


Data management for early hearing detection and intervention in South Africa

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Introduction: Internationally, newborn hearing screening is becoming part of standard neonatal healthcare service guidelines for the implementation of early hearing detection and intervention (EHDI) initiatives, including screening, diagnosis, data management and intervention. Data management includes the processes of data collection and storage thereof, as well as analysis and interpretation of data to guide the future planning, implementation and evaluation of EHDI programmes. There have been limited studies on data management in the South African EHDI context.

Methods: The aim of this study was to determine the type of data management systems in use in South Africa and whether they allow for cross-disciplinary sharing and evaluation of the EHDI processes. A survey instrument on the management of EHDI data was developed and sent to HI HOPES referral agents in both public and private sectors.

Results: A return rate of 80% was achieved, with 19 (59%) public sector and 13 (41%) private sector audiologists participating in the study. The data revealed that there was no uniform data management system in use nationally, and no consistent shared system within the public or private sectors. The majority of respondents (44%) used a paper-based system for data recording. No institutions were using data management systems that enabled sharing of information with other medical professionals.

Conclusion: Data management and tracking of the pathway from screening to diagnosis to intervention is necessary to ensure quality care and outcomes for children identified with hearing loss. International studies reveal the importance of effective implementation of data management systems; however, to date these have focussed on developed country contexts. Data management challenges identified in this study reflect international challenges as well as challenges unique to a developing country context.

Introduction

Internationally, newborn hearing screening is becoming part of standard neonatal healthcare services within developed countries (including the UK, Australia, Canada and some European countries). The importance of early detection of paediatric hearing loss and the benefits of early intervention for these babies have been recognised through extensive international research (Yoshinaga-Itano 2003:252–266, 2014:43; Yoshinaga-Itano et al. 1998:1161–1171). The Joint Committee on Infant Hearing (JCIH) (2007:898–921) has clear guidelines for the implementation of early hearing detection and intervention (EHDI) initiatives, including principles and process guidelines for screening, diagnosis, data management and intervention. These guidelines have come to represent the international gold standard as it serves as a reference document for countries globally, including those that are resource-constrained such as low- and middle-income countries (Olusanya 2015:51–64).

Within the South African context, the Health Professions Council of South Africa (HPCSA) recognised the importance and value of early hearing screening and diagnosis, and commissioned the development of a South African position statement on EHDI programmes. This statement was modelled closely on the JCIH position statement (JCIH, AAP & ASHA, 2000) and includes principles and guidelines for screening, diagnosis and data management with specific adaptations for the South African EHDI contexts. The HPCSA (2007) EHDI position statement therefore recommends screening by 2 months, diagnosis by 4 months and intervention by 8 months of age as opposed to the JCIH which recommends the 1:3:6 timeline for these three phases. In addition to these time-based guidelines, the importance of information systems for data management has been outlined in both the JCIH (2007) and HPCSA (2007) EHDI position statements. Data management refers to the processes of data collection and storage, as well as the analysis and

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interpretation of the data to guide the future planning, implementation and evaluation of specific EHDI programmes (JCIH 2007).

Data management (from a medical records perspective) involves the keeping of records and logging of data from appointments as a means of supporting patient care (Mann & Williams 2003), and is 'primarily created to provide an account of diagnosis and care' (Parkes 2004:899). Häyrynen, Saranto and Nykänen (2008:291–304) state that medical data can take one of the three formats: (1) a personal health record which is a summary of all health information on an individual and is kept by the individual; (2) an electronic medical record which is an electronic version of paper-based medical records and which is owned by healthcare providers from a single organisation providing medical care; and (3) electronic health records which are healthcare information records containing longitudinal information that has been collected from various sources, the purpose of which is efficient and integrated healthcare. Young and Spencer (2008:648–656) identified a fourth online format of data that would allow for the interface and potential linking of database systems for the improved information flow within and between the different components of the EHDI referral process. The key advantage of such an online data management system would be the immediate access and availability of the complete patient healthcare records to authorised healthcare providers at the point of consultation (Mostert-Phipps, Pottas & Korpela 2012:326–331), which would include doctors, audiologists and interventionists.

Globally such an online central data management system, allowing for interdisciplinary access to the pathway from screening to diagnostic and follow-up appointments, has been shown to be a key component in ensuring the success of a comprehensive hearing screening programme (Finitzo & Grosse 2003:73–78). Within the South African public healthcare context, such a system would be essential to the success of a universal newborn hearing screening (UNHS) programme because of the hierarchical nature (Legodi & Wolvaardt 2015) of our three-tier public health referral system. An online data management system would allow for interdisciplinary tracking along the referral pathway, where paediatric hearing screening occurs at the primary healthcare facility with referral to a secondary or tertiary healthcare facility if advanced diagnostic testing and confirmation of hearing loss is required. This is then followed by the return to the primary healthcare provider for habilitation and/or intervention. It is therefore clear that, to ensure a seamless referral process along the three-tiered health system, online data would need to be as up-to-date, accurate and complete as possible (Alam, Gaffney & Eichwald 2014:220–223).

Since the development of the HPCSA EHDI position statement (2007), which is not a legislated document, some institutions in South Africa have begun implementing screening initiatives. Voluntary screening programmes are

offered at private hospitals, and routine high-risk screening occurs at certain government hospitals. Pilot studies reported thus far include a newborn hearing screening programme at one private healthcare hospital in Gauteng (Swanepoel et al. 2007:881–887), infant hearing screening at an immunisation clinic in Gauteng (Swanepoel, Hugo & Louw 2006:1241–1249), the use of nurses as screening personnel in the Western Cape (Friderichs, Swanepoel & Hall 2012:552–559) and screening at Maternity Obstetric Units (MOUs) (de Kock, Swanepoel & Hall 2016:124–131) in the Western Cape. Results from these screening forums indicated that once hearing was screened and a referral result was obtained, parents did not bring the child for the rescreening appointment. A follow-up study was done to gain a South African perspective on why parents were not bringing their children in for rescreening, and the results showed that 24% of caregivers forgot about the appointment with a further 32% believing that the follow-up appointment was not necessary. This loss to follow-up of 56% of families highlights the benefit of a quality data management system for the effective tracking of referred infants, and telephonic reminders by dedicated personnel to improve follow-up compliance. Before such a central system could even be considered, it is important to explore the current status and practice of data management. South Africa does not have standard methods for audiology record keeping.

As stated in a recent review of EHDI in South Africa, limited studies were found on data management (Moodley & Storbeck 2015:1–10), despite the fact that such data management systems have been identified globally as part of the gold standard because of the importance for both patient care and evaluation and quality control (Finitzo & Grosse 2003:73–78).

It is therefore necessary to determine what, if any, data management practices and systems are in use in South Africa and if they allow for cross-disciplinary sharing and evaluation of the EHDI processes employed in the screening, diagnosis and intervention of paediatric hearing loss.

The aims of this study were to:

- identify the data recording and management systems used by South African audiologists in the public and private healthcare sectors
- determine whether these data management systems allow for sharing of information across healthcare professionals
- establish the challenges associated with the use of an online or electronic database system in the South African public and private healthcare systems.

Methods

Study population

This survey on the practice of data management in three provinces of South Africa is part of a larger study, which includes a broader survey on diagnostic audiology practice.

The sample for the survey included audiologists who referred children to the HI HOPES early intervention programme from September 2006 to December 2011, and who are part of a larger research project involving this longitudinal data set on deaf children ($n = 532$) in South Africa (Störbeck & Young 2016:45). The survey was sent to the 40 referral agents, where 21 were from the public and 19 were from the private health sector. Six surveys were not returned, with an additional one private sector audiologist choosing not to participate and a second who did not fully complete the survey. The response rate for the data management component of the survey was thus 32 of the 40 audiologists, making the response rate 80%. Completed surveys were from 19 public sector audiology departments (59%) and 13 from private sector audiologists (41%). In terms of provincial breakdown, 20 (63%) were from Gauteng, 10 (31%) were from Kwazulu-Natal (KZN) and 2 (6%) were from the Western Cape.

Procedures

A survey instrument was developed and included questions on diagnostic audiology practices as well as EHDI data management in South Africa. The survey instrument was developed to be quickly completed and provide information on the aspects of data management that were identified to be important from the literature, i.e. data record systems, sharing of audiology diagnostic information and challenges with the use of database systems. The survey comprised six close-ended questions in a multiple choice format. Options from which respondents could choose were those identified as common to EHDI data management systems and options specific to a developing county context. Respondents were given the option of providing their own responses as well as including further comments.

After the development of the survey instrument, it was piloted on audiologists who were not referral agents to the programme and were thus not eligible to complete the survey. Pilot respondents included an international as well as South African expert in the field of audiology, as well as two audiologists in the public and private health sectors, respectively. The piloting of the questionnaire allowed for checking of the appropriateness of the questionnaire for answering the research questions, as well as detecting any flaws in the questionnaire (Brink, van der Walt & van Rensburg 2006).

Before the survey could be sent to public sector audiology departments, permission was obtained from the government research council for each province (Gauteng, KZN and Western Cape). Permission was then obtained from each individual hospital medical manager for the audiology department to complete the survey. Once written permission was obtained from the hospital medical managers, the audiology departments were contacted telephonically to inform them of the study and to request completion of the survey. Surveys were emailed to the audiology department at those hospitals that agreed to fill in the survey.

Each private audiologist was contacted telephonically to inform them of the study and to invite them to participate in the study. If agreed, the survey was emailed directly to the audiologist.

Data analysis

A data collection sheet was designed specifically for the comprehensive logging of the survey information relating to data management. Data were coded and collated.

The coded data were then transferred to an Excel spreadsheet for systematic analysis. Data were grouped and analysed according to the variables of private versus public sector and the province in which the practices were located to determine the variation in data management with respect to these variables.

Data analysis techniques included basic descriptive statistics such as average values, standard deviation, frequencies and percentages.

Results

Results will be presented in the format of: (1) the data system used for recording of the audiology information, (2) information included in audiology records, (3) data sharing and, (4) challenges encountered by audiologists in the implementation of an electronic or online database system.

Data recording systems

Audiologists were asked to indicate what data system they were using for recording of EHDI data in their audiology department/practice. The majority of respondents (44%; $n = 14$) use only a paper-based system for recording of data. An additional 27% ($n = 9$) of respondents use a paper-based system in addition to a computer-based (Excel or Access) program to generate reports. 25% ($n = 8$) of public sector audiologists use a computer-based programme system only. Two respondents (6%), both in the private healthcare system (one in the province of Gauteng and one in KZN), use a web-based data tracking system in addition to computer- and paper-based systems.

The systems used for recording data are varied, with both the private and public health systems using both paper-based and computer systems for data capture.

Information included in audiology records

The next question in the survey focussed on the information that is included in data records. Multiple choice options included demographic and medical information as well as the capability of the system to allow for generation of reports, account (billing) information and flag for follow-up appointments.

The analysis of information reported to be included in data systems indicates that the majority of data records

include medical information (Table 1). A flag for follow-up appointments is available in 16 (47%) institutions (10 in the public sector and 6 in the private sector). Respondents in KZN and Gauteng in both the private and public healthcare sectors have data recording systems that can generate and record reports, with account information being recorded more in the private sector (12; 92%) than the public sector (4; 21%).

Data sharing

The next question in the survey focussed on data sharing amongst professionals within and across hospitals. The Gauteng public sector (70%, $n = 7$), as well as some KZN public sector audiology departments (57%, $n = 4$), uses systems that are available to other medical professionals in the hospital, as well as two (20%) audiology departments in Gauteng having systems that are accessible to professionals in other hospitals. There is no sharing of audiology data across hospitals in the private sector, with only two practices (one in Gauteng and one in KZN) having a system that is accessible to other medical professionals within their hospital.

Implementation of an electronic/online database system

Audiologists were asked to indicate difficulties they would face if they were to implement the use of an electronic database system and online database system in their audiology department/practice. A list of challenges to choose from was provided, as well as providing an option to list additional challenges. The most common difficulty with implementing the use of an electronic/online database

system (Table 2) was the lack of time and limited staff for data entry. A limited budget and frequent electricity cuts were identified as difficulties by a few institutions across the public and private healthcare sectors, with one public sector institution identifying limited electricity points as a difficulty. The public sector identified Internet connection as a difficulty with implementing an online database system, with one public sector institution commenting that there is a shortage of computers in the department.

Ethical consideration

According to research protocol at the University of the Witwatersrand, an application is made to the University research committee for ethical clearance relating to each research project. Formal ethics approval is required before data collection can begin. The University of the Witwatersrand Ethical Clearance Medical Board provided ethical clearance (Protocol number: M111144) for a comprehensive survey study of audiologists in the public and private sectors who referred deaf and hard of hearing children to the HI HOPES early intervention programme in the 5-year period between September 2006 and December 2011. This is part of a larger longitudinal study of EHDI data for children receiving comprehensive home-based intervention in the HI HOPES programme during this time period.

Discussion

Through hearing screening programmes being implemented in a number of countries (including South Africa), more hearing loss is being identified early. However, a factor that has been identified as a challenge within the EHDI system is the variability in the level of diagnostic follow-up services.

TABLE 1: Information included in EHDI data management systems.

Data records – information included	Public						Private						Total ($n = 32$)	
	GT ($n = 10$)		KZN ($n = 7$)		WC ($n = 2$)		GT ($n = 10$)		KZN ($n = 3$)		WC ($n = 0$)			
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Demographic information	10	10	7	100	2	100	8	80	3	100	-	-	30	94
Medical Information	10	10	7	100	0	0	9	90	3	100	-	-	29	91
Generate and record reports	6	60	6	86	0	0	7	70	2	67	-	-	21	66
Account information	2	20	2	29	0	0	8	80	3	100	-	-	15	47
Flag for follow-up appointments	6	60	3	43	1	50	3	30	3	67	-	-	15	47

GT, Gauteng; KZN, Kwazulu-Natal; WC, Western Cape.

TABLE 2: Difficulties implementing an online or electronic database system.

Electronic database implementation – difficulties	Public						Private						Total ($n = 32$)	
	GT ($n = 10$)		KZN ($n = 7$)		WC ($n = 2$)		GT ($n = 10$)		KZN ($n = 3$)		WC ($n = 0$)			
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Limited electricity points	0	0	1	14	1	50	0	0	0	0	-	-	2	6
Frequent electricity cuts	1	10	3	43	0	0	1	10	0	0	-	-	5	16
	-	-	-	-	-	-	2	20	-	-	-	-	6	19
Limited budget	3	30	4	57	2	100	3	30	0	0	-	-	12	38
	4	40	3	43	-	-	2	20	-	-	-	-	11	34
Lack of time for data entry	3	30	3	43	2	100	6	60	1	33	-	-	15	47
	-	-	-	-	-	-	5	50	-	-	-	-	14	44
Limited staff for data entry	4	40	3	43	2	100	4	40	1	33	-	-	14	44
<i>Internet connection</i>	8	80	3	43	0	0	0	0	1	33	-	-	12	38

GT, Gauteng; KZN, Kwazulu-Natal; WC, Western Cape.

Bold, electronic database system; italics, online database system;

Note: If values were the same it is listed normally.

To ensure quality EHDI programmes and services aligned with evidence-based care, there is a need to continuously monitor access, quality and outcomes of services (Russ, Dougherty & Jagadish 2010:S7–S18).

The monitoring of systems and data are through analysis of details from data records. This allows for identification of factors that will be effective in (as well as prevent effective implementation of) EHDI services across the continuum of screening, diagnosis and intervention.

The majority of respondents using a paper-based system for data recording could pose a difficulty with transfer and access of information when referring between the primary, secondary and tertiary departments of the South African public healthcare system. Mostert-Phipps et al. (2012:326–331) found that referral between healthcare providers using a paper-based record system results in insufficient information being provided in the referral letter as well as the possibility that information may not be provided in time for the primary healthcare providers (as well as at each step of the EHDI pathway) to be informed of all factors for follow-up care. In addition, Shulman et al. found that reporting systems relying on handwritten forms were found to be more prone to errors than those using computer-based systems (Shulman et al. 2010:S19–S27). In South African audiology, it has been found that paper-based audiology records provided by audiologists conducting diagnostic testing, in both the public and private sectors, are varied in terms of format as well as details included in the report (Moodley 2016:1–7).

In this sample of 32 audiologists, the information they state are included in reports indicates that these audiologists may have difficulty with following up on appointments, as few institutions have a flag for follow-up included in their reporting system. This is important as South African research has indicated that following up on appointments for screening is a challenge (de Kock et al. 2016:124–131; Scheepers, Swanepoel de & le Roux 2014:652–658; Swanepoel et al. 2007:881–887). To improve the documented rate of follow-up testing in the USA EHDI programmes, data management systems were amended to include a component for reminding parents of follow-up testing (Williams, Alam & Gaffney 2016). This has been a recommendation from a South African study on parental reasons for not complying with follow-up testing recommendations and appointments (Scheepers et al. 2014:652–658).

The nature of healthcare provision in the public sector relies on referral from primary to secondary to tertiary healthcare for different steps of the EHDI pathway. This means that children will move between various healthcare providers, at the different levels of healthcare, for provision of services.

No institutions in this sample were using systems that enabled sharing of information with other medical professionals. The Gauteng public sector is most likely to use a system that is compatible with systems used by other medical professionals

in the same hospital, indicating the ability for development of a system for data sharing. Data sharing within institutions can be achieved through the use of an electronic system accessible by all healthcare providers, while an online database system is necessary for sharing information with medical professionals at other institutions.

The use of an electronic healthcare system has been shown to result in more complete and accurate documentation by EHDI healthcare professionals, as well as being important for health policy planning (Finitzo & Grosse 2003:73–78; Hutt & Rhodes 2008:87–91). An electronic health record system may assist in avoiding double or unnecessary tests as well as providing data for comparison with earlier tests conducted and a reduction of ineffective treatments (Ueckert et al. 2003:99–108). A study on the use of electronic records in South African healthcare concluded that there is an increased need for sharing of information on procedures and tests done, across the different levels of healthcare provision (Mostert-Phipps et al. 2012:326–331), to ensure integrated, quality EHDI services.

Challenges faced in the implementation of an integrated data system in the United States included a lack of funding for: (1) a web-based data system accessible to providers, (2) staff for the development of the system, and (3) provider training on the use of the system (Uhler et al. 2014:34–43). Challenges identified in the current study include those common to the USA, that is, challenges of funding and a lack of staff for data entry. However, South Africa also has additional challenges such as provision of electricity and Internet connection, which are reflective of a developing country.

Conclusion

This study has looked at EHDI data management systems used by public and private sector audiologists in three provinces of South Africa. There was mainly use of a paper-based system, with the majority of records including medical information. While paper-based systems are not easily accessible and could be prone to errors, the inclusion of medical information allows for some holistic evaluation and care. However, systems did not allow sharing of information between different professionals or for following up of appointments. This indicates a lack of integrated care.

An online data system for integrated care and decision support is especially important in South Africa where there is the implementation of pilot screening initiatives. Data can be used to gather information on the cost of screening, determining the best screening forums, and the best screening techniques. Especially since screening is conducted at different forums by different personnel, data management and analysis are important for the evaluation of quality of services provided, and monitoring of accuracy and timeliness of services.

South Africa has the advantage of learning from global studies on the importance of data management, and including

this as part of EHDI programmes from the beginning. The identification of challenges in implementing data management systems allows for effective preparation and formulation of ideas for how these challenges can be overcome. From this study, difficulties such as lack of time and staff for data entry reflect the international challenges of having a shortage of audiologists. Difficulties such as electricity access and Internet connection are part of difficulties related to being a developing country.

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Competing interests

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

Authors' contributions

This article is part of S.M.'s PhD study. C.S. was the study supervisor and assisted with study conceptualisation, drafting and revision of the article.

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