

## The role of the neonatal nurse in early hearing detection and intervention in South Africa

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### Abstract

There is a lack of direct recognition of children with disabilities and the importance of early screening and identification of disability, particularly within Africa. Within the South African healthcare setting, the role of screening for disability within a neonatal or paediatric nursery could be facilitated by the nurse. Hearing loss is a disability that can be identified early through the availability of screening equipment, and for which beneficial outcomes have been associated. The diversity of roles performed by the nurse will be discussed with reference to early detection of hearing loss and concomitant intervention for children who are identified with hearing loss.

### Introduction

*"The central focus of the profession of nursing is using the art and science of caring to improve the health of human beings within their environments."*<sup>1</sup>

However, it is not just within the realm of caring for patients that the definition of nursing lies. A study on nursing in Australia identified five additional roles that the nurse can play in a general practice environment, namely organiser, quality controller, problem solver, educator and agent of connectivity.<sup>2</sup> These are all diverse roles that are part of a nurse's general workload and serve to ensure the best possible care for the patient within the healthcare setting. In addition to these traditional roles, the nurse fulfils specialty duties, such as those carried out within the neonatal intensive care unit (ICU). The paediatric nurse often assists with emotional support and counselling.<sup>3</sup> In these settings, the nurse has been known to play an important role in decision-making on technology that is available to care for the neonate. The nurse also performs an advocacy role<sup>4</sup> and has been shown to have a personalised communication style with mothers, which is particularly apparent in neonatal nurseries. This communication style is valued by mothers as it helps them to develop a connected relationship with their infant. It is also essential in planning individualised care to suit the infant and the family.<sup>5</sup>

In South Africa, the focus is on a primary healthcare system. This is a system in which initial medical consultations are carried out at clinics that are mainly nurse-driven.<sup>6</sup> However, this system has been fraught with difficulties as

there has been a decrease in the nurse:population ratio: from 149 registered nurses per 100 000 in the population in 1998, to 110 per 100 000 in the population in 2007, as determined by Day.<sup>6</sup> The South African public healthcare system has also been shadowed by poor service delivery, the growth of HIV/AIDS and a failure within the health system to appropriately deal with the HIV epidemic.<sup>7</sup>

However, an area of strength has been child health and woman and maternal care through the development of a number of national policies and clear areas of focus. Policies that directly relate to the area of child and maternal health include the *Free Health Care Policy*<sup>8</sup> which ensures that all children who are less than six years of age, children with disabilities, and pregnant and lactating mothers have free access to public health services. *The Strategic Priorities for the Public Health System, 2004-2009*<sup>9</sup> focuses on the improvement of family practices that impact on child health. The importance of the interaction between health, education and the well-being of children, and its ability to positively influence poverty reduction has been recognised by international policymakers, leaders, lobbyists and researchers.<sup>10</sup> This has led to five of the eight Millennium Development Goals that focus on health, nutrition and the education of children.

Despite this significant progress internationally, there is still a lack of direct recognition of children with disabilities and the importance of early screening and identification of disability, particularly within Africa. The availability of funding to conduct screening programmes for early detection of disability is a particular challenge, as the primary focus is on improving the high under-five

mortality rate. Considerable funds are invested in this area. This means that it is likely that a reduction in the mortality rate could result in an increase in the number of children who survive with disabilities. This raises the need for the sufficient recognition and funding of screening for infant disabilities. Putting policies in place that will ensure the provision of early detection and intervention services as soon after birth as possible is the first step in achieving this goal.

Despite, or rather because of, the diversity of roles played by the nurse within the healthcare setting, the role of screening for disability within a neonatal or paediatric nursery could be facilitated by the nurse. Hearing loss is a disability that allows for early identification, and screening is possible at birth or as close as possible thereafter. Beneficial outcomes have been associated with this.

### Paediatric hearing loss

Hearing loss has an estimated incidence of 6 per 1 000 live births in sub-Saharan Africa, and 2–4 per 1 000 live births in industrialised countries.<sup>11</sup> Every day, 16–17 babies are born with some degree of hearing loss in South Africa.<sup>12</sup> The effect of delayed diagnosis and intervention has a severe negative effect on the development of a hearing-impaired infant's speech and language, as well as cognitive and social skills.<sup>13,14</sup> The goal of establishing a formal early hearing detection and intervention (EHDI) pathway is to ensure that screening, identification and diagnosis of the hearing loss occur before the infant reaches three months of age. Early intervention must start as soon as possible after diagnosis, but no later than six months of age.<sup>15</sup> Early intervention would minimise the effects of the hearing loss through techniques that promote the holistic development of the child, including amplification, therapy, family support and holistic development. Since 50% of children with hearing loss have identified risk factors, such as neonatal jaundice requiring blood transfusion, ICU admittance of more than five days, respiratory distress syndrome, and infections such as cytomegalovirus,<sup>16</sup> hearing screening for children in the ICU will significantly improve the early identification and intervention rate. The nurse monitors neonates and conducts comprehensive assessments during their stay in ICU. This means that the nurse is within the boundaries of, and communicates with, other health professionals who are responsible for the infants' well-being.<sup>17</sup> The nurse is in an ideal position to identify risk factors for disability, such as hearing loss, and inform the team. In partnership with doctors, specialists and parents, the neonatal nurse has "particular expertise in discussing health history, interpreting medical records, and offering information about the physical and developmental status of the child from a holistic perspective".<sup>17</sup>

In addition to high-risk screening, most developed health systems (UK, USA and Australia) implement

universal hearing screening of newborn babies, which means that every baby is offered screening. Screening is conducted using either otoacoustic emission testing (OAE) or automated auditory brainstem response (AABR) testing.

These are simple, quick procedures that can be completed by trained personnel in the wards of clinics, hospitals, maternity wards and ICUs. Screening is followed by diagnostic testing by a qualified paediatric audiologist. On diagnosis of hearing loss, there is subsequent referral to early intervention services. Intervention includes audiological management (amplification), as well as intervention for the holistic development of the child (communication, language and socio-emotional development). This international drive towards early identification of hearing loss, and subsequent initiation of early intervention services, is to ensure that infants with hearing loss have access to opportunities to develop typically, on par with their hearing peers, despite their disability. This should be part of the services that are available to all infants in South Africa in terms of their right to access appropriate medical services, including caregivers who can recognise their healthcare needs and who will take them to healthcare providers for the appropriate assessments.<sup>18</sup> This EHDI process has compelling and ethical imperatives, as research has shown that the lack of intervention impacts on the holistic development and quality of life of the deaf child and adult. Financially, this would impact on governments to the value of US\$1 million for each deaf infant without intervention.<sup>19</sup>

### Multiple roles of the nurse

Implementing screening is seen as the essential first step in the EHDI process, and the nurse should play a vital role in this. The multiple roles of the nurse will be discussed with reference to the implementation of hearing screening services for newborn babies in South Africa. The roles, noted earlier by Phillips et al.,<sup>2</sup> namely patient carer, organiser, quality controller, problem solver, educator and agent of connectivity will be deliberated.

#### *The nurse as patient carer*

Because of the shortage of audiologists in South Africa, as well as understaffing of audiologists at government hospitals,<sup>20</sup> there is a need for personnel to conduct hearing screening tests. Although there is a shortage of nurses in the health system, this is a task that could be facilitated by the nurse who has access to infants, works with them daily in the wards, and is in a favourable position to help parents understand the importance of having their baby's hearing screened.

The nurse is aware of the risk factors for acquired hearing loss following illnesses such as meningitis and certain infections and viruses. He or she has access to patients and their families, too. This means that the nurse will be

able to refer the infant for hearing tests as soon as he or she is well enough to undergo hearing screening before discharge from the hospital.

### *The nurse as educator*

While in the maternity ward, ICU or specialist ward, it is essential to inform parents of the importance of hearing screening of newborn babies. Children could otherwise be lost in the system and not receive the intervention services that are necessary to ensure typical development. Results from pilot studies on hearing screening of newborn babies in South Africa<sup>21,22</sup> have indicated that a large number of children, who had a screening result that warranted referral and indicated the possibility of hearing loss, did not return for the follow-up appointment. This could be attributed to a lack of understanding of the importance of hearing in development and the necessity for follow-up and early intervention.

The manner in which parents are made aware of the importance of hearing screening and the available intervention options is especially important in a multicultural context like South Africa. This is because any intervention that may be associated with social stigmatisation,<sup>23</sup> or that offends cultural norms, could result in parents missing appointments or cancelling intervention services.<sup>24</sup> Societies and cultures also differ with respect to what is considered to be normal and pathological.<sup>25</sup> It is important that this is recognised and acknowledged, so that parents receive information and intervention options in a non-threatening, culturally sensitive manner. It has been shown that nurses are often best able to use communication and language to make parents feel relaxed and confident,<sup>5</sup> as well as respected for their choices and culture.<sup>26</sup>

In line with international trends, it is also essential that informed choice is the guiding principle, and allows parents the right to choose whether or not to screen.<sup>27</sup> As a professional, the nurse is ideally placed to explain the importance of screening and returning for diagnostic appointments, as well as informing parents of intervention options.

### *The nurse as screener and quality controller*

The screening test requires a few minutes. The nurse can be trained to use equipment to conduct the test appropriately. Having screeners on site and that have access on a daily basis to infants will ensure that fewer infants are lost to follow-up. If a refer result is obtained, for which no interpretation of the results is required, the nurse is able to counsel the parents immediately and inform them of the importance of returning for follow-up and diagnostic appointments. The role of agent of connectivity is applicable here in terms of liaison with the audiologist.

### *The nurse as agent of connectivity*

It has been recognised that infants and toddlers who have disabilities or who are at a risk of developing a disability will often need the expertise of a number of different personnel, services and agencies.<sup>28</sup> Integration and coordination of early intervention practices is needed to ensure effective outcomes. The nurse gathers case-history information, is aware of risk factors and monitors the infant's health and development during visits to immunisation and wellness clinics. Therefore, he or she is in a good position to integrate information and provide parents with appropriate referral sources. The nurse plays an important role in coordinating first-level detection and intervention. The role is then handed over to a dedicated EHDI coordinator.

### *The nurse as organiser*

The lack of coordination and multiple visits to different practitioners to treat the same condition<sup>7</sup> is a challenge that is faced by the primary healthcare system. This results in increased time being needed for diagnosis and the provision of early intervention services. The nurse has a key function to play as an intermediary agent by organising follow-up and diagnostic appointments. This results in a more integrated approach to early identification of disabilities and intervention for such infants. In South Africa, the focus is on the primary healthcare system. This facilitates hearing screening which could be carried out when the infant returns to the clinic for his or her immunisations.

In addition to the roles that the nurse can play in the EHDI system, and implementation of hearing screening for newborn babies, there are other opportunities that can add value to the nurse's skills and expertise.

These opportunities include:

- *Training:* Following training, the nurse would be skilled in the use of OAE and AABR screening equipment. This would provide him or her with a marketable skill that would be an asset in any paediatric workplace setting, i.e. both the public and private healthcare sectors.
- *Early interventionist skills development:* In collaboration with the South African early intervention programme (HI HOPES), the nurse could receive training in specialist intervention and how to work with parents to make informed choices regarding all aspects of their child's development.<sup>29</sup> This would open up a long-term career path, with the possibility of a future role as an advisor to parents, upon retirement.
- *Training in sensory disabilities:* Following training, the nurse would be knowledgeable about all aspects of child development and the attainment of milestones. This would be a highly marketable skill in any paediatric workplace setting.

- *Research opportunities:* There is an international move towards the inclusion of practitioners as researchers. If implemented in South Africa, this would provide the nurse with research opportunities.

In conclusion, there is an ethical imperative to begin screening infants for hearing loss, as the research provides evidence of the detrimental impact of not having an EHDI pathway in place.

The important place occupied by the nurse in the lives of infants and their families is clear. His or her multiple roles and interface between parents and doctors ideally positions him or her within the first phase of the EHDI pathway in three ways:

- To raise awareness of the importance of early detection of hearing loss and intervention for such children, as well as children with other disabilities.
- To educate parents on the importance of follow-up and diagnostic appointments.
- To act as a first-level coordinator in the EHDI system, ensuring that there is compliance on the part of doctors, as well as parents.

The involvement of the nurse in the EHDI pathway would facilitate the skills that the nurse possesses, and the central role that he or she could play in making a positive difference in the paediatric population with hearing loss.

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