alternative locations are only used if test conditions in the respective wards were suboptimal. Screening results are disclosed by the screener who in the private health care sector is almost always an audiologist. The target screening disorder was bilateral hearing loss across all programs surveyed in line with recommendations in current guidelines [11, 13]. In resource-constrained environments, a bilateral hearing loss target disorder may be more cost-effective, although unilateral losses may often progress and become bilateral in infants [12, 27-29]. Should the screening results indicate a refer result in any ear, the majority (79%; 61/77) of participants reported that the baby was re-screened immediately and scheduled for a follow-up screen if the results of the re-screen indicate a failure yet again.

Referral and follow-up performance and protocols

Follow-up screening was most commonly performed using AOAEs for healthy baby nursery and NICU babies. Sixty-seven per cent (12/18) of screening programs that utilized AABR as initial screening technology in NICU babies also used AABR during the follow-up screening. The

remaining 33% (6/18) conducted only AOA screening on NICU graduates at the follow-up appointment. Consequently, AABR screening is conducted during the initial and follow-up screening in only 16% (12/76) of NICU programs in the South African private health care sector that offer screening. This means that 84% (64/76) of NICU hearing screening programs nationally will not identify auditory neuropathy [21, 30].

High frequency (1000Hz probe tone) tympanometry was utilized by 47% (36/76) of programs as part of their follow-up screening protocol for healthy baby nursery and NICU graduates. High frequency tympanometry may be useful to differentiate the etiology of a failed screening result and to direct referrals for further medical management if necessary [12, 27, 31]. A recent study demonstrated that otitis media with effusion is an underestimated cause of transient, moderately severe hearing loss during the first months of life with a prevalence of 0.38% [31]. Appropriate and timely referrals can be made if high frequency tympanometry is conducted routinely in failed AOA screenings [27]. Unfortunately, due to the unregulated practice of newborn hearing screening, less than half (47%) of follow-up assessment centers performed high frequency tympanometry. Early hearing detection services are currently based on individual initiatives from private practice audiologists, which is accompanied by individual variability in terms of equipment, procedures and follow-up characteristics employed [26].

According to international benchmarks [11-12], hospital-based universal newborn hearing screening programs should have referral rates for audiological and medical evaluation of less than 5% within one year of program initiation. Only 14% of obstetric units in South Africa offer universal newborn screening programs. Eighty per cent of these universal programs reported a referral rate for audiological and medical evaluation of less than 5%, on par with international benchmarks. Previously reported referral rates from South African studies have however been higher [27, 32]. A review of a private health care universal newborn screening program indicated a referral rate of 11% across a 4 year analyses [32]. Similarly a pilot infant hearing screening program at a public health care immunization clinic reported an even higher initial referral rate of 14% but only evaluated the initial 5 months of implementation [27]. Suboptimal referral rates reported by the remaining 20% of universal programs in this survey may have been due to factors such as poor data management or quality control, recently commenced programs, suboptimal

screening technologies (such as AOA implemented in NICUs) and test environment or procedural issues [16, 32-33].

In terms of follow-up return rates, only 28% (10/36) of private healthcare sector programs in South Africa reported rates of 70% and higher in line with current recommendations [11-13]. Although audiologists reported that parents are reminded to bring their babies for follow-up screening by means of various methods, there was no significant association between the number of methods used and reported return rates. Loss to follow-up at all stages of the EHDI process clearly continues to be a serious concern in South Africa as in many other countries such as the USA [13, 21, 27, 34]. Similar suboptimal follow up return rates were reported by pilot programs in Pakistan and Malaysia where loss to follow-up after the first screening was 66% and 43% respectively [35-36]. Also, a suboptimal follow-up return rate of 60% was reported for a pilot screening program at an immunization clinic in South Africa [27]. Since hearing screening is not yet mandated or regulated in South Africa there is a lack of program quality control and no systematic protocol for tracking parents and their babies to attend follow-up appointments which may contribute to poor follow-up compliance[32-34]. In addition, insufficient support from other key health professionals such as family physicians and pediatricians may discourage parents from prioritizing hearing screening follow-up [16, 34, 37]. Parental compliance throughout the various stages of the screening protocol is essential for effective early detection of infants with permanent hearing impairment [37]. Furthermore, various maternal and infant factors, such as the lack of knowledge about the prevalence of infant hearing loss or unfavorable attitudes towards childhood deafness, anxiety about the possibility of hearing loss or low priority for audiological follow-up when other medical conditions are present, maybe associated with loss to follow-up in hospital-based hearing screening programs [21, 32, 37].

Data management practices

Successful screening programs rely on data management systems to ensure the process of screening through to diagnosis and intervention is efficient with adequate quality control [12, 32-34]. Screening information should be managed by integrated information systems to provide data for service development and to monitor infants at risk for developing late onset or progressive hearing loss [12, 32-34]. Less than a third (23/77) of programs in the private health care sector

used an electronic database. The lack of integrated information management systems in the private sector of South Africa may be partly ascribed to the fact that screening is not monitored by hospital management or universally included as part of maternal birthing services [6].

CONCLUSION

Newborn hearing screening should be considered standard of care for neonates [3, 10]. An estimated 3% of birthing units in South Africa offer universal newborn hearing screening programs. In the private health care environment of South Africa, which serves a sector of society who either pays for services out-of-pocket or depends on private medical insurance, less than half of infants are afforded the opportunity to have their hearing screened. Early hearing detection, follow-up and data management protocols vary greatly and often do not meet recommended quality indicators [6, 11-12]. Although reported referral rates are less than 5% in the majority of programs, the protocols are mostly insufficient to identify auditory neuropathy especially in high risk NICU populations. The major weakness of existing programs remains the number of infants lost to follow-up, which may partly be related to poor utilization of electronic data management systems. Improving the current status of services will require newborn hearing screening in the private health care sector to be integrated with hospital-based birthing services, preferably with a centralized data management and quality control service.

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