

MASTERS DEGREE IN COMMUNICATION PATHOLOGY 2012

National survey of early hearing detection and
intervention in the private health care sector

In fulfilment of the requirements for the degree of M.Communication Pathology in the
Department of Communication Pathology, Faculty of Humanities, University of Pretoria,
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ABBREVIATIONS

JCIH-Joint Committee on Infant Hearing

HPCSA-Health Professions Council of South Africa

EHDI-Early hearing detection and intervention

PCEHL-Permanent congenital and early-onset hearing loss

USA-United States of America

UK-United Kingdom

NIHS-Neonatal and infant hearing screening

WHO-World Health Organization

HL-Hearing loss

AOAE-Automated otoacoustic emission

OAE-Otoacoustic emission

AABR-Automated auditory brainstem response

ABR-Auditory brainstem response

NICU-Neonatal intensive care unit

HF-High frequency

1. INTRODUCTION

Background

All children with hearing impairment should have access to resources necessary to attain their maximum potential (JCIH, 2007; Swanepoel, 2010). In order to reach this potential, auditory input is essential for development and social functioning (Korver, Konings, Dekker, Beers, Wever, Frijns & Oudesluys-Murphy, 2010). Hearing loss is the most frequently occurring birth defect, affecting more than twice the number of neonates than all other screenable newborn disorders combined (O'Neal, Finitzo & Littman, 2000; Smith, Bale & White, 2005). It has been estimated that annually, approximately 798 000 infants worldwide are born with, or acquire permanent hearing loss (>40dBHL) within the first weeks of life (Olusanya, Wirz & Luxon, 2008a). More than 90% of these infants are born in developing countries and approximately 25%, estimated at 199 500 infants, are born in sub-Saharan Africa (Olusanya & Newton, 2007; Olusanya et al., 2008a; Olusanya, 2008; Swanepoel & Störbeck, 2008; Swanepoel, Störbeck & Friedland, 2009; Swanepoel, 2010). The estimate for permanent hearing loss is even higher if other categories of hearing loss are also considered, including unilateral and/or minimal hearing losses (Olusanya, 2008; Watkin & Baldwin 2011).

However, there is a paucity of quality epidemiological data describing hearing impairment in African countries, especially in children, due to limited systematic or routine screening programmes (Smith et al., 2005; Clark, 2008; Van der Spuy & Pottas, 2008; Swanepoel et al., 2009). As a result, hearing loss has been coined a silent, overlooked epidemic in developing countries (Swanepoel, Hugo & Louw, 2006; Swanepoel, 2008; Swanepoel, 2010). It is referred to as an epidemic due to the high prevalence, and as silent because it cannot be detected by routine clinical examination (Swanepoel et al., 2006; Swanepoel, 2008; Swanepoel, 2010). Since hearing loss is not considered to be life threatening, it is often not visible on global health care agendas (Swanepoel et al., 2006; Swanepoel, 2008; Swanepoel, 2010). This results in late detection of hearing loss in infants in many developing countries.

The South African health care system is divided into the public and private sectors (Swanepoel et al., 2009; Theunissen & Swanepoel, 2008; Blecher & Harrison, 2006). Recent South African reports evidence some progress in initiating pilot early hearing detection and intervention (EHDI) programmes in both public and private health care settings (Theunissen & Swanepoel, 2008; Van der Spuy & Pottas, 2008; Swanepoel & Störbeck, 2008; Swanepoel et al., 2009; Störbeck & Pittman, 2008). However, all reports to date indicate poor coverage in screening infants with permanent congenital and early-onset hearing loss (PCEHL). Furthermore, these reports point to late identification, late commencement of intervention (amplification, medical and speech-language therapeutic services) and limited enrolment in available non-profit, family-centred, home-based services (Van der Spuy & Pottas, 2008; Theunissen & Swanepoel, 2008; Swanepoel & Störbeck, 2008; Swanepoel et al., 2009; Störbeck & Pittman, 2008; Yoshinago-Itano & Thomson, 2008). Previous South African studies also report limited quality assurance of services and poor parental support and empowerment throughout the EHDI process (Van der Spuy & Pottas, 2008; Theunissen & Swanepoel, 2008; Swanepoel & Störbeck, 2008; Swanepoel et al., 2009; Störbeck & Pittman, 2008; Yoshinago-Itano & Thomson, 2008).

National surveys on available resources (including financial, equipment, facilities and trained personnel resources) in African countries in general and in South Africa in particular, could provide valuable information on the state of EHDI services in these countries (HPCSA, 2007; Swanepoel et al., 2009). This in turn could provide a baseline on which to build and coordinate the implementation of improved widespread EHDI services in the foreseeable future.

Impact of hearing loss

Children develop and acquire functional skills in different, but interdependent domains of language (receptive and expressive), motor, psychosocial, emotional and cognitive development in early childhood, which lay the foundation for later educational and vocational accomplishment (Korver et al, 2010; Olusanya: 2008; Yoshinaga-Itano & Thomson, 2008; HPCSA, 2007). This foundation is established within the first 5 years

of life when the brain is most susceptible to physiological and experiential influence (Olusanya; 2008).

Although delays and/or impairments in speech and language development are the most direct consequences of PCEHL, hearing impairment in early childhood compromises optimal development in all other interdependent domains including psychosocial, emotional and cognitive (Korver et al., 2010; HPCSA, 2007; Olusanya, 2008; Swanepoel, 2010; Smith et al., 2005; Morton & Nance, 2006; Olusanya et al., 2008). This in turn undermines later educational prospects and vocational accomplishment (Watkin & Baldwin, 2011; WHO, 2010; Olusanya, 2008; Swanepoel, 2010; Korver et al., 2010; Morton & Nance, 2006; JCIH, 2007; Yoshinaga-Itano & Thomson, 2008; HPCSA, 2007; Smith et al., 2005).

These consequences are exacerbated by the significantly poorer socio-economic conditions and fragile health care systems in a developing country such as South Africa, where a considerable number of the disabled population resort to begging as an occupation and are nearly always economically dependent (Olusanya, 2008). The longer the hearing impairment goes undetected, the poorer the language and speech outcomes are likely to be for the developing child (JCIH, 2007; Olusanya, 2008; Korver et al., 2010; Morton & Nance, 2006; Yoshinaga-Itano & Thomson, 2008). Stigma, stress and other psychosocial problems associated with hearing loss further compound the burden of PCEHL for the child, the family and society (Swanepoel, 2008; Olusanya, Ruben & Parving, 2006; Olusanya, 2008).

EHDI services globally

Hearing loss is the most prevalent sensory deficit (Olusanya et al., 2008a). Unlike many other congenital or early-onset disabilities, infants with hearing loss could develop speech and language skills on par with normal hearing peers, provided that the loss is identified early and intervention initiated by 6-9 months of age (Smith et al., 2005; Nelson, Bougatsos & Nygren, 2008; Watkin et al., 2007; Yoshinaga-Itano, 2004). EHDI services ensure that infants with hearing loss are identified early in order to reduce or

eliminate the adverse consequences of hearing loss and promote normal development (JCIH, 2007; Swanepoel et al., 2009; Smith et al., 2005; Nelson et al., 2008; Watkin et al., 2007; Yoshinaga-Itano, 2004).

Within the EHDI process there are three key phases: firstly the screening for or detection of possible hearing loss, secondly referral for diagnosis and confirmation of the hearing loss (if present), and thirdly, the subsequent referral to applicable intervention services (Boudewyns et al., 2011; HPCSA, 2007; JCIH, 2007; Störbeck & Pittman, 2008). Research suggests that screening of infants should occur as early as possible after birth, diagnostic audiologic and medical evaluations should occur before 3 months of age, confirmation of PCEHL no later than 4 months of age and intervention before 6 months of age (no later than 8 months) (HPCSA, 2007; JCIH, 2007; Boudewyns et al., 2011; Yoshinaga-Itano & Thomson, 2008). The desired outcome of earliest possible identification of PCEHL has proven to be achievable, reliable and effective in developed countries such as the USA, UK and Australia where more than 95% of babies are screened within the first month of life (Watkin & Baldwin, 2011; Morton & Nance, 2006; JCIH, 2007; WHO, 2010; Smith et al., 2005).

It is therefore clear that there is growing commitment to EHDI programmes globally as it assumes unsurpassed prominence as a measure of best practice in health care, although occurrence of such programmes is less common in developing countries (Olusanya, 2005; Van der Spuy & Pottas, 2008; WHO, 2010).

EHDI services in South Africa

South Africa is classified as an upper middle-income country that consists of pockets of developed contexts within an overall developing context (World Bank, 2008; Swanepoel et al, 2009). The South African health care system is divided into the public health care sector, which serves 85% of the population and is mainly funded by general taxation, and the private health care sector which serves the remaining 15% of the population but encompasses the majority of national health care expenditure (Swanepoel et al., 2009; Blecher & Harrison, 2006; Theunissen & Swanepoel, 2008; Dambisya & Modipa, 2009).

The private health care sector is funded by companies, individuals and government departments (Dambisya & Modipa, 2009).

Recent South African reports evidence some progress in the initiation of pilot EHDI programmes in public and private health care settings, but no national mandated systematic hearing screening programmes are available (Swanepoel et al., 2009; Theunissen & Swanepoel, 2008). 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 (Swanepoel et al., 2009). These infants can only be identified early enough for optimal intervention outcomes through widespread newborn and infant hearing screening programmes using objective screening technologies (Swanepoel et al., 2009, Korver et al., 2010; Morton & Nance, 2006; JCIH, 2007; HPCSA, 2007; WHO, 2010).

A recent national study of the EHDI services in the public health care sector of South Africa, reported that only 28% of public sector hospitals provided speech therapy and/or audiology services, only 7.5% of public sector hospitals nationally provided some form of neonatal and infant hearing screening (NIHS) and less than 1% provided universal screening (Blecher & Harrison, 2006, Theunissen & Swanepoel, 2008). From the study conducted by Theunissen and Swanepoel (2008) it is evident that more than 90% of babies born in South Africa are therefore left without the prospect of early detection of hearing loss (Theunissen & Swanepoel, 2008).

A parent survey study performed on an urban sample from the Western Cape Province in South Africa reported a mean age of diagnosis of hearing loss of 23 months (ranging from 2-27 months) (Van der Spuy & Pottas, 2008). A mere 22% of participating parents' children were diagnosed with hearing loss before 6 months of age (Van der Spuy & Pottas, 2008). Without NIHS, detection is dependent upon parental suspicion, which may only occur after 18 months of age when the associated speech and language delays become apparent (Olusanya, 2008). In the absence of a systematic effort to screen infants with hearing loss, the average age of detection is often well over 2 years,

and may be as late as 6 years (Olusanya, 2008). All research results indicate that the current state of EHDI services in South Africa stands in stark contrast to the international targets of the three EHDI phases.

Due to the fact that the private health care sector serves a minority (15%) of the population but comprises the majority of national health care expenditure (Dambisya & Modipa, 2009), it may appear as though more resources are available for EHDI services in this sector as opposed to the public health care sector. However, NIHS programmes in these private health care institutions are mostly dependent on individual initiatives from private practice audiologists and may therefore face similar problems with programme implementation as the public health care sector (Blecher & Harrison, 2006; Swanepoel et al., 2009; Dambisya & Modipa, 2009).

The principles of EHDI programmes are essentially supported by the HPCSA Position Statement (2007) and the White Paper on the Integrated National Disability Strategy (1997) and therefore the government (Swanepoel et al., 2009), but it is not mandated by hospital management or universally included as part of maternal packages of birthing services. Subsequently efforts in implementing EHDI programmes remain mostly unstructured, unsystematic and only available in certain hospitals (Swanepoel et al., 2009).

Rationale

All children with significant hearing loss have the basic human right to access to human communication, regardless of where they are born, of their race, ethnicity or national origin, of what their family income is, the level of education of their parents, or their type of occupation (Yoshinaga-Itano & Thomson, 2008). All infants in South Africa should subsequently have access to EHDI services, and support from management in both public and private health care sectors in South Africa is crucial for the implementation of widespread, successful EHDI programmes (Swanepoel et al, 2009).

In a recent article Olusanya (2008) emphasised the importance of promoting public-private partnerships for EHDI service development and implementation. Yoshinaga-Itano and Thomson (2008) also stressed the importance of interagency collaboration in order to establish and implement EHDI systems. However, there is no systematically documented information on the status of EHDI services and resources in the private health care sector of South Africa, which may serve as a baseline upon which to build the aforementioned partnership (Swanepoel et al., 2009).

A national survey on EHDI services in the private health care sector could start to fulfil this information need and consequently be of great value to the emerging and growing advocacy for children with PCEHL recently brought under the spotlight in South Africa (Störbeck & Pittman, 2008; HPCSA, 2007). By determining the current status of EHDI services in the private health care sector, findings could be compared to recommended benchmarks and quality indicators in order to assess the current performance and to advocate for improved EHDI services in identified areas.

2. METHODOLOGY

2.1. Research objective

The main objective of the study was to determine and describe the current status of EHDI services in the private health care sector of South Africa.

The secondary research objectives subsequently identified were:

Secondary research objective #1:

To describe the current status of newborn and infant hearing screening in the private health care sector.

Secondary research objective #2:

To describe challenges to the development and availability of EHDI services in the private health care sector.

Secondary research objective #3:

To describe protocols implemented for newborn and infant hearing screening services in the private health care sector.

Secondary research objective #4:

To describe the performance and protocols related to referral and follow-up in EHDI programmes.

Secondary research objective #5:

To describe the national status of data management for EHDI services in the private health care sector.

Results of secondary objectives 1 and 2 were compiled and described in the article titled “Newborn hearing screening in the private health care sector – a national survey” (chapter 3) which was published in the South African Medical Journal (September 2011).

Results of secondary objectives 3, 4 and 5 were compiled and described in the second article titled “Early detection of infant hearing loss in the private health care sector of South Africa” (chapter 4) which was published electronically ahead of print on 3 March 2012.

2.2. Research design

A descriptive national survey in the private sector of South Africa was conducted within a quantitative paradigm (Mouton & Marais, 1992; Babbie & Mouton, 2001; Leedy & Ormrod, 2005). In the current study, a national descriptive survey was conducted as this type of survey was used to acquire knowledge about, and describe the incidence, frequency, and distribution of certain characteristics in a population accurately and in depth (Leedy & Ormrod, 2005; Mouton & Marais, 1992; Babbie & Mouton, 2001).

Research participants who formed part of this population consisted of two groups; firstly all private health care sector institutions with obstetric units, and secondly all private practice audiologists who provided infant hearing screening services at these units. The required data was collected from the first group of participants (all private health care sector institutions with obstetric units) via structured telephonic survey. Data was subsequently collected from the second group of participants (private practice audiologists who provide infant hearing screening services at these units) via written questionnaires, which were either sent per email or fax, depending on the respondent’s preference at the time.

2.3. Ethical considerations

During any study where humans are the focus of investigation (such as the present study), the ethical implications of the execution during the research process, need to be examined in depth (Leedy & Ormrod, 2005; Salkind, 2006). A few ethical considerations were consequently addressed in the planning and execution of this study. During this study the two groups of participants were firstly all private health care sector institutions with obstetric units, and secondly all private practice audiologists who

provided infant hearing screening services at these units. It was therefore necessary for the researcher to obtain ethical clearance from the ethical committee of the institution she represented prior to commencing the study (Mouton, 2001; Leedy & Ormrod, 2005). Ethical clearance, compliant with the regulations of the Ethical Committee of the Faculty of Humanities, was obtained prior to commencing the study.

Furthermore, the group of audiologist participants (private practice audiologists, registered with the HPCSA, who provided infant hearing screening services at obstetric units) in the study were issued with a covering letter of informed consent (attached as Appendix C). By completing and returning the questionnaire, responding participants gave informed consent to the researcher to use the data collected for research purposes. This was mentioned in bold type on the first page of the questionnaire. The content of the covering letter of informed consent has been described below (refer to *vi. Informed consent*). The following ethical aspects were therefore taken into account in the planning and execution of this research project:

i. Objectivity and integrity

It has been attempted to maintain the highest possible technical standards during the execution and representation of information (Mouton, 2001; Babbie & Mouton, 2001). Research findings and results were reported in an accurate fashion without misinterpreting, misrepresenting, intentionally misleading others or withholding findings or results (Mouton, 2001; Leedy & Ormrod, 2001). Furthermore, all information regarding methods, procedures and research designs of the study that were relevant to the interpretation of the research results, was documented (Mouton, 2001; Babbie & Mouton, 2001). Upon completion of the study, results, along with possible limitations, were reported (Mouton, 2001; Babbie & Mouton, 2001). Personal particulars of participants and names of institutions have, however, been kept confidential at all times.

ii. Reporting of information

All research information, in terms of the methodology, techniques of analysis and findings, were reported and made readily available to other researchers in a complete

and consistent fashion (with appropriate references) (Mouton, 2001; Babbie & Mouton, 2001). Confidentiality of audiologists and of any associated institution has not been breached.

iii. Publication

All individuals that contributed to, as well as all references that were consulted directly or indirectly during the execution of this study, were acknowledged (Mouton, 2001; Babbie & Mouton, 2001). This ensured that plagiarism was avoided during the execution of this study (Mouton, 2001; Babbie & Mouton, 2001).

iv. Society

Researchers are held responsible for their research and consequently have an obligation towards society to conduct research in a socially acceptable and responsible fashion (Mouton, 2001; Babbie & Mouton, 2001). Research results were readily made available to other researchers and society within the limits of maintaining confidentiality of responding participants and institutions involved (Mouton, 2001; Babbie & Mouton, 2001).

v. Research participants

When the gathering of research information occurs based on mutual trust, it is of the utmost importance that participants' rights, interests and sensitivity are protected (Mouton, 2001). Participants' right to privacy was taken into account by informing them that they had the right to refuse to answer the questions in the telephonic survey or the questionnaire and therefore reject participation in the study (Mouton, 2001, Babbie & Mouton, 2001). Furthermore, participants' right to confidentiality (principle of keeping shared information confidential), was practiced at all times (Mouton, 2001; Babbie & Mouton, 2001).

As a consequence, no individuals or individual institutions were named in the research report. Research subjects were allocated a specific code, where necessary for data processing, and the names of participants and institutions have not been used in data

analysis or reporting. This was clearly explained in the informed consent covering letter. It was mentioned in bold type on the first page of the questionnaire that questionnaires were pre-numbered with respondent codes for statistical purposes.

vi. Informed consent

Informed consent is a crucial ethical consideration (Mouton, 2001; Hegde, 2003; Leedy & Ormrod, 2001). Subsequently, a covering letter of informed consent (attached as appendix C) explaining the rationale, aim, possible benefits of participating in the study, who would benefit from the study, as well as expected results following completion of the study, were presented along with the questionnaire (attached as appendix D) (Mouton, 2001; Hegde, 2003; Leedy & Ormrod, 2001). The covering letter also informed potential audiologist participants that participation was completely voluntary, that he/she could withdraw from the study at any time, that all information remained confidential and that data would be stored for archiving purposes for a 15 year period at the University of Pretoria (Leedy & Ormrod, 2005; Mouton, 2001; Babbie & Mouton, 2001).

Thereafter, each audiologist participant was requested to complete and return the questionnaire to indicate that he/she gave informed consent to participate in the study. Audiologist participants will receive the results of the study in abbreviated format following the completion of the study (Leedy & Ormrod, 2005; Mouton, 2001).

vii. Beneficence and non-maleficance

The potential inconvenience of participating in the study (the time and effort required to answer the telephonic survey and complete the questionnaire) was indicated at the commencement of the telephone call to the private health care institutions with obstetric units as well as in the covering letter of informed consent to the audiologist participants. The aforementioned letter also explained that the information collected would potentially provide useful data to the speech, language and hearing professionals in South Africa by publication of results upon conclusion of the study (Hegde, 2003). However, no incentives or rewards (financial or other) were offered for participating in the study.

viii. Cultural and linguistic diversity

Questionnaires (attached as Appendix D) were compiled and issued for completion in English, as it is the main medium of instruction at most universities in South Africa and the language of correspondence with the HPCSA. Therefore, the ethical consideration of cultural and linguistic diversity should not have had any effect on this particular study.

2.4. Study population

2.4.1. Population

The current study focused on the private health care sector in South Africa which serves approximately 15% of the country's citizens (Blecher & Harrison, 2006; Dambisya & Modipa, 2009). The total population considered for potential inclusion was firstly all private health care institutions with obstetric units and secondly all private practice audiologists (registered with the Health Professions Council of South Africa) who provided infant hearing screening services at these units.

2.4.2. Criteria for selection of subjects

The following selection criteria were taken into consideration during the selection of the two groups of participants:

i. Private health care sector institutions

- **National registry:** Every private (non-government funded) health care sector institution in South Africa listed in a national registry (www.medpages.co.za) was included if the institution rendered obstetric services.
- **Private sector:** Only institutions that were privately funded were included. Institutions that were fully or partially government funded were therefore excluded.
- **Area:** This national study included private health care sector institutions that rendered obstetric services in all nine provinces in South Africa.

ii. Private practice audiologists

- **Health Professionals:** All private practice audiologists, registered with the HPCSA, and who provided infant hearing screening services at institutions that offered obstetric services.
- **Area:** As this was a national study, private practice audiologists from all nine provinces in South Africa were included in the study.
- **Language:** All participants (private practice audiologists) had to be proficient in English, as questionnaires were only conducted in English in order to minimize the researcher's influence on the participants' responses and ensure consistency amongst participants (Leedy & Ormrod, 2005).

2.4.3. Population size

The total population firstly included all private health care institutions with obstetric units and secondly the private practice audiologists (registered with the HPCSA) who provided infant hearing screening services at these units.

A total of 166 private health care sector institutions had obstetric units and formed the first participant population group. These units were subsequently surveyed telephonically regarding newborn hearing screening services. Eighty-seven of the 166 institutions with obstetric units rendered newborn hearing screening services. Private practice audiologists who rendered hearing screening services at these 87 units therefore formed the second participant population group. Questionnaires (attached as Appendix D) were subsequently sent to these private practice audiologists. Audiologist participants who worked at more than one private institution were asked to complete one questionnaire per institution to ensure that data were representative of each private health care institution.

2.4.4. Description of participants

Figure 2.1 gives a graphic representation of the national distribution of private health care sector institutions that had obstetric units and therefore comprised the first group of the participant population. The largest numbers of these institutions were situated in the Gauteng, Western Cape and KwaZulu-Natal provinces. Only 53% (87/166) of these institutions rendered newborn hearing screening services.

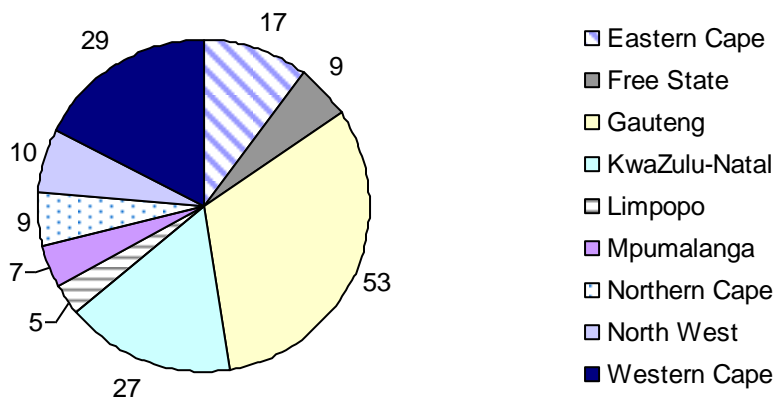
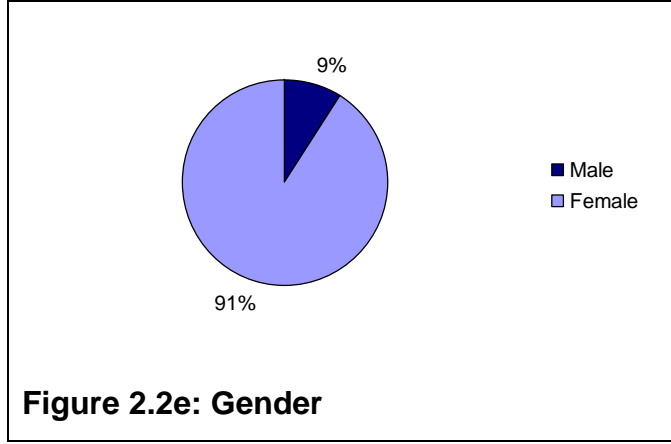
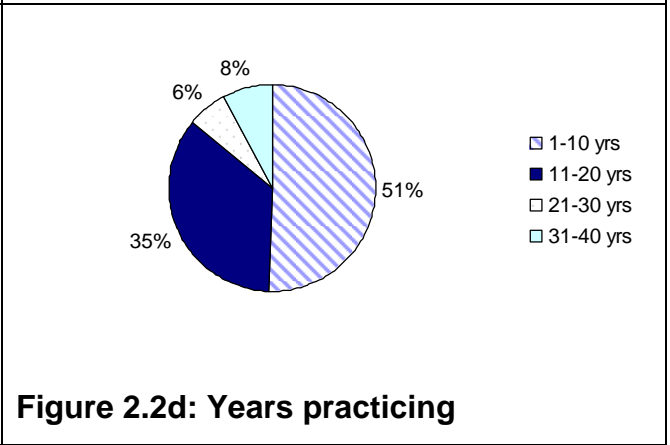
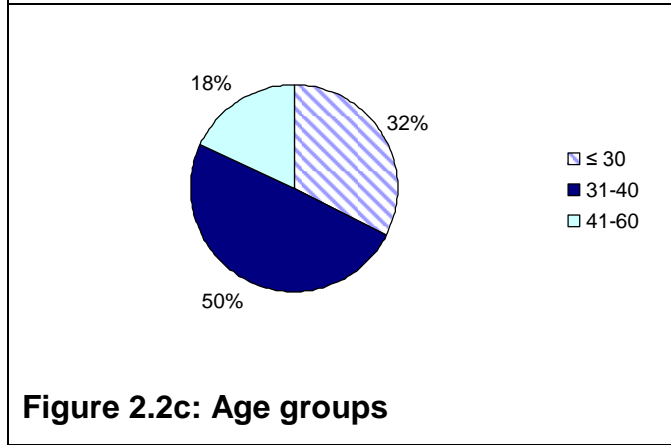
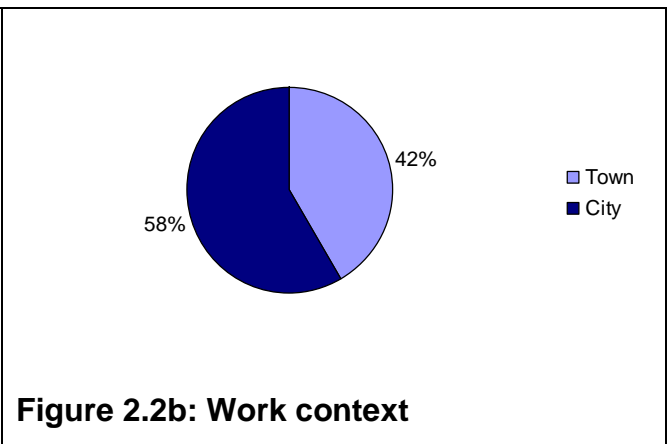
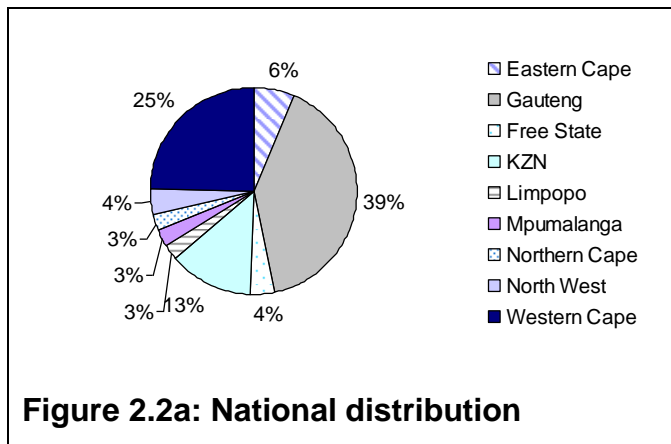


Figure 2.1: National distribution of private health care institutions that render obstetric services (n=166)

Private practice audiologists that provided newborn hearing screening services at these 87 institutions formed the second group of the participant population. Questionnaires were sent to these private practice audiologists and data collected from responding participants are represented in figure 2.2.



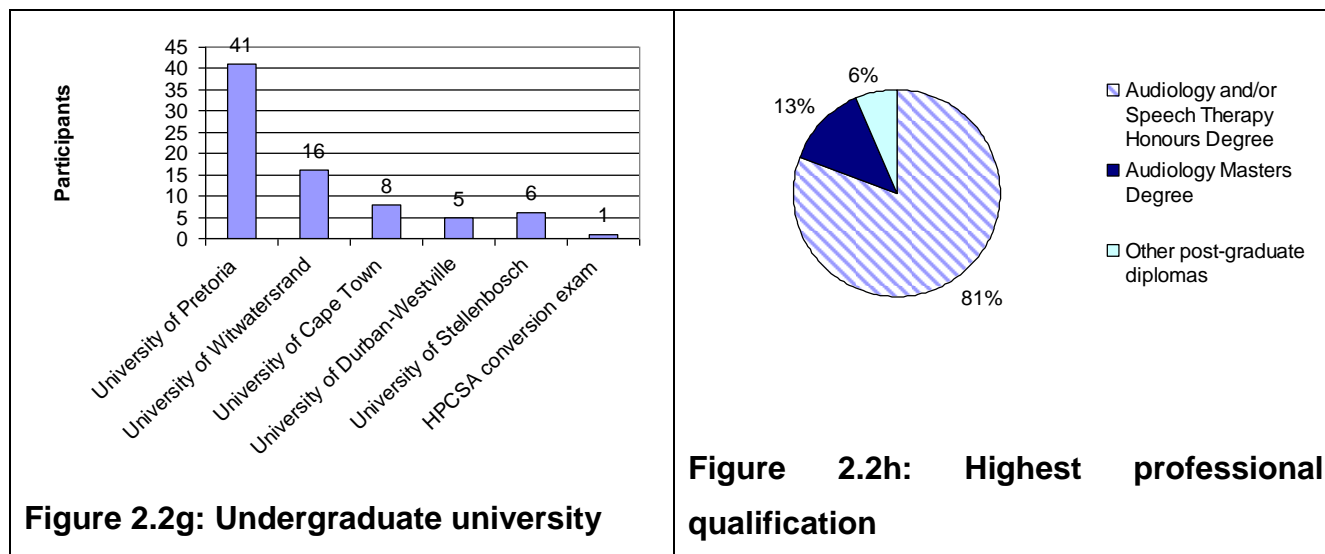


Figure 2.2: Description of participants (n=77)

Section A of the questionnaire consisted of questions relevant to the biographic information and work context of the audiologist participants. It is clear that the majority of responding participants practised in Gauteng (39%) and the Western Cape (25%) provinces (Figure 2.2a). Most (58%) of the audiologist participants worked in a city and no private health care sector audiologic services were rendered in rural areas (Figure 2.2b). The responding participants' age distribution (represented in Figure 2.2c) predominantly represented the 31-40 years (50%) and 25-30 years (32%) age groups. It also became apparent from Figure 2.2d that these participants' practising years in the professional field were distributed across the spectrum of 1-34 years experience but corresponded with their age in figure 2.2c, as most of the audiologist participants had been practicing professionals for 1-10 years (51%) or 11-20 years (35%).

The largest group of responding participants (46%) was dually qualified and practised in both the fields of Audiology and Speech Therapy (refer to Figure 2.2f). More than half (53%) of these participants obtained their qualifications at the University of Pretoria (figure 2.2g). No University of Limpopo (Medunsa) graduates were represented in the current study. One responding participant did not obtain an undergraduate qualification in South Africa but wrote the HPCSA conversion examination. Furthermore, 13% of the

audiologist participants have achieved post-graduate degrees in Audiology and another 6% have obtained post-graduate diplomas in fields not directly related to the Audiology scope of practice (Figure 2.2h).

2.5. Material and apparatus

A structured telephonic survey of all private health care institutions that rendered obstetric services was used for initial data collection amongst private health care sector institutions with obstetric units. Subsequently a self-administered emailed or faxed questionnaire was used as method for data collection amongst private practice audiologists who render newborn hearing screening services at these private health care institutions. This was a viable, easy and speedily accessible method of communication, had a relatively low cost and could reach respondents all over South Africa, as all private institutions and/or health care professionals had the necessary telephone, fax or email technology readily available (Oppenheim, 2004).

The structured telephonic survey consisted of a specific set of questions that were directed to matrons of maternity or neonatal wards. The self-administered questionnaire that was sent to private practice audiologist participants was developed to gather the data required from this subset of the population. The content of the questionnaire was drawn from the following resources:

- A review of the relevant literature to determine the aspects or components of EHDI services that required further investigation.
- A preliminary or pilot study questionnaire was applied prior to the commencement of the study as it was an excellent way to determine if the questionnaire was feasible, practicable and effective in achieving identified aims of the study (Leedy & Ormrod, 2005; Babbie & Mouton, 2001). The pilot study was applied to at least three audiologists performing or participating in the management or implementation of NIHS and EHDI services in the public sector.

The pilot study was conducted in the public sector firstly because the public sector faced similar challenges to the private sector when performing or participating in the management or implementation of NIHS and EHDI services and secondly, to ensure that suitable participants working in the private audiology practices were not approached during the pilot study. Feedback from the pilot study assisted the researcher in optimising the final questionnaire before distributing it to participants.

Predominantly closed response questions were included in the final questionnaire but an additional 'other' option was included where applicable. While closed questions were easier to process and took less time to answer (Oppenheim, 2004), some questions required an open response format to ensure that respondents had the freedom to provide information about their individual situation. Minimal inclusion of open-response questions was therefore apparent in the final questionnaire.

The content of the questionnaire included questions on the following topics:

- Section A:** Biographic information on the participant
- Section B:** Work context and screening protocols adhered to
- Section C:** Data management and quality control of EHDI services
- Section D:** Diagnostic protocols and practices
- Section E:** Intervention practices

The content of the questionnaire was finalised once an in-depth literature review as well as the pilot study had been completed. The questionnaire was recoded for data analysis once the content was finalised. The final questionnaire that was sent to participants has been included as Appendix D.

2.6. Data collection procedure

- Contact details of private (non-government funded) health care sector institutions in South Africa, including hospitals, clinics or private practices were obtained from institutions listed on www.medpages.co.za, in order to compile a comprehensive list of 304 private institutions that were potentially appropriate for the study.
- Duplicated listings were removed and the remaining 298 institutions were contacted and surveyed telephonically to determine whether the respective institutions were in fact true private health care sector institutions and whether these institutions rendered obstetric services.
- The switchboard operator answering the telephone was firstly asked whether or not the institution was fully privately funded or partly government funded. This information was documented accordingly.
- From the telephonic survey, it was clear that eight of these hospitals were not eligible for the current study since they were partly government funded and therefore not solely private sector institutions. It was established that another three of the listed private sector institutions no longer existed. Another institution could not be contacted despite numerous calls to all documented numbers in the national telephone directory which could be an indication that the institution also no longer existed. This information was documented accordingly and the relevant institutions were removed from the contact list. Two-hundred and eighty-six eligible private health care sector institutions remained on the contact list.
- The switchboard operator answering the telephone was secondly asked whether or not the institution had an obstetric unit, maternity or neonatal ward and what the telephone extensions to those wards were. This information was documented accordingly and it was established that 120 private health care institutions did not render obstetric services.
- Ward matrons at the obstetric units, maternity and/or neonatal wards at the remaining 166 private health care sector institutions that were solely privately funded were contacted to determine the estimated amount of annual births per year. Information was documented accordingly.

- All those matrons at the obstetric units, maternity and/or neonatal wards were furthermore asked whether or not NIHS services were rendered in those wards. Information was documented accordingly.
- Matrons at those obstetric units, maternity and/or neonatal wards that rendered NIHS services, were asked what the nature of the hearing screening services were (i.e. universal, almost universal, parental or paediatric request only, targeted or high risk screening), which was documented accordingly. It was established that 87 of the 166 institutions with obstetric units rendered newborn hearing screening services. Private practice audiologists who rendered hearing screening services at these 87 institutions therefore formed the audiologist participant population.
- The abovementioned matrons at obstetric units, maternity and/or neonatal wards that rendered NIHS services were then asked to supply the contact details of the audiologists providing the NIHS services in the units or wards. Information was documented accordingly.
- Audiologists participating in or managing the implementation of NIHS programmes at those 87 private sector institutions were contacted telephonically to obtain their email addresses or fax numbers.
- A self-administered faxed or emailed questionnaire was used as subsequent data collection method. A covering letter of informed consent (refer to Appendix C) was attached to the questionnaire (refer to Appendix D).
- Questionnaires were emailed or faxed to all the potential private practice audiologist participants identified as fulfilling the selection criteria as described under section 2.4.2. Potential private practice audiologist participants who worked at more than one private institution were asked to complete one questionnaire per institution to ensure that data were representative for each private health care institution.
- Potential private practice audiologist participants were requested to return the questionnaire within 10 working days of receipt by a return email or faxed questionnaire. Contact details (telephone, fax and email) of the researcher were indicated in the covering letter of informed consent of the questionnaire.

- After the 10 working days, potential private practice audiologist participants were reminded to complete the questionnaire via a reminder email, fax and/or telephonic correspondence.
- Potential private practice audiologist participants were granted another 10 working days, whereafter a second reminder email, fax and/or telephonic correspondence was issued.
- Another five working days were granted before the data collection period was closed. A return rate of 89% was achieved, as 77 out of 87 potential private practice audiologist participants returned the questionnaires. This can be described as an excellent return rate (Leedy & Ormrod, 2005).
- Data collected were organised, coded and prepared for data analysis as described below.

2.7. Data analysis procedure

Data gathered from the telephonic survey of private institutions and subsequent maternity or neonatal wards were integrated with data gathered from the self-administered questionnaire completed by audiologists at the specific institutions. Data gathered was quantitative in nature. Responses to the telephonic survey and self-administered questionnaire were coded to enable quantitative analysis of the data. Coded responses were subsequently statistically analysed to yield percentages and frequency distributions, which were graphically represented as bar charts and frequency tables. In addition the use of statistical procedures such as Chi-Squared and, where appropriate, Fisher's Exact tests were discussed with a representative of the Department of Statistics and accordingly submitted for processing.

These tests were used to ascertain the possible significant association between certain variables. The first set of variables tested was private practice audiologists' years experience and their awareness of the HPCSA 2007 Position Statement, which proved to be statistically significant. The other set of variables tested were the association between the numbers of methods used to remind parents to return for follow-up

appointments and the reported follow-up return rates. The latter tests proved that no significant association could be found.

3. NEWBORN HEARING SCREENING IN THE PRIVATE HEALTH CARE SECTOR – A NATIONAL SURVEY

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3.1. Abstract

Objectives. To determine: (i) the national status of newborn hearing screening services in the private health care sector of South Africa; (ii) screening approaches implemented; and (iii) challenges to screening implementation.

Design. A descriptive quantitative national survey was conducted in the private sector of South Africa.

Method. All private health sector institutions with obstetric units ($N=166$) were surveyed telephonically and self-administered questionnaires were subsequently sent to all audiologists in private practice ($N=87$) who provide newborn hearing screening services at the units with hearing screening.

Results. Nationally 53% of private sector obstetric units offer some form of newborn hearing screening. Universal hearing screening was only offered by 14% of units, while the most

common approaches were universal screening on some days of the week (18%) and screening on request (18%). The most prominent challenge to successful screening implementation was the omission of newborn hearing screening from maternity birthing packages at the health care institutions.

Conclusion. The vast majority of newborns nationally are not screened for hearing loss, and existing programmes are not sufficiently systematic and integrated to ensure

adequate coverage. Hospital management and paediatric health services must prioritise hearing screening as part of standard of care in birthing services.

3.2 Introduction

Approximately 180 000 babies are born with or acquire permanent bilateral hearing loss (>40 dB hearing level (HL)) within the first few weeks of life across sub-Saharan Africa every year (Olusanya, 2008). In South Africa an estimated 17 babies are born with a significant permanent bilateral hearing loss every day (Swanepoel et al., 2009). These infants can only be detected early enough for optimal intervention outcomes through widespread newborn and infant hearing screening programmes using objective (oto-acoustic emissions and auditory brainstem response screeners) screening technologies (Swanepoel et al., 2009; Korver et al., 2010; Morton & Nance, 2006; JCIH, 2007; HPCSA, 2007; WHO, 2010).

Identification is considered late when children are diagnosed after 9 - 12 months of age and have missed access to auditory input during the critical language acquisition period in the first year of life (Morton & Nance, 2006; JCIH, 2007; Swanepoel, 2009). Late identification impedes language, psychosocial, emotional and cognitive development in early childhood, which undermines educational and vocational outcomes (Olusanya, 2008; Korver et al., 2010; Morton & Nance, 2006; JCIH, 2007; HPCSA, 2007, WHO, 2010; Swanepoel, 2009; Smith et al., 2005). The effect on quality of life for these children, who become isolated and stigmatised, is dramatic and severe (Olusanya, 2008; Korver et al., 2010; Swanepoel, 2009). From an economic perspective the burden on families, communities and countries has led many countries, including Australia, Canada, the UK and the USA, to adopt universal newborn hearing screening programmes as standard practice in neonatal care (Morton & Nance, 2006; WHO, 2010; Smith et al., 2005). Many of these countries screen 95% and more of all babies for hearing loss within the first month of life (Morton & Nance, 2006; JCIH, 2007; WHO, 2010; Smith et al., 2005).

In South Africa infant hearing loss is primarily detected passively when parents become concerned about speech and language delays, and usually occurs after 2 years of age (Swanepoel et al., 2009; Swanepoel, 2009; Van der Spuy & Pottas, 2008). The pervasive lack of systematic newborn hearing screening programmes across the country means that children with hearing loss suffer lifelong deficits in various developmental areas that are essentially preventable (Olusanya, 2008; Swanepoel et al., 2009; Van der Spuy & Pottas, 2008). A recent national survey of early hearing detection and intervention (EHDI) services in the public health sector, which service approximately 85% of the South African population (Blecher & Harrison, 2006), reported that only 7.5% of public sector hospitals nationally provide some form of neonatal or infant hearing screening and less than 1% provide universal screening (Theunissen & Swanepoel, 2008). The survey estimated that more than 90% of babies born in South Africa do not have the prospect of early detection of hearing loss (Theunissen & Swanepoel, 2008). To date, however, no national survey of newborn hearing screening services in the private health sector has been conducted (Swanepoel et al., 2009; Swanepoel, 2009).

EHDI services for optimal outcomes are recommended to identify children with hearing loss before 1 month of age, to complete diagnostic assessments before 3 months of age, and to initiate intervention (amplification and language-based intervention) before 6 months of age (Morton & Nance, 2006; JCIH, 2007; HPCSA, 2007; WHO, 2010). This can only be attained if the very first step, newborn hearing screening, is systematically employed and followed up appropriately (Swanepoel et al., 2009; Korver et al., 2010). The current study conducted a national survey on the status of EHDI services in the private health care sector of South Africa.

3.3. Method

3.3.1 Population

A survey was conducted nationally in the private health care sector across all provinces of South Africa. The total population included all private health care hospitals or clinics

that offer obstetric services and the audiologists in private practice (registered with the Health Professions Council of South Africa) who provide infant hearing screening services at these units. Ethical clearance was obtained before commencing the study.

All private health sector (non-government-funded) institutions in South Africa listed on www.medpages.co.za (2009) were contacted telephonically in order to determine whether the respective institution rendered obstetric services (www.medpages.co.za, accessed 30 August 2009). There were 304 such institutions, including hospitals, clinics and private practices, listed for potential inclusion in the sample (www.medpages.co.za, accessed 30 August 2009). After removing duplicated listings, 298 hospitals were contacted. Eight of these were not applicable to the current study because they were partially government funded and therefore not private sector institutions. Another three hospitals or clinics no longer existed as functioning private institutions, and one could not be reached after numerous calls to all documented numbers in the national telephone register.

All maternity and/or neonatal wards at those institutions that rendered obstetric services were surveyed, and questionnaires were subsequently sent to the audiologists who conducted hearing screening at the respective private sector institutions with hearing screening services. Participants who worked at more than one private institution were asked to complete one questionnaire per institution to ensure that data were representative for each respective hospital or clinic. The survey aimed: (i) to determine the estimated number of births at each institution; (ii) to find out whether newborn or infant hearing screening services were rendered; (iii) if hearing screening was offered, to find out what the nature of the service was (i.e. universal, parental or paediatrician request only, targeted or high-risk screening) and (iv) to identify the most significant challenges towards implementation of newborn hearing screening programmes.

3.3.2 Questionnaire

A self-administered questionnaire was sent out by e-mail or fax. The questionnaire consisted of several sections. The first section surveyed biographical information and the second information on work context and hearing screening practices. Subsequent sections covered data management and quality control, diagnostic protocols and intervention services and are not reported here.

3.3.3 Data Analysis

Data collected from the telephonic survey with private hospitals and subsequent maternity wards were integrated with data collected from the questionnaire completed by audiologists at the specific institutions. The data were analysed to yield percentages and frequency distributions nationally and across provinces.

3.4. Results

3.4.1 Screening coverage

Of the 286 eligible private health care institutions, 120 (42%) did not render obstetric services. The remaining 166 institutions with obstetric units were surveyed, and 53% (87/166) reported some form of newborn hearing screening service. Questionnaires were subsequently sent to audiologists managing the screening programmes at these institutions to ascertain the nature of the services. A return rate of 89% (77/87) was achieved.

Reported estimates by the private health care institutions with obstetric units indicated that approximately 136 934 babies were born each year across these units in South Africa. Audiologists managing hearing screening at the units (87/166) were asked to indicate the number of babies screened monthly at the respective institutions. Reportedly, an estimated 39 564 babies are screened annually (3 297 per month) at the institutions for which responses were obtained ($N=70$). Compared with the reported number of estimated births at all private institutions with obstetric units, at least 29% of

newborns born at private health care institutions are screened for hearing loss. Seven (9%) of the respondents did not complete this question because regular statistics of screenings were not documented.

Table 3.1: Distribution of reported births and available screening approaches across private health obstetric units per province

Province (No. of units)	Estimated annual births	No screening (% (No. of units))	Screening approach				
			Question- naires not returned (% (No. of units))	On request (% (No. of units))	Targeted/ high risk (% (No. of units))	Almost universal* (% (No. of units))	Universal (% (No. of units))
Eastern Cape (17)	14 892	71 (12)	–	–	–	6 (1)	23 (4)
Free State (9)	5 880	67 (6)	–	11 (1)	–	–	22 (2)
Gauteng (53)	51 026	34 (18)	7 (4)	19 (10)	–	21 (11)	19 (10)
KwaZulu-Natal (27)	25 704	52 (14)	11 (3)	19 (5)	7 (2)	7 (2)	4 (1)
Limpopo (5)	5 310	60 (3)	–	20 (1)	–	20 (1)	–
Mpumalanga (7)	7 086	71 (5)	–	–	–	29 (2)	–
Northern Cape (9)	3 054	78 (7)	–	22 (2)	–	–	–
North West (10)	5 310	60 (6)	10 (1)	20 (2)	–	10 (1)	–
Western Cape (29)	18 672	28 (8)	7 (2)	17 (5)	7 (2)	28 (8)	14 (4)
Nationally (166)	136 934	47 (79)	6 (10)	16 (26)	2 (4)	16 (26)	13 (21)

*Universal screening some days of the week but not all days.

Table 3.1 provides a breakdown of the estimated number of births and the reported availability and nature of newborn hearing screening services. The highest screening coverage was in the Western Cape and Gauteng provinces, where 72% and 66% of obstetric units respectively offered some form of hearing screening. In the Eastern Cape, the Free State, Mpumalanga and the Northern Cape, more than two-thirds of obstetric units do not offer any form of hearing screening.

3.4.2 Screening approaches

Applying the distribution of reported screening approaches ($N=77$) to the entire population sampled, i.e. including those who did not return the questionnaires ($N=10$), indicates that nationally only 14% of private health obstetric units offer universal hearing screening (Fig. 3.1). The two most common screening approaches are universal screening offered on certain days of the week only (18%) and screening on request (18%). A small number of units employed risk-based screening (3%) and reported a combination of methods to determine risk and subsequent need for screening. These included neonatal intensive care unit (NICU) admittance only, and risk factors listed by the Joint Committee of Infant Hearing (2007) and/ or the HPCSA Position Statement on Newborn and Infant Hearing Screening (2007).

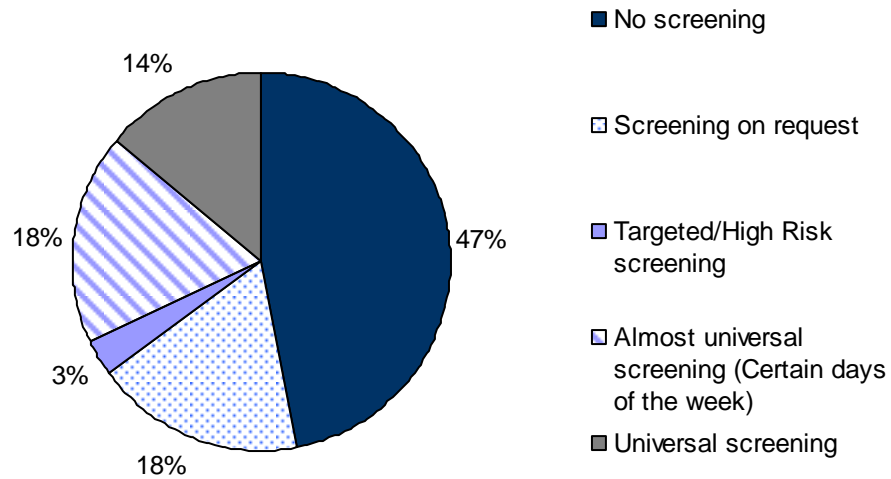


Figure 3.1. National distribution of newborn hearing screening in private health care obstetric units. Distribution of reported screening approaches (N=77) applied to the entire population of units offering screening (N=87)

3.4.3 Challenges to implementation of newborn hearing screening

The three most important perceived challenges to successful implementation of newborn hearing screening in the private health care sector were prioritised by participants as illustrated in Fig. 3,2. Most prominently prioritised as the first (40%) and second (39%) most significant challenge was the apparent omission of newborn hearing screening from maternity birthing packages and institutional policy at the health care institutions. The small percentage of challenges listed under ‘other’ related mainly to test environment and procedural issues.

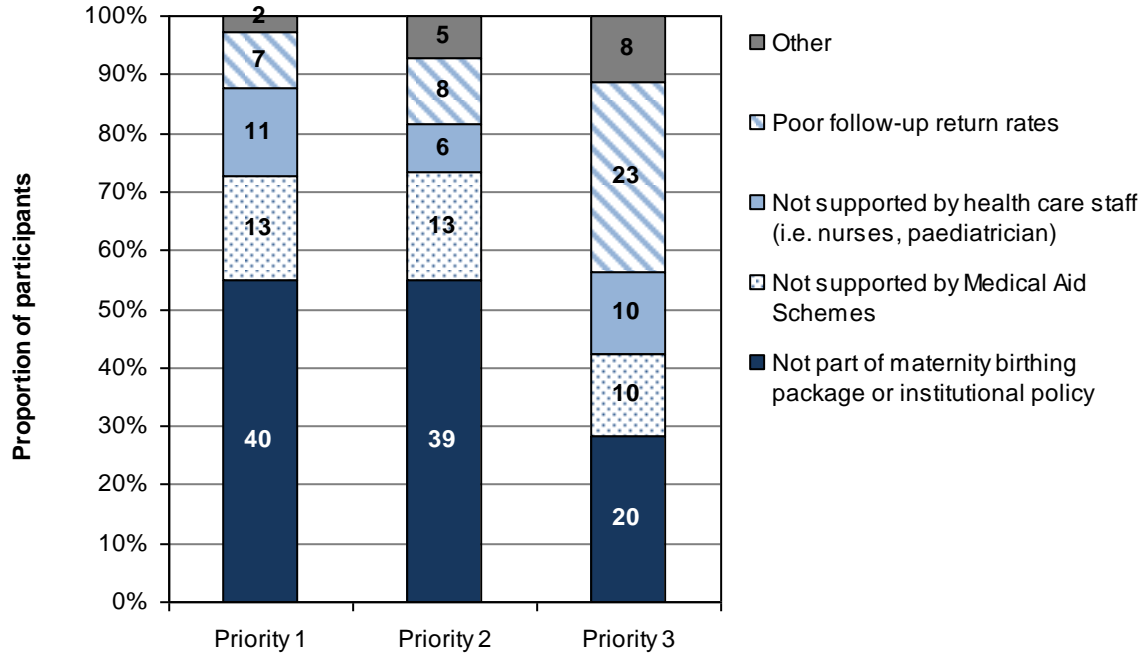


Figure 3.2. Most important challenges to successful implementation of newborn hearing screening programmes (N=77)

3.5. Discussion

This survey was the first to report the national status of newborn hearing screening services in the private health care sector of South Africa, which serves approximately 15% of the population (Blecher & Harrison, 2006). A similar survey in the public health sector of South Africa indicated that 7.5% of public birthing hospitals provide some form of newborn hearing screening and less than 1% offer universal newborn hearing screening (Theunissen & Swanepoel, 2008). Screening in the private sector is more comprehensive, with 53% institutions with obstetric units offering some form of newborn hearing screening but only 14% offering true universal hearing screening. Being born in a unit that offers screening does not guarantee that a baby will be screened, since parents must indicate whether they agree to the service. Hearing screening is not included as an integrated part of maternity birthing services and is not covered by all

medical aid schemes. The best practice recommendation for newborn hearing screening programmes is universal screening with coverage exceeding 95% (Morton & Nance, 2006; JCIH, 2007; WHO, 2010). The current study demonstrates coverage rates for hearing screening in the private health sector that are significantly less than 50%.

Considering both the public and private health sectors, approximately 90% of newborns in South Africa will not be screened for hearing loss (Theunissen & Swanepoel, 2008). Almost half of private health obstetric units nationally do not offer any form of hearing screening despite apparent world-class neonatal care. The estimated prevalence rate of permanent bilateral infant hearing loss in the private health care sector of South Africa is 3 in every 1 000 births (Swanepoel et al., 2009). Based on the reported figures in this study, an estimated 411 babies will present with permanent bilateral congenital hearing loss annually in the private health care sector, of which 193 will be born in units without any hearing screening. The remaining babies, born in units where some form of screening is offered, may or may not be screened. The lack of systematic screening programmes means that the vast majority of babies with hearing loss go undetected until 2 - 3 years of age, as demonstrated by the initial age of diagnoses (Swanepoel et al., 2009; Van der Spuy & Pottas, 2008). By this stage critical developmental periods for language acquisition have passed, resulting in irreversible delays as opposed to developmental trajectories within normal ranges that are possible through early detection (Swanepoel et al., 2009; Morton & Nance, 2006; WHO, 2010; Yoshinaga-Itano & Thomson, 2008).

The recommended hearing screening tests, which measure the integrity of the cochlea (oto-acoustic emissions) or of the auditory nerve and brainstem (auditory brainstem response), are simple, safe, inexpensive and can be completed within minutes (Olusanya, 2008; Morton & Nance, 2006; JCIH, 2007; WHO, 2010). The screening can be conducted by trained nursing personnel with oversight and programme management by audiologists (Morton & Nance, 2006; Yoshinaga-Itano & Thomson, 2008). Early identification of hearing loss is feasible, and its developmental, academic, vocational and economic benefits have been convincingly demonstrated over the past two

decades (Korver et al., 2010; Morton & Nance, 2006; JCIH, 2007; WHO, 2010; Yoshinaga-Itano & Thomson, 2008). Newborn hearing screening should be part of neonatal standard of care, as is the case in the majority of developed countries of the world (Swanepoel et al., 2009; Morton & Nance, 2006; Swanepoel, 2009).

The most frequently reported challenge to successful implementation of hearing screening in the private health care sector was the omission of newborn hearing screening from maternity birthing packages and institutional policy. As a result newborn hearing screening is not implemented or monitored systematically, but is dependent on individual initiatives without being an integrated part of routine neonatal care (Swanepoel et al., 2009; Swanepoel, 2009). Hospital management and paediatric services must prioritise hearing screening to include newborn screening as part of the birthing package services as opposed to being an optional extra, if available at all. Other secondary challenges to address include improving awareness among health care personnel regarding the importance of early identification and the comprehensive reimbursement of hearing screening services by medical aid schemes.

3.6. Conclusion

All children with hearing loss have the basic human right of access to human communication (Yoshinaga-Itano & Thomson, 2008). The overwhelming majority of babies with hearing loss in South Africa will not be screened at birth, which leads to late identification and restricted developmental outcomes. Current screening programmes in private health care are not sufficiently systematic and integrated with birthing services to ensure adequate coverage. The successful implementation of these programmes is the first step towards optimal outcomes for affected individuals and lifelong savings for the family and the economy (Olusanya, 2008; Swanepoel et al., 2009; Morton & Nance, 2006; WHO, 2010; Swanepoel, 2009; Smith et al., 2005). Achieving this goal requires support from health care management and neonatal health providers.

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

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4.1 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.

4.2. 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 [Yoshinaga_Itano & Thomson, 2008]. Every year more than 800 000 infants globally are estimated to be born with, or acquire permanent bilateral hearing loss (>40 dBHL) within the first few weeks of life [Olusanya et al., 2008a; Swanepoel, 2010]. This estimate is even higher if unilateral, fluctuating and/or minimal hearing losses are also included [Olusanya et al., 2008a; Swanepoel, 2010]. 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 [Swanepoel, 2010; Clark, 2008; Van der Spuy & Pottas, 2008; Swanepoel et al., 2009].

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 [Theunissen & Swanepoel, 2008; Blecher & Harrison, 2006]. 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 [Swanepoel et al., 2009; Theunissen & Swanepoel, 2008]. 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 [Swanepoel et al., 2009]. 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 [Swanepoel et al., 2009; Korver et al., 2010; Morton & Nance, 2006; JCIH, 2007; HPCSA, 2007; WHO, 2010].

Late detection of hearing loss impedes language, psychosocial, emotional and cognitive development in early childhood, which in turn undermines later educational and vocational attainment [Yoshinaga-Itano & Thomson, 2008; Swanepoel, 2010; Korver et al., 2010; Morton & Nance, 2006; JCIH, 2007; HPCSA, 2007; WHO, 2010; Olusanya, 2008]. The negative effects of hearing loss are exacerbated by the poor socio-economic conditions and burdened health care system in South Africa [Olusanya, 2008]. The longer the hearing impairment goes undetected, the poorer the language and speech outcomes are likely to be with higher associated costs [Yoshinaga-Itano & Thomson, 2008; Korver et al., 2010; Morton & Nance, 2006; JCIH, 2007; Olusanya, 2008]. 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 [Van der Spuy & Pottas, 2008; Swanepoel et al., 2009]. 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 [Theunissen & Swanepoel, 2008]. As a result more than 90% of babies born in South Africa are left without the prospect of early detection of hearing loss [Theunissen & Swanepoel, 2008].

Although the principles of EHDI programs are supported by the Integrated National Disability Strategy White Paper [1997] and the Position Statement produced by the Health Professions Council of South Africa [2007] it is not mandated by hospital

management or universally included as part of maternal birthing services [Swanepoel et al., 2009]. Consequently, efforts to implement EHDI programs remain mostly unsystematic and only available in certain hospitals with the exact status unknown [Swanepoel et al., 2009]. 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 [Swanepoel et al., 2009; HPCSA, 2007]. In response, a survey of newborn screening services in the public health care sector was completed in 2008 [Theunissen & Swanepoel, 2008].

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 [Meyer & Swanepoel, 2011]. 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.

4.3. 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.

4.3.1. 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, accessed 30 August 2009) 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.

4.3.2. 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.

4.3.3. 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.

4.4. Results

4.4.1. 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 4.1 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 4.1). 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 4.1).

Table 4.1: 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%

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) 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 Fig. 4.1.

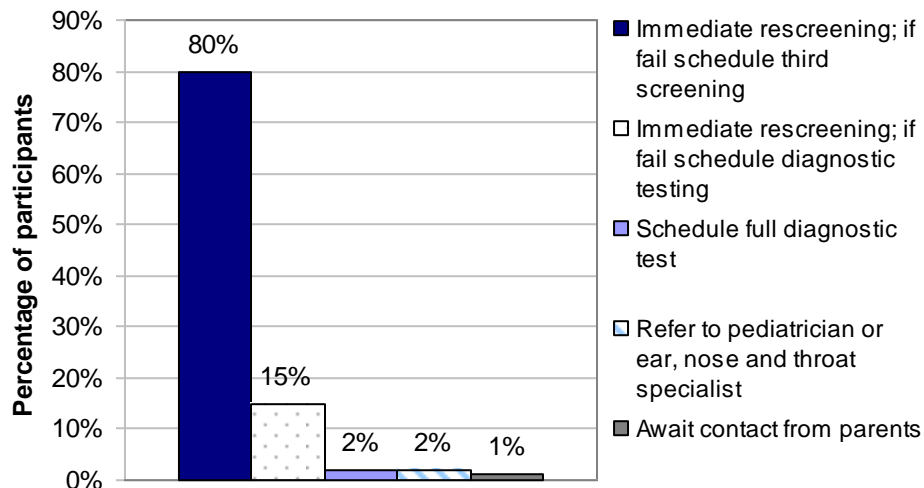


Figure 4.1: Protocol following first screening fail result (n= 77)

4.4.2. Referral and follow-up performance and protocols

Fig. 4.2 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.

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; $p > 0.05$).

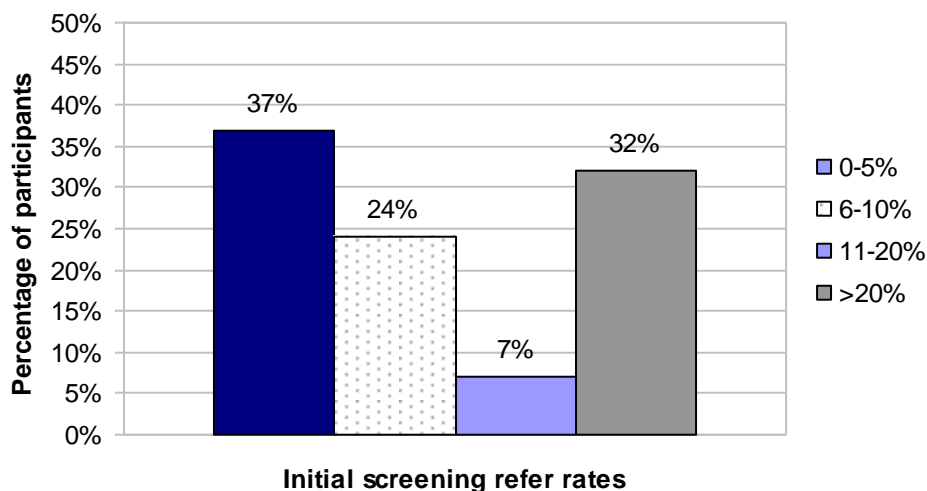


Figure 4.2: Distribution of reported initial screening failure rates (n=68)

Similar to methods used for initial screening, the most commonly used (80%; 61/76) screening approach for follow-up screening was AOA testing for both healthy and NICU baby graduates (Table 4.1). 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.

4.4.3. 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.

4.5. Discussion

4.5.1. 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 [Meyer & Swanepoel, 2011], which serves approximately 15% of the population [Blecher & Harrison, 2006]. 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 [Dambisya & Modipa, 2009]. 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 [Meyer & Swanepoel, 2011] which means a small minority of private health care birthing units provide recommended best practice in neonatal care [Morton & Nance, 2006; JCIH, 2007; WHO, 2010].

Universal screening is provided by 14% of birthing units in the private health care sector that provides services to 15% of the population [Meyer & Swanepoel, 2011]. These services are rendered by less than 1% of birthing units in the public health care sector which serves 85% of the population [Theunissen & Swanepoel, 2008; Blecher & Harrison, 2006]. 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 [Olusanya, 2008]. 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 [Olusanya, 2008; Kennedy, McCann, Campbell, Kimm & Thornton, 2005]. 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 [Olusanya, 2008]. This is a preferred protocol recommended in many developed countries including England and the USA [Morton & Nance, 2006; HPCSA, 2007; WHO, 2010; Smith et al., 2005].

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 AOAE 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 [Yoshinaga_Itano & Thomson, 2008; WHO, 2010; Russ, Dougherty & Jagadish, 2010]. Auditory neuropathy is a condition where OAEs are mostly present whilst ABRs are absent or grossly abnormal [Berlin et al., 2010]. 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 [Berlin et al., 2010; Kirkim et al., 2008; Sininger, 2002; Rea & Gibson, 2003].

Despite being the measure of choice for NICU screening to identify auditory neuropathy and reduce referrals related to transient middle ear effusion [Russ et al., 2010], 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 [Swanepoel, 2009]. 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 [JCIH, 2007; WHO, 2010]. 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 [HPCSA, 2007; Swanepoel et al., 2006; Brookhouser, Worthington & Kelly, 1995; Murphy & Radford, 2006]. 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 rescreen indicate a failure yet again.

4.5.2. 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 AOAe 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 [Russ et al., 2010; Watkin & Baldwin, 2011].

High frequency (1000 Hz 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 [HPCSA, 2007; Swanepoel et al., 2006; Boudewyns et al., 2011]. 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% [Boudewyns et al., 2011]. Appropriate and timely referrals can be made if high frequency tympanometry is conducted routinely in failed AOA screening [Swanepoel et al., 2006]. 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 [Swanepoel, 2009].

According to international benchmarks [JCIH, 2007; HPCSA, 2007], 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 [Swanepoel et al., 2006; Swanepoel et al., 2007]. A review of a private health care universal newborn screening program indicated a referral rate of 11% across a 4 year analyses [Swanepoel et al., 2007]. 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 [Swanepoel et al., 2006]. 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 [Meyer & Swanepoel, 2011; Swanepoel et al., 2007; Fintizo & Grosse, 2003].

In terms of follow-up return rates, only 28% (10/36) of private health care sector programs in South Africa reported rates of 70% and higher in line with current recommendations [JCIH, 2007; HPCSA, 2007; WHO, 2010]. 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 [WHO, 2010; Russ et al., 2010; Swanepoel et al. 2006; Shulman et al., 2010]. 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 [Ali et al., 2000; Mukari, Tan & Abdullah, 2006]. Also, a suboptimal follow-up return rate of 60% was reported for a pilot screening program at an immunization clinic in South Africa [Swanepoel et al. 2006]. 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 [Swanepoel et al., 2007; Fintizo & Grosse, 2003; Shulman et al., 2010]. In addition, insufficient support from other key health professionals such as family physicians and pediatricians may discourage parents from prioritizing hearing screening follow-up [Meyer & Swanepoel, 2011; Shulman et al., 2010; Olusanya, 2009]. Parental compliance throughout the various stages of the screening protocol is essential for effective early detection of infants with permanent hearing impairment [Olusanya, 2009]. 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, may be associated with loss to follow-up in hospital-based hearing screening programs [Russ et al., 2010; Swanepoel et al., 2007; Olusanya, 2009].

4.5.3. 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 [HPCSA, 2007; Swanepoel et al., 2007; Finitzo & Grosse, 2003; Shulman et al., 2010]. 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 [HPCSA, 2007; Swanepoel et al., 2007; Finitzo & Grosse, 2003; Shulman et al., 2010]. 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 [Swanepoel et al., 2009].

4.6 Conclusion

Newborn hearing screening should be considered standard of care for neonates [Swanepoel, 2010; Morton & Nance, 2006]. 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 [Swanepoel et al., 2009; JCIH, 2007; HPCSA, 2007]. 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.

5. DISCUSSION AND CONCLUSION

5.1. Discussion of results

Reported results established that widespread variations exist in newborn and infant hearing screening (NIHS) protocols and practices including screening protocols, referral practices, follow-up protocols and data management amongst programmes in the private health care sector of South Africa. Significant variations exist in the efficacy of programmes with only a few programmes being on par with international benchmarks and quality indicators whilst others fell short of these benchmarks.

The variations in protocols and practices could be partly ascribed to a lack of awareness of national and international recommendations, benchmarks and quality indicators of early hearing detection and intervention (EHDI) programmes. From the data collected in this study, it was established that 80% of participants (61/76) were aware of the *Health Professions Council of South Africa (HPCSA) 2007 Position Statement on Early Hearing Detection and Intervention Programmes in South Africa*, a document that specifies recommended protocols, practices and targets for early hearing detection and intervention programmes. On analysis of the data it was found that a significant association existed between years of experience of the participants and awareness of the HPCSA 2007 Position Statement (Chi-Square and Fisher's Exact tests; $p < 0.05$). Figure 5.1 illustrates that the more years of experience participating private practice audiologists had, the less likely they were to be aware of the *HPCSA 2007 Position Statement on Early Hearing Detection and Intervention Programmes in South Africa*. By raising awareness amongst private practice audiologists on recommended protocols, international benchmarks and quality indicators, early hearing detection programmes might be improved to attain the recommended targets.

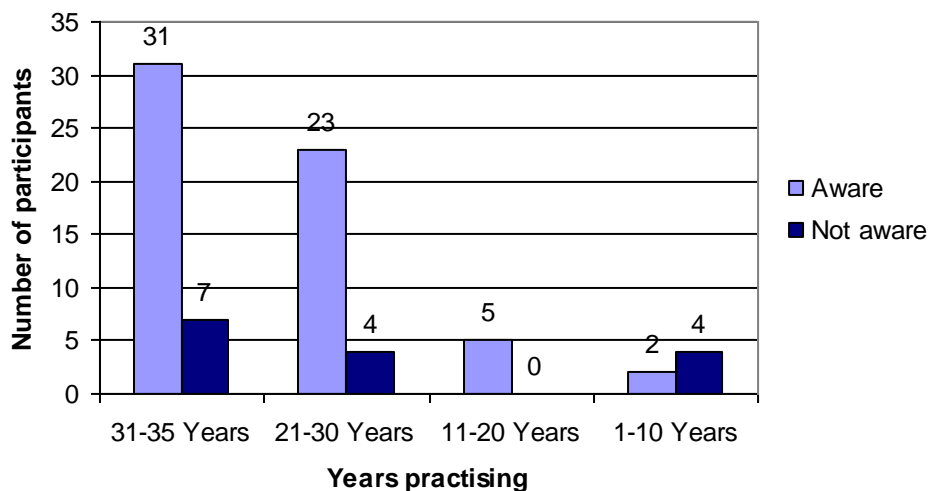


Figure 5.1: Association between years practising and awareness of HPCSA 2007 Position Statement on Early Hearing Detection and Intervention Programmes in South Africa

Loss to follow-up in NIHS programmes has been reported to be a significant challenge in many countries including developing and developed contexts, especially in the first few years of programme implementation (WHO, 2010; White 2004; Olusanya et al., 2007; Olusanya, 2009). Successful universal NIHS programmes in developed countries proved that the challenge of loss to follow-up after the initial screening can be overcome or significantly diminished by addressing socio-demographic and economic factors that underpin loss to follow-up (Olusanya, 2009). By mandating and regulating universal NIHS programmes to be included as part of maternal birthing services at all private health care institutions with obstetric units and by tracking infants through the early hearing detection and intervention (EHDI) process, loss to follow-up could be significantly reduced (Swanepoel et al., 2009; Olusanya et al., 2008a; Olusanya, Wirz & Luxon, 2008b).

Numerous factors contribute to variations in early hearing detection programme efficiency and success. From the reported findings, the main obstacles that hampered existing programmes were the fact that programmes were not mandated, regulated or universally included as part of maternal birthing packages and institutional policy. In

addition, not all medical insurance schemes approve funding for NIHS services and as a result not all parents consent to or pay for these NIHS services if costs are not covered by medical insurance schemes. In effect this creates a financial burden on private practice audiologists implementing these services, as they have to spend time resources to convince parents to consent to the NIHS services. Equipment and disposable item costs further compound the financial burden on private practice audiologists and could limit the type and quantity of equipment acquired by audiologists (Swanepoel, 2009). This may cause the utilisation of suboptimal screening technologies (such as AOAE implemented in NICU's) and suboptimal programme protocols, as well as limited screening coverage due to shortage of equipment. This could subsequently impede EHDI programme efficacy.

A lack of public awareness of the importance of NIHS and EHDI programmes might contribute to limited EHDI programme efficiency and success in the private health care sector of South Africa (WHO, 2010; Russ et al., 2010). Parents and key health care professionals alike should be informed of the developmental and financial implications of late detection of permanent hearing impairment, as well as the developmental and financial benefits of early detection of impairment (Swanepoel et al., 2007; Korver et al., 2010; Russ et al., 2010; Kennedy et al., 2005; HPCSA, 2007). Increased public awareness could promote key health care professionals' motivation to encourage parents to prioritise newborn hearing screening and adhere to all the different steps of the EHDI process (Russ et al., 2010; HPCSA, 2007). This in turn could reduce the large loss to follow-up in the EHDI process and improve programme efficiency and success.

5.2. Clinical implications

Hearing screening coverage in the private health care sector of South Africa is limited. Existing screening programmes are not sufficient to identify all infants with congenital hearing loss, as programme protocols and test procedures reported by the current study were not in accordance with international benchmarks and quality indicators (JCIH, 2007; HPCSA, 2007). In order to increase the hearing screening coverage and improve

the national status and quality of NIHS services, these services should be mandated and regulated in the private health care sector. Universal newborn hearing screening should be included as part of routine maternal birthing package services. Also, newborn hearing screening services should be enforced by hospital management and financial costs should be covered by medical aid schemes to ensure that all infants born at every private health care hospital receives newborn hearing screening (HPCSA, 2007).

Maternity units of the various private health care sector hospitals could act as administrators of universal newborn hearing screening programmes by monitoring and documenting coverage of screening, documenting hearing screening results on hospital records for all infants and reporting any problems encountered with programme implementation to the audiologist. Hospital management could contract private practice audiologists to the respective private health care hospitals with obstetric units. If audiologists were contracted to manage screening, their practices would find it economically feasible to appoint personnel to conduct screening seven days a week and overcome some of the main challenges to implementing these programmes reported in this study.

As experts in infant hearing loss, these contracted private practice audiologists could develop the NIHS programme according to the characteristics of the specific context, manage and troubleshoot these programmes implemented at the private health care hospitals (HPCSA, 2007). Protocols must be developed within the specific private health care hospital context to maximise follow-up return rates and minimise the number of false-positive referrals for audiological and medical diagnosis (HPCSA, 2007). The audiologists would be responsible for ensuring that equipment is regularly serviced and calibrated; and that the correct screening protocols are implemented. They would also be responsible for the raising of public awareness about the importance of newborn hearing screening and for monitoring of hearing as children get older (WHO, 2010; Russ et al., 2010; HPCSA, 2007).

Audiologists would communicate with, and give feedback about results and recommendations to other involved professionals such as paediatricians, ear, nose and throat specialists, geneticists, psychologists, speech therapists and nursing personnel. Newborn hearing screening does not have to be conducted solely by audiologists (WHO, 2010; Olusanya et al., 2008a; Olusanya et al., 2008b; HPCSA, 2007). Audiologists could train nursing personnel, community health care workers or community volunteers to conduct the screening (WHO, 2010; Olusanya et al., 2008a; Olusanya et al., 2008b; HPCSA, 2007). Audiologists would, however, be responsible for all follow-up testing of infants who failed the initial screening in the hospital in order to ensure data management and to track those infants through the different stages of the EHDI process. This would also enable audiologists to set quality indicators and ensure quality control (Russ et al., 2010; HPCSA, 2007). This proposed model for mandated NIHS programmes is represented graphically in figure 5.2.

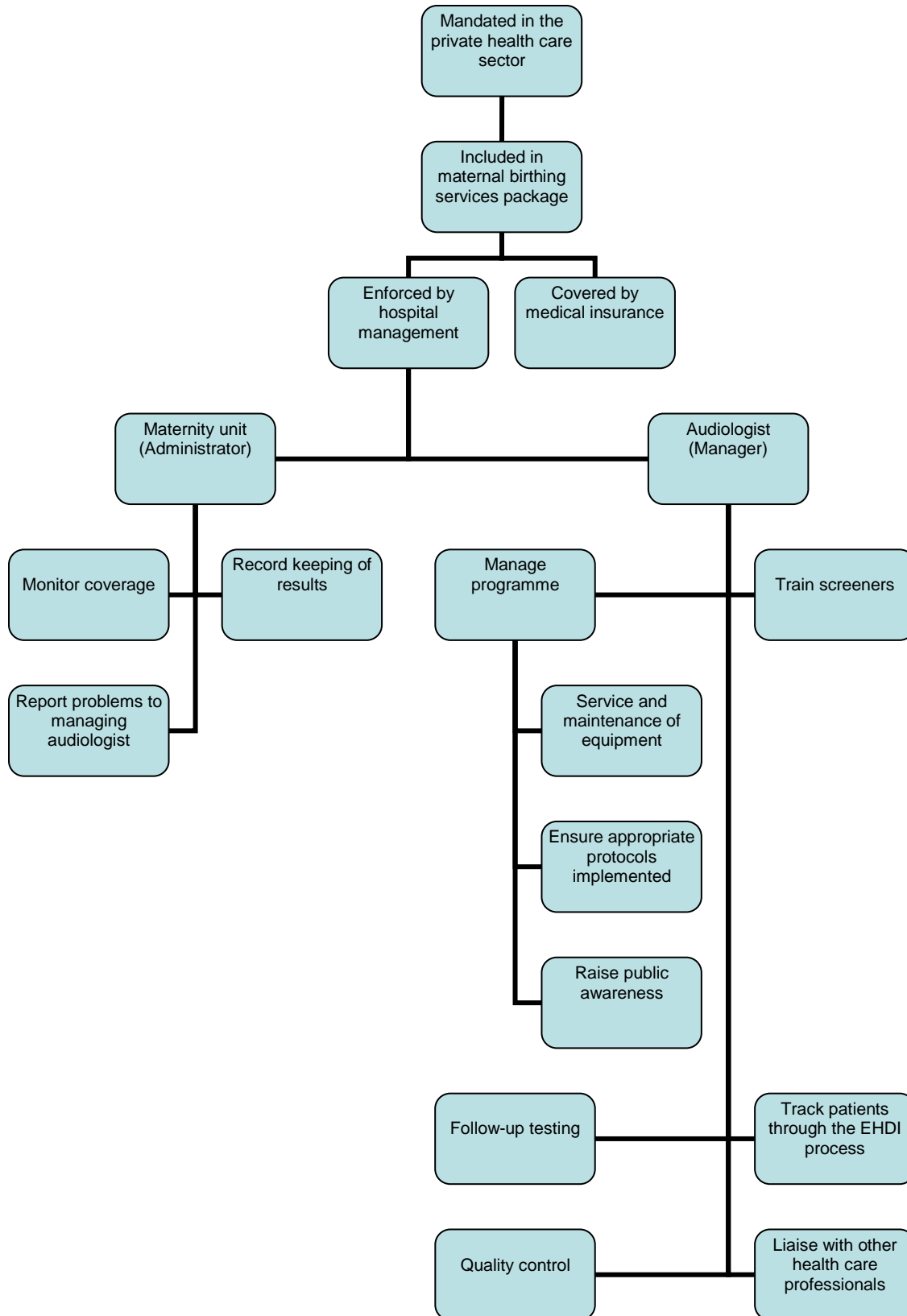


Figure 5.2: Proposed model for mandated universal newborn hearing screening

5.3. Critical evaluation

The current study was the first of its kind to conduct a national survey of EHDI services in the private health care sector of South Africa. It subsequently rendered imperative information upon which to build future private-public health sector partnerships and to advocate for universal newborn hearing screening in South Africa. However, the following limitations of the study were identified and have to be taken into consideration during the interpretation of results and the planning of future research:

Early hearing detection and intervention programmes in the private health care sector of South Africa are emerging and constantly evolving as they rely on individual initiatives from private practice audiologists. These initiatives or programmes are often driven by a single private practice audiologist and due to various reasons (including financial, time, personnel or personal restrictions), these programmes may cease at any given point. This is evident from data collected for the current study as 3 established programmes were terminated and 4 new programmes commenced over the period of 10 months from the time when initial data collection via telephonic surveys started until the questionnaires were sent to potential audiologist participants. In the time that has lapsed since completion of data collection, the current status of EHDI programmes could therefore have changed yet again. If these programmes were enforced by legislation or funded by medical insurance companies, there would not have been a decrease in the amount of programmes in South Africa's private health care sector.

Private practice audiologists do not receive referrals for infant hearing screening and/or diagnostic testing solely from hospital-based NIHS programmes. Additional referral sources might include referrals from paediatricians, general practitioners, ear, nose and throat specialists, other health care professionals, teachers or parents. Due to the general lack of tracking systems in most EHDI programmes in the private health care sector of South Africa (Swanepoel et al., 2007), it could have been difficult for audiologist participants to separate the statistics for children referred from external sources from those who were referred for diagnostic testing following newborn hearing

screening failure. This may have influenced the statistical accuracy of audiologist participant responses to certain questions in the questionnaire.

5.4. Future research

This study provided important information on the national coverage and current status of EHDI services in the private health care sector of South Africa. Reported results created potential for future research on a number of aspects. It is important to identify the socio-demographic and economic factors that might underpin loss to follow-up in the South African private health care sector context in order to address these factors (Folsom et al., 2000; Vohr, Moore & Tucker, 2002; Prince et al., 2003; Liu et al., 2008; Olusanya, 2009). In addition, the knowledge and perceptions of primary health care providers (including paediatricians, general practitioners, gynaecologists, immunisation or nursing staff) regarding the importance of EHDI services could be investigated. Primary health care providers serve as advocates for children's medical welfare (WHO, 2010; HPCSA, 2007). If they are not familiar with NIHS programmes, they may not sufficiently motivate parents to comply with every step in the EHDI process (Shulman et al., 2010; Olusanya et al., 2006; Olusanya, 2009). It is possible that certain health care providers might still doubt that infants could be tested reliably at such a young age, especially when symptoms associated with hearing loss are not yet evident (Olusanya et al., 2006; Olusanya, 2009).

This study could be repeated in future to determine progression or deterioration in the efficacy of the respective programmes. As EHDI programmes are dependent on individual initiatives from private practice audiologists and are not yet mandated or regulated in South Africa, programmes' sustainability and efficiency could vary greatly at any given point. The progressive nature of programme efficiency might allow for necessary capacity building in programmes to reach the specified international benchmarks and quality indicators for accurate identification of infants with hearing loss (Swanepoel et al., 2007).

5.5. Conclusion

The current study was the first to report on the national coverage and current state of EHDI programmes in the private health care sector of South Africa. Reported results indicated that NIHS programmes in the private health care sector of South Africa are not sufficiently systematic or integrated with hospital-based birthing services in order to guarantee adequate coverage. Most infants born in South Africa do not have the prospect of early identification of hearing loss and therefore may not have access to age-appropriate speech, language and social-emotional development. Early hearing detection, follow-up, referral and data management protocols and practices vary greatly amongst programmes in the private health care sector of South Africa, with no centralised data management system to standardise programmes or track patients.

Reporting on protocols, practices and coverage of pilot studies is important to provide contextual evidence of the burden of childhood hearing loss and the efficacy of screening programmes in the country (HPCSA, 2007; Olusanya et al, 2007 Swanepoel et al., 2007). This contextual research evidence should guide the expansion and widespread implementation of services to meet the existing health care need of identifying PCEHL as soon as possible. By identifying infants with PCEHL by 3 months of age, diagnosing or quantifying the hearing loss by 4 months and enrolling infants and families into family-centred early intervention programmes, one can capitalise on the potential of age-appropriate development and avoid the adverse developmental, financial, societal and social consequences of late identification (Swanepoel et al., 2007; Olusanya, 2008; Korver et al., 2010; Morton & Nance, 2006; JCIH, 2007; Smith et al., 2005).

The private health care sector of South Africa has the opportunity and moral obligation to invest in infants with hearing loss through the implementation of widespread NIHS programmes as part of maternal packages of birthing services (HPCSA, 2007). This could act as a spur to subsequent expansion of diagnostic and intervention service provision for all infants with hearing loss (WHO, 2010).

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7. APPENDICES

Appendix A: Ethical clearance letter

Appendix B: Email covering letter

Appendix C: Covering letter of informed consent

Appendix D: Questionnaire